Promoting Wellbeing for Individuals Living with Dementia in Care Homes by Improving Opportunities for Engagement in Meaningful Activities

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This thesis is dedicated
to my Grandad
og til min Morfar

Abstract

Rationale

Research highlights that people living with dementia have identified the opportunity to engage in activities as important to their wellbeing. However, evidence suggests that individuals living with dementia in care homes spend the majority of their time in a state of passivity and inactivity. This thesis considers how it might be possible to improve the wellbeing of people with dementia living in care homes by improving opportunities to engage in positive and meaningful activities.

Research Design

This thesis draws upon the approaches of ethnography and action research and seeks to examine the lived experience of thirteen people with dementia living in a care home with a rich and varied programme of activities. Dementia Care Mapping, unstructured observations, conversations and a focus group were the principal methods used to gather data with particular reference to participants' mood and engagement, their activity preferences and the effect that engagement had upon their wellbeing. In addition, the researcher worked in partnership with care workers during staff workshops to co-create a strategy to improve opportunities for resident engagement within the context of everyday care. This study was designed to be conducted over four phases comprising three cycles of action research. This predominantly qualitative data was analysed using thematic analysis.

Findings

Within this research, residents reported a wish to take part in activities and were clear about the type of activities they wanted to engage in. However, this thesis found that despite residents' wishes and the programme of activities

offered within the home, individuals living with dementia spent the majority of their time in behaviours associated with passivity and disengagement and consequently experienced a fairly neutral mood. One of the reasons for this appeared to be that residents were not supported to engage in activities beyond the activity programme and that the programme could only support engagement for a relatively short period. The findings of this thesis suggest that an activity programme alone may not be the best way to sufficiently engage people living with dementia in care homes. Therefore, careful consideration should be given to identifying how to improve the opportunities for residents to engage throughout the day within the context of everyday care.

This thesis identified seven factors that might facilitate or act as a barrier to engagement. These were cognitive and physical limitations, the physical environment, the activity programme, care workers' perception of their role, individual care workers, the culture of care and care workers' time constraints. With these factors in mind, care workers were asked to develop a strategy to improve opportunities for resident engagement throughout the day. Within this strategy they suggested that it might be possible to engage residents in quick activities that were simple to set up and in activities as part of their everyday care routine.

Recommendations

This thesis demonstrates that to improve opportunities for resident engagement, activity provision needs to be woven into everyday care rather than seen as a separate sphere of care facilitated by dedicated staff; supporting activities need to be part of the role and responsibility of every member of the care team. It is acknowledged, however, that achieving this is no easy task and that to increase opportunities for residents to engage in activities, a wider shift in the culture of care and a reconceptualisation of the role of the care worker is necessary.

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Declaration

I declare that none of the work contained within this thesis has been submitted for any other degree at any other university.

Sophie Bushell, August 2018

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Chapter One – Introduction

The word 'dementia' is a term used to describe a set of symptoms that are caused by one of a number of diseases that affect the brain, the most common of these is Alzheimer's disease (Alzheimer's Research UK (AR UK) 2018a). Estimates suggest that there are currently 50 million people living with dementia worldwide (World Health Organisation (WHO) 2017) and that approximately 850,000 of these live in the UK (Prince et al. 2014). Instances of dementia are expected to increase to 125 million globally (Prince et al. 2015) and two million in the UK (Prince et al. 2014) by the year 2050 in line with the anticipated rise in life expectancy (AR UK 2018b). This is because the prevalence of dementia significantly increases with age and although the condition is not unique to older people, the vast majority of the instances of dementia occur amongst individuals over the age of 65 (Prince et al. 2014; AR UK 2018b).

With increasing numbers of people living with dementia, worldwide governmental dementia strategies and plans have helped to establish more dementia focused health and social care programmes in an attempt to accommodate the growing number of people living with the condition (Alzheimer's Disease International (ADI) 2017). Global dementia strategies have predominantly focused on three key areas: diagnosis, treatment and research (ADI 2017). More specifically, international policy innovations designed to support people with dementia include increasing public and professional awareness, knowledge and understanding, reducing stigmatisation, encouraging early diagnosis, providing post diagnostic support and improving the quality of care for people with dementia in the community, institutional care and hospital settings (Department of Health and Social Care (DH) 2009; Alzheimer's Disease International and World Health Organisation (ADI and WHO) 2012; ADI 2017; DH 2016). In addition, there is now a public agenda to support people to 'live well with dementia' (DH 2009; ADI and WHO 2012; DH 2016).

With dementia comes an increased likelihood of the need for long-term care and support either at home, in a care or nursing home or in a hospital setting (Prince et al. 2014). The quality of this care is an important issue for people living with dementia (Dementia Alliance International (DAI) 2016) and this is reflected in national (DH 2009; Department of Health and Social Care and Prime Minister's Office (DH and PMO) 2013; DH 2016) and international policy (ADI and WHO 2012). Within the context of long-term dementia care, ongoing social engagement, a homelike environment and care practices that meet individuals' psychological (as well as physical) needs have been shown to contribute to residents' wellbeing and quality of life (Bradshaw et al. 2012). In addition, people living with dementia have reported the opportunity to participate in activities as a key factor affecting their wellbeing (Phinney et al. 2007; Williamson 2010; Edvardsson et al. 2014; Tak et al. 2015; Kaufmann and Engel 2016). Indeed, engagement in activities has been identified in dementia specific UK policy as 'a major determinant of quality of life affecting mortality, depression, physical function and behavioural symptoms' (DH 2009, p. 58). As such, activities can be seen as a fundamental human need and therefore central to individuals' wellbeing and quality of life (National Institute for Health and Care Excellence (NICE) 2018). Both the UK Care Act (UK Government 2014) and the National Institute for Health and Care Excellence (NICE 2018) support the idea that individuals, particularly those living with dementia, should have opportunities to participate in leisure, recreational and worklike activities which correspond to their unique needs, preferences and capabilities. Yet the evidence suggests that people living with dementia often do not have sufficient opportunities for engagement (Harper Ice 2002; den Ouden et al. 2015; Smit et al. 2016).

RESEARCH OVERVIEW

This thesis considers how it might be possible improve opportunities for people living with dementia in care homes to engage in positive and meaningful activities. Within the context of this study, these were defined as activities that have a positive social, recreational or vocational element and as such are distinct from engagement associated with physical care, and passivity and disengagement. This definition is grounded in Kitwood's definition of 'occupation' (Kitwood 1997a, p. 83), directives in the UK Care Act (2014), which state the importance of work and recreational activities to individual wellbeing and guidance from the National Institute of Health and Care Excellence (NICE, 2018).

There is a body of evidence to suggest the importance of activity to people living with dementia and a growing academic interest in the specific activities that these individuals may like to become involved in (Harmer and Orrell 2008; Williamson 2010; Menne et al. 2012; Tak et al. 2015; Han et al. 2016). However, despite the fact that most nursing homes in the UK have a weekly programme of activities run by dedicated staff as a means to support engagement (Buettner and Fitzsimmons 2003; Holthe et al. 2007), research suggests significant levels of inactivity and occupational deprivation within care homes (Innes and Surr 2001; den Ouden 2015). This is problematic as prolonged inactivity can lead to poorer wellbeing among these individuals (Harper Ice 2002). Supporting people living with dementia to engage in activities is an issue that needs to be addressed. Therefore, this thesis seeks to answer the question:

> *Can we improve wellbeing for people living with dementia in care homes by increasing their opportunities for engagement in positive and meaningful activities?*

An ethnographic, action research design was employed to answer this research question. The ethnographic element of this research sought to develop a greater understanding of daily levels of engagement amongst people living with dementia. Data was collected using unstructured observations, Dementia Care Mapping (DCM, Bradford Dementia Group 1997), conversations and a focus group with people living with dementia in a care home. Within this approach, self-reported activity preferences amongst residents and the factors that made activities meaningful to these individuals were explored. In addition, observations enabled a thorough examination of the complex factors that impacted residents' level of engagement. This data was used to inform the action research element of this study. Workshops with members of staff at the care home were used to investigate how opportunities for residents to engage in positive and meaningful activities might be increased within the context of everyday care. During these workshops the researcher worked with care workers to develop a strategy to increase levels of positive engagement with the intention of evaluating and refining this strategy during the field research. This strategy was directly informed by the activity preferences reported by residents and with consideration to the identified barriers to supporting activity in the home. This research was embedded in academic, political and practice literature concerning engagement and wellbeing amongst people living with dementia in care homes.

RELEVANT RESEARCH

Engaging in a variety of activities is a basic human need (Wolcock 2003; Wenbourn et al. 2008). This need to engage continues into old age (Bowling 2008; Foster and Walker 2015) and remains despite the progression of dementia (Kitwood 1997a; Phinney et al. 2007). Successful aging theories suggest a positive association between an individual's level of engagement in activity and their overall life satisfaction (Foster and Walker 2015). Activity theory has long asserted that those who remain engaged and connected to their social surroundings experience greater levels of wellbeing as a result (Havighurst 1961). Similarly, 'successful ageing' emphasises the value of remaining both cognitively and physically active (Foster and Walker 2015). Within social research, people living with dementia often report a wish to continue to engage in positive activities and consider the opportunity for participation in activities to be an important facet of wellbeing and quality of life (Phinney et al. 2007; Williamson 2010; O'Sullivan and Hocking 2013; Edvardsson et al. 2014). Further research suggests that engagement in activities is central to physical health, cognitive functioning and wellbeing of these individuals (Snowdon 2002; Pressman et al. 2009; Ikezoe et al. 2013).

Conversely, occupational deprivation amongst individuals living with dementia is associated with boredom, loneliness and helplessness (Harper Ice 2002) and also has a negative impact on an individual's physical health and cognitive function (Ikezoe et al. 2013; den Ouden et al. 2015; Mansbach et al. 2017). Yet despite this, a 'marked occupational poverty' (Perrin, 1997, p. 938) often exists amongst people living with dementia in care homes. This appears incongruous with the fact that these individuals continue to report a wish to engage in a range of positive and meaningful activities and remain clear about the type of activities they would like to undertake (Harmer and Orrell 2008; Tak et al. 2015; Kaufmann and Engel 2016). This suggests that residents living with dementia may need more appropriate support from others to enable optimal engagement. Conversely, the high levels of disengagement amongst care home residents imply that many care facilities might find it difficult to offer this support (Green and Cooper 2000; Holthe et al. 2007).

Creating a holistic picture of the specific factors that may premote or prevent opportunities to engage in activities witthin care homes may be a first step in trying to resolve this issue and a number of studies have considered these factors (Smit et al. 2017). Research has shown, for example, that the realisation of person-centred care within an institution (Pulsford 1997; Edvardsson et al. 2014), strong leadership (Green and Cooper 2000; Brooker et al. 2007), a clear care philosophy (Green and Cooper 2000) and appropriate staff training (Perrin 1997; Kuhn et al. 2004; Brooker et al. 2007) may facilitate activity provision (Smit et al. 2017). Equally, a poor culture of care (Buettner and Fitzsimmons 2003; Kolanowski et al. 2006; Edvardsson et al. 2014), a limited understanding of the importance of activities (Pulsford 1997; den Ouden et al. 2015) and low staff to resident ratios (Harmer and Orrell 2008; Smit et al. 2017) might have a negative impact. In addition, while many care homes attempt to increase activity levels by providing a weekly activity programme, this has been identified as a potentially suboptimal way to support engagement (Buettner and Fitzsimmons 2003). Integrating activities into care practices might be more successful in promoting engagement in activities and supporting wellbeing (Buettner and Fitzsimmons 2003; Knun et al. 2004; Vollicer et al. 2006; Hammer and Orrell 2008). Yet it remains unclear *how* this might be achieved in practice despite policy objectives and practice literature championing engagement amongst individuals living in care homes.

POLICY AND PRACTICE CONTEXT

This thesis builds upon academic research about promoting wellbeing amongst people living with dementia in a care home environment by offering opportunities for meaningful engagement. In so doing, it is consistent with the following international and UK dementia policy objectives and practice initiatives:

- ‘Improving care for people with dementia in care homes’ (DH 2009, p. 57).
- ‘Improving standards in care homes and domiciliary care’ (DH 2012, p. 9).
- Providing ‘clear steps for supporting physical and mental functioning and wellbeing [including] the provision of social engagement and recreational activities’ (ADI and WHO 2012, p. 63).
- ‘Innovation to improve the quality of life for people with dementia and their carers’ (DH and PMO 2013, p. 1).
- To promote wellbeing amongst people living with dementia, including wellbeing relating to ‘participation in work, education, training or recreation’ (UK Government 2014).
- ‘We want the person with dementia […] to be at the heart of everything we do. We want their wellbeing and quality of life to be first and foremost in the minds of those commissioning and providing services, recognising that each person with dementia

and their carer is an individual with specific and often differing needs' (DH 2016, p. 29).

- 'Activity helps to sustain both physical and mental health, so it is important that older people living in care homes are able to maintain interests and have opportunities to develop new ones' (NICE 2018).

During the past few decades, national and European dementia policy appears to have been focused on a reasonably humanitarian approach (Longley and Warner 2002; ADI 2017). And currently, there appears to be a political agenda to focus upon the person living with dementia and the quality of care and support they receive (DH 2009; 2016; Hampson and Morris 2017). Therefore, this research is relevant to the current academic landscape and political agenda and corresponds to what people living with dementia value.

Chapter Two – Literature Review: Dementia, Care Homes and Wellbeing

As the number of people living with dementia is expected to increase significantly, the long-term care and support of these individuals has fast become one of the most significant challenges facing health and social care today, both nationally (Department of Health and Social Care (DH) 2015) and internationally (Alzheimer's Disease International and World Health Organisation (ADI and WHO) 2012; Alzheimer's Disease International (ADI) 2017; Prince et al. 2016). In the UK, dementia is the most common reason for admission into long-term care (Quince 2013) and with the ever increasing prevalence of people living with dementia in health and social care settings it becomes imperative that relevant professionals have the necessary skills and expertise to appropriately support these individuals (Grealish et al. 2018). Recent UK and international policy is focused on the provision of good quality and individually tailored care and support for people living with dementia with an emphasis upon their wellbeing and quality of life (ADI and WHO 2012; Prince et al. 2013; DH 2009; 2015; 2016).

People living with dementia, their families and care workers have identified opportunities for engagement in activities as one of a number of essential components of good quality care (Bradshaw et al. 2012; Edvardsson et al. 2014). Research points to the fact that the need for activity endures cognitive decline associated with dementia (Quince 2013) and therefore, promoting activities is key to quality care delivery (Wenborn et al. 2013; DH 2014; Milte et al. 2016) and central to individuals' wellbeing (Brooker and Duce 2000; DH 2009; Sjögren et al. 2013; Cedervall et al. 2015). Yet despite strategies that seek to improve opportunities for engagement amongst people living with dementia in care homes (Brooker and Wooley 2007; Brooker et al. 2007; Pool 2012) the evidence suggests that the lived experience in care homes is one of a state of passivity and disengagement (Harper Ice 2002;

den Ouden et al. 2015). This is likely to have negative consequences upon individuals' physical and mental health (Brooker et al. 2016). There appears to be an overall lack of awarenss of how to meet individuals' needs for engagement in care homes (Hancock et al. 2006; Holthe et al. 2007). Yet while it is clear that people living with dementia in care homes need to be given more opportunities to engage in activities, *how* that might be achieved in practice is less clear owing to the complexity of the factors that impact upon care delivery (Nolan et al. 1995; Khun et al. 2002; Smit et al. 2017).

LITERATURE SEARCH STRATEGY

A literature review was conducted between October 2013 and May 2014 with the intention of identifying academic literature appropriate to this project. A follow-up literature search was conducted in May 2018 to identify additional work published in the interim. Search terms were employed using different combinations of words to build up a coherent picture of available texts within this field (Appendix i - *Literature Review: Key search terms*). Medical Subject Heading (MeSH) terms (National Library of Medicine (NLM) 2018) were used to ensure that database searches were systematic, however free text was also employed where no appropriate MeSH term was available. Databases searched included CINAHL Complete, Medline Complete, PsycARTICLES, PsycINFO, Science Citation Index and Social Science Citation Index as these best reflected academic disciplines appropriate to this research topic. No lower cut-off date was set. However, as a result of the comparative recentness of academic interest in the care and support of people living with dementia, few articles were identified predating the 1980s. No formal data limits were set, with the exception that the text was written in English. Articles were screened for inclusion by title and then by abstract. Copies of those considered appropriate following this preliminary process were obtained from Bournemouth University's Library and the articles read in full to ensure their suitability for this review. In view of the fact that systematic reviews of complex evidence may not yield all of the expedient material available (Greenhalgh and Peacock 2005), a 'snowball' technique (identifying further references from references) and the author's own knowledge were used to identify additional texts. In addition, internet searches were conducted to find relevant reports and policy documents. Alzheimer's Disease International (ADI), Alzheimer's Society, Department of Health and Social Care (DH), National Institute for Health and Care Excellence (NICE), the UK Government and World Health Organisation (WHO) websites were scrutinised, yielding several key documents.

Conceptualising Dementia

Once believed to be a 'natural' part of the ageing process (Bond 1992), dementia is now used as an umbrella term to describe a number of symptoms caused by neurological conditions associated with changes or damage to an individual's brain (World Health Organization (WHO) 2017; Alzheimer's Research UK (AR UK) 2018a). The most common reason for this damage is Alzheimer's disease, which causes a build-up of abnormal proteins in the brain (amyloid and tau) leading to nerve cell damage and vascular dementia, which occurs when blood vessels in the brain become damaged (AR UK 2018a). The symptoms caused by dementia depend on the specific disease and vary from person to person but generally include an element of memory loss combined with behavioural changes, communication and language difficulties and difficulties processing information or solving problems which are severe enough to affect an individual's daily life (AR UK 2018a). As a result of these symptoms, it is likely that a person living with dementia will require additional care and support at some point during their journey either in the community or in a long-term care facility such as a care home or hospital (Zimmerman et al. 2013).

During the 1970s, dementia was identified as a major cause of death (Katzman 1976). However, it was not until 2015 that the disease became the leading cause of death in the UK overtaking those from heart disease and cancer (Public Health England 2017). It is also the most common reason for admission to a care home (Zimmerman et al. 2013) with approximately 70% of individuals living in care homes expected to have dementia (Prince et al. 2014). As life expectancy rises, the number of people living with dementia in the UK is expected to increase from 850,000 (in 2014) to one million by 2025 (Prince et al. 2014). Therefore, the care and support of these individuals is likely to continue to be a significant social challenge, with the cost of doing so far outstripping that of other prevalent chronic conditions such as cancer (AR UK 2018b). Nevertheless, while public spending on dementia research continues to grow (DH 2016), spending remains proportionately low in comparison to other long-term health conditions (AR UK 2015). For every ten pounds spent on health and social care research for example, eight pence is spent on research into dementia. This is thirteen times less than that spent on research into cancer (Luengo-Fernandez et al. 2016).

Yet, the prevalence of dementia has resulted in a social and economic-political response to the condition, bringing it into the political and public spotlight (DH 2009; ADI and WHO

2012; Department of Health and Social Care and Prime Minister's Office (DH and PMO) 2013; DH 2015). In addition, academic interest in dementia from a biomedical and a social science perspective has significantly increased (Knapp et al. 2007), as has the discussion surrounding quality of life, wellbeing and dementia care (Bradshaw et al. 2012; Smit et al. 2016; National Institute for Health and Care Excellence (NICE) 2018). This has resulted in a wide-ranging collection of theoretical approaches and a significant shift in our understanding of the condition (Downs et al. 2006; Innes 2009). Half a century ago, for example, the dominant view within Western society was that the symptoms associated with dementia were part of a normal ageing process (Downs et al. 2006; Innes 2009). Certainly, as dementia becomes more common with age and because most instances of dementia occur amongst the older members of society, the study of dementia often appears inexorably bound up with gerontology (Downs et al. 2006). Nevertheless, today we know more about 'dementia' as a neuropsychiatric condition and social experience than ever before (AD UK 2018a).

DEMENTIA AS A NEUROLOGICAL DISEASE

In 1907, German neuroscientist Alois Alzheimer first identified the relationship between brain lacerations in one of his patients and her 'abnormal behaviours' (Holstein 1997; Swerdlow 2007). Upon this discovery, the newly named Alzheimer's disease was considered a rare brain condition in younger adults (Holstein 1997; Chaufan et al. 2012) while the same symptoms in older people were viewed as inevitable senility and a normal part of the ageing process (Bond 1992). It was not until the mid 1970s that the neurological damage associated with Alzheimer's and what was then known as senile dementia were found to be almost identical and dementia as a disease in older adults was identified (Katzman 1976). Thus, dementia as a neuropsychiatric disorder replaced the idea of senility as a normal part of ageing (Downs et al. 2006). Within this biomedical model, dementia is viewed as an abnormal, pathological condition to be controlled within the biomedical sphere and the lived experience of those with dementia is seen as a direct result of the damage to the brain (Sabat 2008; Innes 2009). Viewed exclusively from this perspective, the symptoms associated with dementia such as memory loss, difficulties in organising or sequencing tasks, problems identifying objects and communication difficulties are seen as a direct result of neuropathy caused by the disease (Sabat 2008; Innes 2012).

The biomedical approaches to dementia have made a considerable contribution to the study of the disease (Holstein 1997). As a result of medical science, researchers are now closer than ever to establishing the specific organic changes in the brain associated with the disease and have identified a number of modifiable and non-modifiable risk factors (Brodaty et al. 2011; AR UK 2018a) as well as strategies for prevention (Frankish and Horton 2017). We now know for example, that Alzheimer's may develop up to 20 years before the first clinical symptoms and that approximately a third of instances of dementia may be preventable with positive lifestyle choices (AR UK 2018a). Biomedical research has also contributed to the development of diagnostic tools and treatment options (Hutchings et al. 2010; Martorana et al. 2010) although the impact of the latter remains significantly limited (Kuhn and Moss 2002). Scientific research has also facilitated the ascension of dementia to the political domain, transforming it from an obscure geriatric condition (Binstock et al. 1992) to a national and international health priority (WHO & ADI 2012; DH & PMO 2013; ADI 2014). In addition, there is evidence that placing dementia within a biomedical sphere has proved beneficial to individuals living with the condition by giving clarity and meaning to otherwise inexplicable symptoms (Hansen et al. 2008) and enabling them to make informed decisions about the future (Exley et al. 2009).

CRITIQUING THE BIOMEDICAL UNDERSTANDINGS OF DEMENTIA

While biomedical models of dementia continue to dominate the understanding of the condition (McParland et al. 2017; AR UK 2018a), there is a growing body of evidence to show that neuropathology alone is insufficient to account for the cognitive limitations and behavioural symptoms associated with dementia (Lyman 1989, Snowdon 1997, Dewing 2008; Sabat 2008; Innes 2009). In addition, the biomedical understandings, with a focus on symptoms and the control of the 'disease', are insufficient for equipping professionals to best support people living with dementia (Kitwood and Bredin 1992a; Downs et al. 2006; Gilmore and Brannelly 2010). Longitudinal research involving annual cognitive and physical examinations of 678 catholic nuns during their lifetime, before studying their brains after death, found a limited correlation between cognitive functioning in life and the extent of physical damage to the brain (Snowdon 1997; 2003). The authors therefore concluded that symptoms of dementia were not only due to biomedical factors but that they may be mediated by an individual's educational levels and their psychosocial environment (Snowdon 1997). This research, The Nun Study (Snowdon 1997; 2001; 2003) echoes concurrent work of social theorists such as Kitwood (Kitwood and Bredan 1992; Kitwood 1997a) and Lyman (1989) who pioneered the idea that the experience of dementia is the result of a complex interplay between neuropathological, psychological and social factors rather than neuropathology alone.

A further criticism of biomedical understandings of dementia lies in the fact that it negatively positions the individuals living with the condition by reframing them in the context of their diagnosis rather than as a unique human being (Kitwood 1997a; Innes 2009). Within biomedical models there remains an unequivocal emphasis upon the loss of function, loss of independence and inevitably on death, resulting in what has been defined as the 'tragedy discourse' (McParland et al. 2017 p. 258). Within this discourse, a person living with dementia is perceived principally as a patient, a passive 'victim' and a 'sufferer' (Downs et al. 2006), or worse, as an 'empty shell' (Bryden 2005, p. 156), 'the living dead' (Beuniak 2011) or as an individual that no longer exists (Cahill 2018). Indeed, within public culture, there is a narrative of alarm associated with dementia. This narrative focuses upon the increasing number of people living with dementia, the financial 'burden of caring for those with dementia and the loss of abilities and ultimate loss of self, experienced by these individuals (Harding and Palfrey 1997; Innes 2009). An example of this narrative is evident within a recent Alzheimer's Research UK promotion, which asserts that Alzheimer's disease 'strips away everything that makes you, you' (Alzheimer's Research UK, 2016). The biomedical approaches to dementia have been fundamental in constructing this public narrative (Harding and Palfrey 1997).

This perception ultimately impacts upon the way these individuals are viewed by society, enabling the continuation of the negative labels and stigmatisation associated with the disease (Innes 2009; Cahill 2018). In addition, this discourse and the perceptions of hopelessness and futility associated with dementia (McPartland et al. 2017) is influential upon how these individuals are supported and cared for (Downs et al. 2006). There is a tacit and incorrect assumption for example, that nothing can be done (Kitwood 1993b; WHO 2017). Evidence suggests that care practices based solely on a biomedical understanding of dementia are reduced to sustaining basic physical needs alone (Kitwood 1997a). Such a model of care is ill equipped to meet complex and extensive psychological and social needs of the individual being cared for (Kitwood and Bredin 1992a) and can therefore be regarded as inadequate (Taft et al. 1997; Kontos and Naglie 2007).

DEMENTIA FROM A BIO-PSYCHO-SOCIAL APPROACH

During the past three decades, social scientists have been instrumental in unpicking the dominant views about dementia based on a unidimensional (biomedical) approach and in challenging the prevailing public narrative of dementia as an illness or disease (Harding and Palfrey 1997; Innes 2009; Sabat 2008). The psychosocial understandings of dementia were developed as a reaction to the dominance of the biomedical paradigm and its failure to fully explain the complex factors contributing to an individual's experience of dementia (Taft et al. 1997; Sabat 2008; Behuniak 2010). Kitwood (1993a; 1997a), for example, highlighted the limitations of the biomedical model and identified the need for a more holistic understanding of the condition calling to attention the psychosocial factors which have a part to play in an individual's experience of dementia and the presentation of their symptoms. Additional research suggests that the behaviour associated with dementia is affected by at least four interconnecting factors:

- Damage to the brain caused by the disease process,
- An individual's reaction to that damage,
- The way the individual is treated by others,
- The reaction of the person living with dementia to the way they are treated by others, (Sabat 2008, pp. 70-71).

Kitwood (1993a; 1997a) summarised these elements using a simple 'equation'. This equation illustrated how the manifestation of dementia (represented in this equation as 'SD') may be understood as a result of a complex interplay between five factors:

$$SD = P + B + H + NI + SP$$

(Kitwood 1993a, p. 541)

Within this equation 'P' refers to an individual's personality and more specifically, to their ability to cope with loss and change and their openness to help from others. 'B' signifies an individual's past experiences (biography) and 'H' their physical health. 'NI' refers to their neurological impairment and 'SP' to social psychology, that is to say to their social environment with particular reference to interactions with others as these interactions have the potential to uphold or diminish an individual's sense of safety, value and personal being (Kitwood 1993a). This approach acknowledges the biological, psychological and social factors that have an impact upon an individual's experience of dementia. Within this framework, the case for appropriate care and support for individuals living with dementia is clearly made by challenging the predominant narrative that 'nothing can be done' for these individuals. The framework offers an alternative way of understanding dementia and highlights the role that interaction with others can have in influencing the experience of dementia thus bringing the individual with dementia to the forefront of the discussion (Kitwood 1997a). In so doing, the importance of providing good quality care and support to people living with dementia becomes imperative in improving wellbeing for those living with the condition (Brooker and Duce 2000; Phinney 2008; May et al. 2009). This challenges the traditional culture of physically orientated dementia care (that is care that focuses primarily on the physical body) and emphasises the need for a more holistic and person-centred alternative (May et al. 2009; Innes 2012).

Personhood and The Self

The theories of 'personhood' (Kitwood and Bredin 1992a) and 'selfhood' (Sabat and Harré 1992) are two of the most significant theories arising from psychosocial understanding of dementia (Innes 2012; Nowell et al. 2013) and have been significant in our understanding of the lived experiences of people with dementia. Developed on both sides of the Atlantic during the 1980s and 1990s, personhood and selfhood further challenge the biomedical model by placing the individual (rather than their dementia) at the centre of the academic discussion and care practices (Kitwood and Bredin 1992a; Sabat and Harré 1992). Both paradigms have successfully challenged traditional western philosophical concepts linking personhood to cognition that have led to the stigmatising perceptions of people living with dementia as sub-human or 'the living dead' (Behuniak 2011). Thus, with these approaches, people living with dementia are reframed as valuable, autonomous and sentient human beings in their own right (Dran 2008; Behuniak 2010). The ideas of the existence of personhood and selfhood underpin the argument for the importance of offering these individuals good quality care and support that facilitates not only their physical but also their psychological and social needs (Kitwood 1997). This shift in the narrative has arguably been one of the greatest contributions to the conceptualisation of dementia (Gilmour and Brannelly 2010).

THE SELF AND DEMENTIA

Taking a social constructivist approach that social reality is formed by individuals' shared views and meanings (Burr 2015, see also p. 50, below), Sabat and Harré (1992) disputed the dominant assumptions that the self and personal identities are lost with the progression of dementia (Cohen and Eisdorfer, 1986). Instead, they argue that the dementia does not inevitably lead to a loss of self and that personal identities remain consistent even in the latest stages of the disease, although they may be masked by the symptoms of the dementia (Sabat and Harré 1992). Furthermore, the authors highlight the need for people living with dementia to be supported in a way that maintains their sense of self and emphasise the importance of quality social interactions in supporting the selfhood; selfhood might be upheld or damaged by interactions with others (Sabat and Harré 1992). The earlier conceptual work of Sabat and Harré was subsequently expanded upon by Sabat (2001) to comprise three expansive properties of the selfhood labelled Self 1, Self 2 and Self 3. Within this framework 'Self 1' reflects the reality that through the use of the first person pronoun (such as 'I', 'me' and 'mine') we are able to express identity and personal preferences. 'Self 1' remains little affected by the onset of dementia. 'Self 2' encompasses an individual's physical or psychological characteristics, their opinions and aspirations and, as such, may be routed within the distant past such as a deeply held religion or the result of a more recent event. Sabat (2001) suggested that while 'Self 2' also remains largely untouched by dementia, it may become vulnerable to the treatment of an individual by others. 'Self 3' represents an individual's multifaceted social identity and refers to that individual's life roles such as that of a wife, grandparent, professional or homemaker. Individuals therefore have numerous aspects to 'Self 3' and may act in accordance with the role being undertaken (for example the role of the professional or the role of a wife). Unlike Selfs 1 and 2, 'Self 3' is reliant upon the social context and is influenced by interactions with others. It is also affected by the symptoms of dementia (Sabat 2001). Social interactions therefore have the potential to nurture or to damage an individual's sense of this aspect of self in people living with dementia (Sabat 2001; Kelly 2010).

More recently, academic discussion has considered the role that the body has to play in the manifestation of the Self in dementia (Kontos 2004; Kontos and Martin 2013). The concept of embodied selfhood reminds us that the Self can also exist in the pre-reflective body and can be conveyed by the way that people living with dementia project their body for example in subtle attentiveness, appearance, spontaneous actions and social etiquette (Kontos 2005). The body therefore is a fundamental means of expression and essential to the expression of the Self and personhood (Kontos 2007). The framework of Selfs 1, 2 and 3 (Sabat 2001) and the theory of embodied selfhood (Kontos 2004) are not only important in their own right but are valuable since they strengthen the case for offering good quality care and support to people living with dementia and make the case for individualised care (Cohen-Mansfield et al. 2006). Furthermore, research has indicated that the opportunity to engage in activities (for example, habitual or familiar activities) has the potential to strengthen an individual's sense of self and identity and therefore have a positive effect upon wellbeing (Phinney et al. 2007; Harmer and Orrell 2008; Cohen-Mansfield et al. 2010; Mansbach et al. 2017; Han et al. 2016).

PERSONHOOD

Approaching the study of dementia from a psychological perspective, Kitwood (1989) began to explore the idea of personhood in relation to dementia. The notion of personhood is one that is well established within western philosophies and was originally founded upon the cognitive capabilities of an individual (cognitive orientated personhood) with the inference that a human being is only a person if they are able to display highly complex forms of thought (Zeiler 2014). However, placing cognitive qualification on personhood may have devastating consequences upon some of the most vulnerable members of society including individuals with brain damage (Cranford and Smith 1987; Farah 2013), those with learning difficulties (Graham 2010) and people living with dementia (Kitwood 1997a; Perry and O'Connor 2002) by positioning individuals as non-persons (Beauchamp 1999). During the end of the twentieth century, Kitwood (1989; 1990; 1993a; 1993b; 1997b; Kitwood and Bredin 1992a) facilitated the recognition of people living with dementia in their full humanity as people by arguing that it was possible for these individuals to retain personhood despite their diagnosis (Kitwood 1997a). Abandoning the cognitive orientated approach to personhood, Kitwood redefined personhood as:

> *[…] a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust* (Kitwood 1997a p. 8).

One might argue with Kitwood's use of the word 'bestow' for it implies that personhood only exists with the permission of others (Zeiler 2014). Indeed, the concept of personhood has been criticised for placing it only within the social world and therefore failing to take into account how the body might define an individual as a person and give essence to the Self (Kontos 2005). However, the narrative of personhood has become a significant challenge to traditional representations of dementia (Gilmour and Brannelly 2010). It provided an alternative idea of dementia by focusing on the psychological factors that may impact the clinical symptoms and the lived experience of people with dementia rather than on the pathology alone (Gilmour and Brannelly 2010).

Using personhood as a conceptual tool focuses attention on the interdependency between individuals living with dementia and the social world and acknowledges the need of human beings for relationships and human contact (Kitwood 1997a; Gilmour and Brannelly 2010). While individuals living with dementia have shown to support their own personhood by drawing on past experiences (Sabat 2001; Nowell et al. 2013), the quality of social interactions with others has the potential to uphold or damage that personhood (Kitwood 1997a) in the same way that interactions may support or weaken 'Self 3' (Sabat 2001). In both narratives the psychosocial environment is key and this has significant implications for the care and support offered to people living with dementia (Caspar et al. 2013). Underpinning this notion is the idea therefore that personhood does not decline as dementia progresses but might be upheld by positive interactions termed 'positive person work' or undermined by negative ones, labelled 'malignant social psychology' (Kitwood 1997a). Malignant social psychology combined with the neurological impairment associated with dementia might lead to personhood becoming undermined or hidden (Kitwood and Bredin 1992a) as evidenced by ill-being such as expressions of anger, grief, agitation or apathy (Brooker and Surr 2005). Within the biomedical approaches to dementia, these expressions may be viewed as part of the process of the condition. However, in acknowledging the impact that an individual's psychosocial environment has upon their lived experience, the idea of malignant social psychology identified the role that other people have to play in shaping that lived experience.

Kitwood (1990; 1997a) identified 17 types of interaction based on malignant social psychology towards people living with dementia. He defined these episodes as being a consequence not of malice on behalf of the care worker but as part of the social construction of dementia and the way individuals with dementia are positioned by society (Kitwood 1997a, p. 46-47):

1. Treachery – Using forms of deception to distract or manipulate a person.

2. Disempowerment – Not allowing a person to use their skills and abilities, failing to help them with tasks they have initiated.
3. Infantilisation – treating a person in a patronising way.
4. Intimidation - inducing fear through the use of threats or physical power.
5. Labelling – using a category such as dementia as the basis for interacting with a person and explaining their behaviour.
6. Stigmatisation – treating a person as though they were a diseased object or outcast.
7. Outpacing – providing information in a way that is too fast for a person to understand or putting them under pressure to do things more rapidly.
8. Invalidation – failing to acknowledge a person’s subjective reality.
9. Banishment – sending a person away or excluding them either psychologically or physically
10. Objectification – treating a person as though they are an object rather than a sentient being.
11. Ignoring – carrying on in the presence of an individual as though they were not there.
12. Imposition – Forcing a person to do something or overriding their decision.
13. Withholding – Refusing to give asked for attention or to meet an evident need.
14. Accusation – blaming a person for their actions that arise from physical or cognitive impairment or their misunderstanding of a situation.
15. Disruption – disrupting a person’s action or reflection, breaking their frame of reference.
16. Mockery – making fun of an individual, teasing them or making jokes at their expense.
17. Disparagement – telling a person that they are incompetent or worthless. Acting in a way that damages their self-esteem.

Wellbeing on the other hand can be achieved through the actions of others (care workers and nursing staff for example) in supporting the fulfilment of five key psychosocial needs. These relate to the interconnected needs for comfort, attachment, identity, inclusion and occupation (Kitwood 1997a, p. 82). Of these five needs, the need for occupation appears to be synonymous with engagement within this context and is defined by Kitwood as:

> *‘To be involved in the process of life in a way that is personally significant, and which draws upon a person’s abilities and powers. The opposite state of boredom, apathy and futility. […] Often occupation involved having some kind of project, whether in*

> *work or leisure; it might, however, simply consist of play. If people are deprived of occupation, abilities begin to atrophy and self-esteem drains away.* (Kitwood 1997a, p. 83).

Engagement is therefore acknowledged as fundamental psychological need for people living with dementia and therefore essential to personhood (Milte et al. 2016) and to improving wellbeing amongst people living with dementia (Kitwood 1997a; Kaufmann and Engels 2016). Kitwood argued that people living with dementia require more intensive support in order to meet their key psychological needs. He (Kitwood 1997a, p. 90 - 92) therefore identified ten areas of 'positive person work' which may assist care workers to support the needs of individuals:

1. Recognition – acknowledging a person by name, affirming their own uniqueness.
2. Negotiation – the process of consulting an individual on things that affect them.
3. Collaboration – Working together with the person with dementia, 'doing with' rather than 'doing to'.
4. Play – enabling positive self-expressionism.
5. Timalation – sensory stimulation.
6. Celebration – sharing a moment of joy with a person with dementia.
7. Relaxation - relaxing with a person with dementia, creating a relaxing environment.
8. Validation – acting with empathy and understanding, validating the experience of a person with dementia.
9. Holding – offering comfort and security.
10. Facilitation – enabling a person with dementia to do what they wish to do by offering appropriate support.

The case for supporting engagement amongst people living with dementia is a clear theme running through the two frameworks of malignant social psychology and positive person work. Within the 17 types of interaction termed malignant social psychology, disempowerment, imposition, disruption and objectification, all of which prevent or disrupt an individual's engagement, are viewed as instances that undermine personhood and affect ill-being. Conversely, within the framework of positive person work, instances of facilitation, collaboration, play and timalation have the potential to empower or enable positive engagement and are identified as interactions that might promote wellbeing amongst people living with dementia. Indeed, Kitwood's terminology of wellbeing in care homes is based upon this framework and assumes a relationship between the quality of care as defined within this framework and the wellbeing of people living with dementia (Fosey et al. 2002). These frameworks are central to the idea of person-centred care which focuses on maintaining the personhood and unique individuality of people living with dementia, thereby promoting wellbeing within the context of a care home environment (p. 34, below).

BEYOND PERSONHOOD TO CITIZENSHIP AND HUMAN RIGHTS

The concepts of personhood and the self are undoubtedly a positive lens through which to view dementia and have made a significant contribution to the way people living with dementia are cared for and supported. However, there has been little within these narratives relating to citizenship and the human rights of these individuals. Certainly, until recently, the rights of people living with dementia were afforded a low priority both nationally and internationally (Cahill 2018). During the last decade, however, the debate surrounding personhood has evolved to include a discussion of citizenship (Bartlett and O'Connor 2007; Bartlett 2014) and argues for dementia to be considered through a human rights lens (Kelly and Innes 2013; Cahill 2018).

The idea of citizenship places the person with dementia within the wider social context and focuses particularly upon their social participation. Within this model, the historical stigmatisation and discrimination directed towards people living with dementia can be challenged by emphasising the rights and responsibilities that these individuals have within a social context (Gilmour and Brannelly, 2010). Within this concept, the perception of persons with dementia evolves from passive recipients of care whose wellbeing relies on the interactions of others to citizens with autonomy and control. This marks a shift in power dynamics moving from the power of professionals to the power of individuals (Gilmour and Brannelly, 2010; Wiersma et al. 2016). Consequently, the concept of citizenship highlights the need for participatory and negotiated relationships between people living with dementia and care providers and policy makers (Barnes and Brannelly 2008). On a macro level, this involves supporting people living with dementia to play a key role in developing policy directives and practice guidelines. This has been achieved by organisations such as the Dementia Engagement and Empowerment Project (DEEP 2018), which supports people living with dementia to change services and Dementia Alliance International (DAI 2018), which represents people with dementia around the globe and has been influential in the consideration of human rights from the perspective of dementia (WHO 2015; DAI 2016).

Human rights are closely linked to the concept of citizenship. The qualification for human rights depends solely upon being human (British Institute for Human Rights (BIHR) 2010). However, evidence suggests that human rights are applied less rigorously and less consistently within long-term care of older adults (BIHR 2010) and particularly of those living with dementia (Kelly and Innes 2013; WHO 2015; Cahill 2018). Arguably, dementia needs to be considered through a human rights based approach since people living with dementia are in themselves holders of human rights (Cahill 2018). Yet, within the context of care homes, it may be argued that people living with dementia experience care practices which may infringe their human rights (Alzheimer Europe 2012), 'including the right to be treated equally, to dignity, privacy, independence and autonomy' (Cahill 2018, p. 100). Furthermore, within the context of this thesis, the Convention on the Rights of Persons with Disabilities (CRPD) has identified the opportunity for 'participation in cultural life, recreation, leisure and sport' as a basic human right (CRPD 2017, p. 22). Within this framework, the opportunities for people living with dementia in care homes to participate in activities is not only desirable as a means to improve their wellbeing but is a fundamental human right. It is imperative therefore that there are sufficient opportunities for such participation within care homes.

Wellbeing in Care Homes

Care homes are an important issue for people living with dementia (DAI 2016). With a diagnosis of dementia comes an increased likelihood of a future need for institutional care (Nwe Winn et al. 2011; Prince et al. 2015). A care home becomes an individual's permanent place of residence and therefore arguably their own home (Cahill 2018). How that individual spends their time in this home, who they spend it with and the quality of their interactions with others is likely to have an impact upon their mood, wellbeing and overall lived experience (Kitwood 1997a; Harmer and Orrell 2008; Bradshaw et al. 2012; Edvardsson et al. 2014).

According to Alzheimer's Disease International, care homes for people living with dementia typically comprise:

- Residential care or assisted living facilities, staffed by care assistants, which provide assistance with activities of daily living and supervision, but no on site specialist medical or nursing care.

- Nursing homes, staffed by registered nurses as well as nursing and care assistants, and able to attend to medical and nursing care needs, as well as high levels of personal care.
- Dementia special care units, staffed by specialist dementia nurses and attended by multidisciplinary care teams, capable of providing specialist care for those with advanced dementia, behavioural problems and psychological symptoms, and complex medical comorbidities (Prince et al. 2013, p. 33).

Moving into a care home involves life changes which have the potential to significantly affect an individual’s quality of life (Bradshaw et al. 2012). Evidence suggests that people living with dementia associate care homes with a loss of independence and control (Boyle 2005; Bradshaw et al. 2012), occupational deprivation (den Ouden et al. 2015), a lack of privacy (Bradshaw et al. 2012), loneliness and isolation (Bradshaw et al. 2012) and poor quality of life (Fossey 2008). Care homes are usually well equipped to appropriately attend to individuals’ physical and environmental needs. However, social needs such as the need for company and stimulating activities often remain unfulfilled (Handcock et al. 2006). Nevertheless, it is possible for people with dementia to live well within a care home environment (Mak 2011; Bradshaw et al. 2012) and national policy advocates an approach to care that enhances the wellbeing of individuals (DH 2009; 2016; UK Government 2014; NICE 2018).

DEFINING WELLBEING

While the term ‘wellbeing’ is widespread in literature and policy concerning people living with dementia in care homes (DH 2009; 2016; UK Government 2014; NICE 2018), there appears to be no universally accepted definition of the term ‘wellbeing’. The academic debate focused on the conceptualisation of wellbeing is complex. Subjective wellbeing, for example, is concerned with the attainment of a state of happiness. Within this framework, wellbeing can be measured simply by the question ‘am I happy?’ and considers that feeling of happiness is an adequate measure of an individual’s wellbeing (Diener 2000). Yet self-determination theory (Ryan et al. 2008) and psychological wellbeing (Ryff 1989) argue that wellbeing is centred on personal growth, concluding that happiness alone is not a sufficient premise to suppose wellbeing. Within the framework of psychological wellbeing, wellbeing is based upon an individual’s acceptance of self, attainment of full potential, a sense of direction, positive relationships, the effective management of the environment and autonomy (Ryff 1989).

This thesis adopts Kitwood's definition of wellbeing in dementia, which identifies four facets of wellbeing within the context of dementia care (Kitwood and Bredin 1992). These are: a sense of personal worth and self-esteem, a sense of agency, social confidence and hope. With reference to a sense of worth and self-esteem, people living with dementia who retain their sense of self-worth and who are able to accept their cognitive impairment may be in a relative state of wellbeing according to Kitwood and Bredin (1992). A sense of agency is an individual's ability to 'control their personal life in a meaningful way, to produce, to achieve, to make some mark upon others and the world' (Kitwood and Bredin 1992, p. 283). Social confidence relates to an individual's sense of being at ease with others and able to move towards them. Hope denotes a confidence that security will endure despite their changing internal and external world (Kitwood and Bredin 1992). This approach emphasises that with dementia, wellbeing is significantly impacted by interactions with others and can be defined in terms of the fulfilment of the five key psychological needs identified by Kitwood, those of comfort, attachment, identity, inclusion and occupation. Comfort carries meanings of closeness to others and the feeling of security that derives from that closeness. Attachment creates a sense of safety in times of uncertainty and a bond of connection with others. Inclusion occurs when an individual feels accepted by others within their social environment. Occupation means to be involved in a way that draws on an individual's own abilities and is defined by feelings of satisfaction and self-esteem. Finally, identity relates to having a continuity between the individual's past and their present life (Kitwood 1997a, pp. 81-84). A recent study that sought self-reports from people living with dementia found that the fulfilment of these psychological needs, with the addition of 'agency', was an appropriate framework with which to consider wellbeing in the context of dementia (Kaufmann and Engels 2016). In addition, this concept makes the case for quality person-centred dementia care since it is essential to supporting an individual's wellbeing.

PERSON-CENTRED DEMENTIA CARE

Person-centred care is associated with improved wellbeing for people living with dementia and wellbeing has become a key outcome measure for dementia care (DH 2009; 2015; 2016; Kaufmann and Engels 2016). Although the terms wellbeing and quality of life are often used interchangeably, there is a general consensus that wellbeing is a personal and subjective component of quality of life (Kaufmann and Engle's 2016). With the advent of psychosocial understandings of dementia and within the conceptual frameworks of personhood and the self, the discourse surrounding care has begun to shift from one that focuses upon physical maintenance to one concerned with wellbeing and quality of life outcomes (Edvardsson et al. 2008). These concepts have, therefore, been instrumental in improving the quality of care for people living with dementia (Nolan et al. 2008).

Traditionally, long-term dementia care has been centred within biomedical models of dementia. Consequently, care delivery has concentrated upon fulfilling the basic physical needs of an individual and on controlling the disease. Within this model, care homes became 'warehouses' (Kitwood 1997a) where older people go to die (Davies and Nolan 2003). Within the new (psychosocial based) model of care, however, attention is given to an individual's more complex psychological needs (Kitwood and Bredin 1992a; Kitwood 1997a; Caspar et al. 2013) and upon offering an enriched lived experience to the individual with dementia (Brooker and Woolley 2007). The concept of person-centred care was developed alongside the theory of personhood (Kitwood and Bredin 1992a; Kitwood 1993b; 1997a) as a response to the biomedical model of care (Edvardsson et al. 2008). With origins in client-centred counselling (see Rogers 1961, Brooker 2016), the person-centred care of people living with dementia sought to combine ways of working with these individuals that emphasised the importance of communication and relationships and of supporting the personhood of an individual living with dementia (Kitwood 1997a; Brooker and Latham 2016). While it is a term that is often used interchangeably with patient-centred (Mead and Bower 2000; Weigel 2017) or personalising care (DH 2016), 'person' centred (Kitwood 1997a) embodies the inherent value of the individual *person* within the approach (Edvardsson et al. 2008).

The cornerstone of person-centred care is the positioning of the PERSON with dementia (rather than the dementia) at the centre of the narrative and the recognition that the psychosocial environment can be pivotal in an individual's experience of the condition (Kitwood 1997a). Person-centred care, therefore, requires that an individual is treated in accordance with their unique personhood and that appropriate and innovative measures are used to ensure that personhood is maintained. It offers an individualised approach to care which takes into account a person's preferences, life history, skills and ability and champions the notion that people living with dementia should be afforded dignity and respect (Edvardsson et al. 2008). As emphasis is placed on the quality of life and wellbeing of individuals (Keating and Gaudet 2012), person-centred care is often considered a 'gold standard' of care (Davis and Pope 2010; Caspar et al. 2013). Furthermore, a person-centred approach to the care and support of people living with dementia has become a key element of national policy (DH 2009). Indeed, a recent Implementation Plan for dementia services in England championed the need for care that recognised each person with dementia as an individual and that was tailored to meet each person's unique and specific needs (DH 2016).

While there appears to be strong support for person-centred approaches to care, there is limited consensus around a single working definition of 'person-centred care' beyond the care that it is a model which seeks to maintain the personhood of an individual (Brooker 2003; Innes 2009; Brooker and Latham 2016). Therefore, the idea of person-centred care means different things to different people (Edvardsson et al. 2008) and in different contexts (Brooker and Latham 2016). It may simultaneously be viewed as a value-base, as individualised care, as a collection of techniques or as a method of successful communication (Brooker and Latham 2016). Based on a review of the literature surrounding person-centred approaches to care, Brooker and Latham (2016) identified that definitions of the approach often comprised four main elements. These were: valuing the person with dementia, treating the person with dementia as an individual, looking at the world from the perspective of the person with dementia and recognising that all life is grounded in relationships and that people living with dementia need enriched social environments (Brooker and Latham 2016, p. 12). These key elements can exist together or independently of one another.

The concept of person-centred care is important as it emphasises the value and uniqueness of the individual living with dementia and promotes the need for providing a type of care that focuses on the fulfilment of individuals' psychosocial needs and promotes wellbeing. This includes their need for individually tailored, positive activities which are an essential part of improving or sustaining wellbeing amongst people living with dementia (Kaufmann and Engels 2016; Milte et al. 2016).

LIVING WELL WITH DEMENTIA IN CARE HOMES

It is important to identify individuals' views on the factors that affect their own ability to live well within the context of care homes (Bradshaw et al. 2012). A review by Bradshaw, Playford and Riaza (2012) into the opinions of care home residents (this review was not limited to people living with dementia) found that living well was associated with an individual's acceptance and adaptation to their new living environment, their connectedness with others, the care practices and a homelike or normalising environment. The literature suggests that an individual's ability to adapt to their new living environment and to retain a positive attitude have been associated with the maintenance of their independence, autonomy and sense of self (Bradshaw et al. 2012). This links to Kitwood and Bredin's (1992) concept of wellbeing amongst people living with dementia in care homes, which highlights that self-esteem, an acceptance of cognitive impairment and a level of autonomy is central to individuals' wellbeing. Feeling a connection with others is also an important element of living well within care, this includes friendships with other residents and positive relationships with staff (Bradshaw et al. 2012). Other authors have identified this as central to wellbeing (Roland and Chapple 2015; Han et al. 2016; Mansbach et al. 2017) and connectedness is also an element of Kitwood and Bredin's (1992) concept of wellbeing in care.

Care practices also have an important influence on wellbeing. Residents have reported that it was important that their needs were appropriately met by care workers whom they knew and who knew them well (Bradshaw et al. 2012). With this in mind, the continuity of care workers and care workers' positive attitudes to their residents become essential to supporting an individual to live well within a care home. Furthermore, the skills, knowledge and expertise of care and nursing staff are essential to meeting the complex physical and psychosocial needs of residents and therefore to providing a good quality of care (Wenborn 2017). Organisational factors or the culture of care have also been increasingly identified as being influential on the care that individuals receive (Killett et al. 2016). The culture of care refers to 'pattern of shared basic assumptions developed by a group and founded to work as it adapts to problems, and taught to new members as the correct way to perceive, think and feel' (Killett at al. 2016, p 161). Therefore, organisational culture can shape the behaviour and attitudes of staff. Research has identified seven key elements of organisational culture that are key to providing good quality care and to enhance wellbeing of residents. These are: a shared goal to provide good quality care, the management's ability to negotiate external pressures so that they do not have a negative impact on care practices, a body of care staff who feel empowered to take responsibility for resident wellbeing, staff and management's openness to change, a sense of community in the home, engagement in activity amongst residents and a care worker's knowledge and understanding of residents (Killet et al. 2016).

Finally, individuals in care have identified a homelike or normalised environment as essential to wellbeing. This might include a homely (rather than an institutional style) physical environment and a meaningful daily lifestyle, as opposed to one that is described as regimented, restricted routine and boring (Bradshaw et al. 2012). Individuals with dementia living in care homes have expressed a wish to get out of the home and visit familiar places such as church or the shops. Simply going for a walk or accessing a garden has also been reported as important to wellbeing (Atwal et al. 2003). Furthermore, the opportunity to participate in stimulating activities has been identified as key to enhance pleasure and improving wellbeing amongst individuals living in care homes (Vernooij-Dassen 2007; Port et al. 2011; Bradshaw et al. 2012; Wenborn et al. 2013; Smit et al 2016). Normal and everyday activities in particular have been associated with wellbeing as these might be central in reaffirming an individual's sense of self and can create a feeling of familiarity or an 'at-homeness' (Edvardsson et al. 2014, p. 270). People living with dementia themselves have reported that engagement is an essential part of enabling and improving wellbeing (Atwal 2003; NeWin et al. 2011; Popham and Orrell 2012; Roach and Drummond 2014). Indeed, engagement in positive and meaningful activities is a key thread running through the academic, political and best practice literature regarding wellbeing amongst people living with dementia in care homes. It is therefore to participation in activities that this review now turns.

Meaningful Activity for People Living with Dementia in Care Homes

Engaging in activities is a basic human need (Wenbourn et al. 2008) that influences quality of life (Tak et al. 2015; Smit et al. 2016) and life satisfaction (Milte et al. 2016). It has also been identified as a fundamental human right (CRPD 2017; Cahill 2018). Activities can support cognitive and physical functioning and increase levels of independence and wellbeing (Sabat 2008; O'Sullian and Hocking 2013; Smit et al. 2016). In addition, people living with dementia retain the willingness to participate in activities (Kitwood 1997a) and have reported 'having things to do' to be of great value (O'Sullivan and Hocking 2013, p. 172, Williamson 2010; NeWin et al. 2011; Popham and Orell 2012; Roach and Drummond 2014). Conversely, low levels of activity can have a negative impact on an individual's physical and mental health (Wenborn et al, 2008; Ikezoe et al. 2013; Brooker et al. 2016) and can lead to feelings of boredom, loneliness and isolation (Harper Ice 2002). Yet, evidence suggests that residents of care homes spend a significant proportion of their time unengaged in any activity (see for example Harper Ice 2002; den Ouden et al. 2015).

MEANINGFUL ACTIVITY FOR PEOPLE LIVING WITH DEMENTIA

Considering what might be meaningful activities for people living with dementia can be split into (i) the *type* of activity that an individual would like to do and (ii) the *meaning* of engagement. The first considers the specific activities that individuals might like to engage in, the second concerns the *meaning* of activities for individuals. Research engaging directly with people living with dementia has sought to identify the types of activities that these individuals value. Findings have included physical activities, being out of doors, arts and craft, listening to music, reading, games, work like activities and social activities (Harmer and Orrell 2008; Tak et al. 2015; Beerens et al. 2016). Self-reported activity preferences appear to remain unchanged with the onset and progression of dementia and are often linked to past hobbies or past leisure activities (Phinney et al. 2007; Tak et al. 2015).

While assessing the types of activities might be a relatively easy task, identifying what makes meaning in an activity is more complex (Mansbach et al. 2017). Yet through engaging with people living with dementia, their family members and professional care workers as well as through observations, research has identified a wealth of potential reasons why participation in activities may hold meaning. Positive effect or feelings of enjoyment and pleasure have been found to be an appropriate measure of meaning in an activity (Phinney et al. 2007; Smit et al. 2016). Certainly, enjoyment of an activity is central to whether an individual with dementia may choose to engage in it (Billington et al. 2013) and therefore, although a simple concept, must not be overlooked. Meaning may be found in activities that help to build and maintain positive relationships (Smit et al. 2016) and support a connection to others (Han et al. 2016) or that foster a connection to the Self and identity (Harmer and Orrell 2008; Roland and Chappell 2015; Han et al. 2016). In addition, engaging in past roles and responsibilities can enable an individual to feel that they continue to be a valued member of society (Gerritsen et al. 2007; Harmer and Orrell 2008) and connected to normality (Edvardsson et al. 2010b) and the social world (Phinney et al. 2007). In addition, the act of simply *doing* an activity can in itself hold meaning for a person with dementia (Phinney et al. 2007) for, as human beings, we all have an innate need for engagement (Wenbourn et al. 2008).

ENGAGEMENT AND PASSIVITY IN CARE HOMES

Within the context of care homes, engagement in activities (beyond those which are related to physical care) and positive social interaction are associated with higher levels of mood and wellbeing amongst individuals living with dementia (Schreiner et al. 2005; Beerens et al. 2016, Smit et al. 2016; Mansbach et al. 2017). However, there is evidence to suggest that levels of engagement amongst people living with dementia in care homes is unacceptably low (Innes and Surr 2001; Chung 2004; Kuhn et al. 2004; den Ouden 2015). Using Dementia Care Mapping (DCM, Bradford Dementia Group, 1997, see also p. 59, below), studies have shown low levels of activity amongst residents living with dementia (Innes and Surr 2001; Kuhn et al. 2002; 2004 Chung 2004). The most prevalent behaviours among these individuals included passive engagement, sleeping, social interaction (although this interaction may have been very brief, see p. 116, below) and eating and drinking while behaviours associated with positive and meaningful activity were observed infrequently (Innes and Surr 2001; Chung 2004; Kuhn et al. 2002). Chung (2004), for example, found that individuals spent 51% of their time in behaviours associated with passivity, social withdrawal or distress with the most prevalent behaviour being passive engagement (43%). This was compared to 10% of their time spent engaged in therapeutic activities. Studies also suggest that residents with dementia spent their time in a fairly neutral mood, showing no signs of ill-being or overt signs of wellbeing. Innes and Surr (2001) argue that this suggests a situation whereby individuals' physical care needs were broadly being met but that their psychological needs remained largely unfulfilled. Additionally, studies that have used DCM to evaluate therapeutic interventions have found that individuals' wellbeing is high when engaging in activities. One study found that during a horticultural intervention, individuals experienced considerable or significant positive mood and engagement for over 60% of their time (Hall et al. 2018). In this study, residents spent the majority of time engaged in positive and meaningful activity (Hall et al. 2008).

Alternative structured observational methods have shown that people living with dementia in care homes spend over half of their time in solitude (Schreiner et al. 2005). Furthermore, these individuals spend between 66.5% and 77.7% of their time displaying behaviours associated with passivity or disengagement (Nolan et al. 1995; Harper Ice 2002; Schreiner et al. 2005; den Ouden 2015) with one study reporting that some residents spent over 85% of their time in passivity (Harper Ice 2002). Correspondingly, studies indicate that residents with dementia spend up to 91.7% of their time in a neutral mood, showing no signs of positive or negative mood (Harper Ice 2002). These findings show that despite the political motivation for good quality dementia care that promotes individual wellbeing, such a model of care is not yet a reality.

While it might be tempting to believe that the answer to suboptimal levels of engagement is to introduce a programme of activities facilitated by dedicated activities staff (Hancock et al. 2006), evidence suggests that such an approach is often unsuccessful in providing adequate levels of engagement (Buettner and Fitzsimmons 2003; Kuhn et al. 2004; Vernooij-Dassen 2007). In reality, activity programmes only appear to be successful in engaging individuals for a relatively small proportion of the day, and there is often little opportunity for engagement beyond these programmes (Edvardsson et al. 2014; Cohen-Mansfield et al. 2009b). In addition, such programmes often focus on engaging residents in leisure activities and do not consider an individual’s need to participate in things such as self-care or work like activities, which are equally as important to individuals (Harmer and Orrell 2008; Edvardsson et al. 2014; Kaufmann and Engel 2016). In addition, such programmes may prevent care and nursing staff from encouraging or supporting participation amongst residents as they do not perceive this to be part of their role (Pulsford 1997). Research suggests that outside of formal activity plans, residents living with dementia have little to do beyond sitting in front of the television (Gústafsdóttir 2015; den Ouden et al. 2015; Milte et al. 2016). This often has limited therapeutic value as an engaging activity (de Medeiros et al. 2009; Gústafsdóttir, 2015) and does not fulfil individuals’ psychosocial needs (Atwal et al. 2003). Therefore, more needs to be done to find a solution to high levels of passivity and inactivity amongst people living with dementia in care (Harper Ice 2002; NICE 2018).

FACTORS INFLUENCING OPPORTUNITIES FOR ENGAGEMENT IN CARE HOMES

A number of studies have considered potential predictors of engagement beyond that which an activity programme can offer. Individuals’ cognitive and physical limitations (Green and Cooper 2000; Harmer and Orrell 2008; Edvardsson et al. 2014; Tak et al. 2015), the length of time an individual has spent in a care setting (Nolan et al. 1995), the physical environment (Brooker and Woolley 2007; Cohen-Mansfield et al. 2010), the culture of care (Butterner and Fitzsimmons 2003; Brooker and Wooley 2007; Edvardsson et al. 2014) and staff time constraints (Pulsford 1997; Volicer et al. 2006; den Ouden et al. 2015) have been shown to influence engagement amongst people living with dementia.

Despite the fact that activity participation remains important to people with dementia (Popham and Orrell 2012; Tak et al. 2015), cognitive limitations may have a negative impact upon levels of engagement (Harper Ice 2002, Kuhn et al. 2004; Tak et al. 2015). Cognitive impairment often caused a lack of motivation to initiate or sustain activity without support (Green and Cooper 2000; Harmer and Orrell 2008). A recent study by Cohen-Mansfield (2017) concluded that cognitive functioning was the most consistent factor influencing engagement in group activities within care homes. In addition, declining physical abilities have also been identified as a barrier to independent pursuits (Tak et al. 2015). However, there is evidence that the physical environment might to some extent mitigate individuals' limitations if designed in a way that maximises remaining skills and capacities (Calkins 2009; Davis et al. 2009) and studies suggest an association between the design of the physical environment and the wellbeing of individuals living with dementia (Calkins 2009). Yet, it is likely that even the best designed environment will not in itself inevitably lead to increased levels of activity amongst individuals living with dementia in care homes (Wenborn 2017) and therefore additional factors need to be considered.

The culture of care is often cited as a predictor of activity involvement amongst residents living with dementia (Green and Cooper 2000; Brooker et al. 2007; Edvardsson et al. 2014; Killett et al. 2016) and has a significant potential to affect the realisation of person-centred care and influence the lived experience of care home residents (Killett et al. 2016). Research suggests that a care culture that values or achieves a higher level of person-centred care (Pulsford 1997; Broker et al. 2007; Edvardsson et al. 2014) and strong leadership or a clear philosophy (Green and Cooper 2000) is likely to offer more opportunities for engagement to residents. Conversely, the routine use of psychotropic medication (Buettner and Fitzsimmons 2003; Khun et al. 2004), a task orientated approach to care delivery (Kolanowski et al. 2006; Edvardsson et al. 2014) and a negative perception of activities amongst staff (den Ouden et al. 2015) have been associated with lower levels of engagement amongst people living with dementia in care.

Furthermore, low staff to resident ratios, care worker workloads and high staff turnover are preventative factors in resident engagement in care homes (Brooker and Woolley 2007; Edvardsson et al. 2014; den Ouden et al. 2015). However, an alternative stance has been put forward to suggest that an increase in staff time might not lead to increased levels of engagement amongst residents but to an increase in physical tasks performed (Nolan et al. 1995). This suggests that limited staff time alone cannot account for high level of disengagement in dementia care. Correspondingly, more recent research proposes that opportunities for engagement are reliant upon care worker knowledge and skill rather than higher staff ratios (Perrin 1997; Kuhn et al. 2004; Harmer and Orrell 2008; den Ouden et al. 2015). Therefore, increasing opportunities for resident engagement might be achievable with appropriate staff training rather than increasing staff numbers. Integrating activities into care practices might be the best way to provide engagement and support wellbeing (Hammer and Orrell 2008; Beerens et al. 2016) and therefore consideration must be given to how this might be achieved in practice and within the complexities of a care home.

Studies which have considered factors which might influence levels of engagement amongst people living with dementia in care homes have often focused on specific elements rather than looking at the care setting as a whole. Nolan, Grant and Nolan (1995), for example, considered levels of engagement in relation to length of stay and Kuhn Fulton and Edelman (2004) focus primarily upon the influence of cognitive impairment upon engagement. A recent piece of research has looked at the factors which might affect engagement in a more holistic manner (Smit et al. 2017). This research used questionnaires and interviews with care staff and home managers across 139 Dutch care homes as part of a much wider investigation about the developments in care homes for people living with dementia. The study suggests that resident characteristics, staff ratios and educational levels, the culture of care, job strain (as perceived by care staff), the physical environment and organised activities might predict engagement amongst residents (Smit et al. 2017). This research considered this issue at a macro level using staff perceptions of practice. While this study is of great value, it may be useful to explore this issue using in-depth observations in order to obtain a more detailed and nuanced perspective of the factors that affect engagement.

It is important to identify the factors which promote or prevent engagement in care homes as it is only by doing so that we might seek to understand how to improve opportunities for engagement amongst residents living with dementia.

Planning and Supporting Activity in Care Homes

Authors seeking a solution to high levels of passivity and disengagement in care have argued for a more integrated approach to activity in care and have developed strategies to make this possible (Brooker and Woolley 2007; Pool 2012). Pool (2012) suggests that successful activity provision hinges on identifying activities that are both meaningful to the individual and appropriate for an individual's unique level of physical and cognitive ability. The Pool

Activity Level (PAL) Instrument is based on the principle that to support engagement, those who care for individuals living with dementia must first acquire in-depth knowledge of their unique preferences, skills and abilities. To this end, the PAL Instrument provides care and nursing staff with a template to collect appropriate information and to use this to offer individuals living with dementia specifically tailored opportunities for engagement in everyday care (Pool 2012). Similarly, Brooker and Woolley (2007) propose the integration of activities into care homes using an Enriched Opportunities Programme. This Programme suggests five main elements are key to supporting positive engagement amongst people living with dementia. The elements include having a specialist senior member of staff to enable residents to achieve their potential for wellbeing (labelled the 'Locksmith'), conducting individualised assessments focused on enhancing wellbeing, increasing the number of structured activities on offer, appropriate staff training and quality leadership (Brooker and Wooley 2007; Brooker et al.2007). Both appear to focus on the importance of integrating activity into everyday care practice and on having in-depth knowledge of residents. It is likely that this is the best way to increase opportunities for engagement.

Yet this body of research into strategies to integrate activities into everyday care remains small and authors have called for more research into how to improve opportunities for engagement in care:

> *Further research and best practice exemplars would be valuable in providing successful strategies to move aged care practices forward towards increasing involvement of residents in meaningful activities. (Edvardsson et al. 2014)*

Therefore, this thesis seeks to identify how we might improve opportunities for residents living with dementia to engage in positive and meaningful activities throughout the day, beyond their engagement in a formal programme of activities.

Summary

While once neglected, the interest in the wellbeing of people living with dementia in care homes, has increasingly become a topic of academic, professional and political discussion (Smit et al. 2014; UK Government 2014; DH 2015; NICE 2018). Participation in stimulating activities and social interaction has a positive effect upon the wellbeing of older adults (Bowling 2008) and amongst people living with dementia (Chung 2004;

Cedervall et al. 2015) These individuals have reported that the opportunity to participate in activities has a significant positive impact upon their lived experience (Phinney 2006; Williamson 2010; Poppam and Orell 2012; Edvardsson et al. 2014). However, studies suggest that people living with dementia in care homes spend a significant proportion of their time in solitude (Schreiner et al. 2005) and in a state of passivity or withdrawn from their surroundings (Harper Ice 2002; den Ouden et al. 2015).

Activity programmes are traditionally used to offer opportunities for activities. Yet, they have a limited potential for proving optimal levels of engagement and wellbeing (Buettner and Fitzsimmons 2003; Kuhn et al. 2004; Vernooij-Dassen 2007). Therefore, opportunities to participate in positive and meaningful activities need to be part of the fabric of everyday care and woven into care practices. Yet achieving this is not without complications as there are a number of factors within care homes, which may promote or prevent engagement in everyday care. While one study has considered overall predictors of engagement in care homes for people living with dementia, it has done so using the perceptions of care staff and home managers alone (Smit et al. 2017). A consideration of this issue using in-depth observations in a care home environment would be valuable. Furthermore, it is important to find ways to improve opportunities for engagement in positive and meaningful activities amongst people living with dementia in care homes. This is likely to have a positive effect upon the wellbeing of people living with dementia in care homes.

Chapter Three – Research Design

To date, there is a limited body of literature regarding practical solutions to the high levels of inactivity in care homes. Therefore the overarching question that this research sought to answer was:

> *Can we improve wellbeing for people living with dementia in care homes by increasing their opportunities for engagement in positive and meaningful activities?*

Underpinning this single study were two interlinked aims. Firstly, this research sought to explore the lived experience of people with dementia living in a care home with particular reference to their levels of engagement in positive and meaningful activities and their self-reported wishes in terms of engagement. Secondly, this research was designed to examine the specific factors that impacted upon individuals’ engagement (or disengagement) and wellbeing within the complex context of care homes and to open up a discussion about how opportunities for engagement might be improved.

The first aim of this study was:

> Aim 1: To consider engagement in activities amongst people living with dementia in a care home.

Within this preliminary research aim were four key objectives:

1. To ascertain current levels of engagement and wellbeing amongst individuals living with dementia in care homes.
2. To examine how activities are currently delivered within a care home environment.

3. To determine the types of activities that individuals living with dementia value and would like to engage in.
4. To examine the relationship between types of engagement and wellbeing.

The second aim of this research was:

> Aim 2: To explore ways in which opportunities for engagement amongst people living with dementia in care homes might be improved in a sustainable way (i.e. within current budgetary and staffing limitations).

Within this aim were the following two objectives:

1. To explore the factors that impact upon levels of engagement amongst people living with dementia in care homes.
2. To work collaboratively with staff to identify how we might use this knowledge to develop a strategy to improve levels of engagement (within current budgetary and staffing constraints).

To best answer the research question and to fulfil the aims and objectives set out above, this research drew upon the research frameworks of ethnography (Wolcott 2008) and action research (Greenwood and Leven 2007; McNiff 2013). This approach enabled a level of depth and richness to the data beyond that which would have been possible by using a single research approach. Within this design, Dementia Care Mapping (DCM, Bradford Dementia Group, 1997) and concurrent ethnographic observations formed the backbone of this research. Interactional methods in the form of focused conversations, spontaneous conversations and a focus group with people living with dementia enabled the voices of these individuals to be heard throughout the research. This was of significance as these individuals were considered to be experts by their experience and therefore best placed to articulate experience. In addition, workshops with care workers were used to reflect upon current practices in the home and to design and develop a strategy to improve opportunities for engagement amongst residents with dementia in the home. Therefore, this study worked with two groups of participants, residents living with dementia and care workers. In this way, data collected during this research was a co-creation between the researcher, residents of Forest View and care workers.

Philosophical Foundations

The core philosophical assumptions underpinning any research project influence both the type of research that is undertaken and how that research is to be accomplished (Grix 2010). This thesis has been informed by a constructivist interpretivist epistemological position and is grounded in the interpretivist approach of social constructivism.

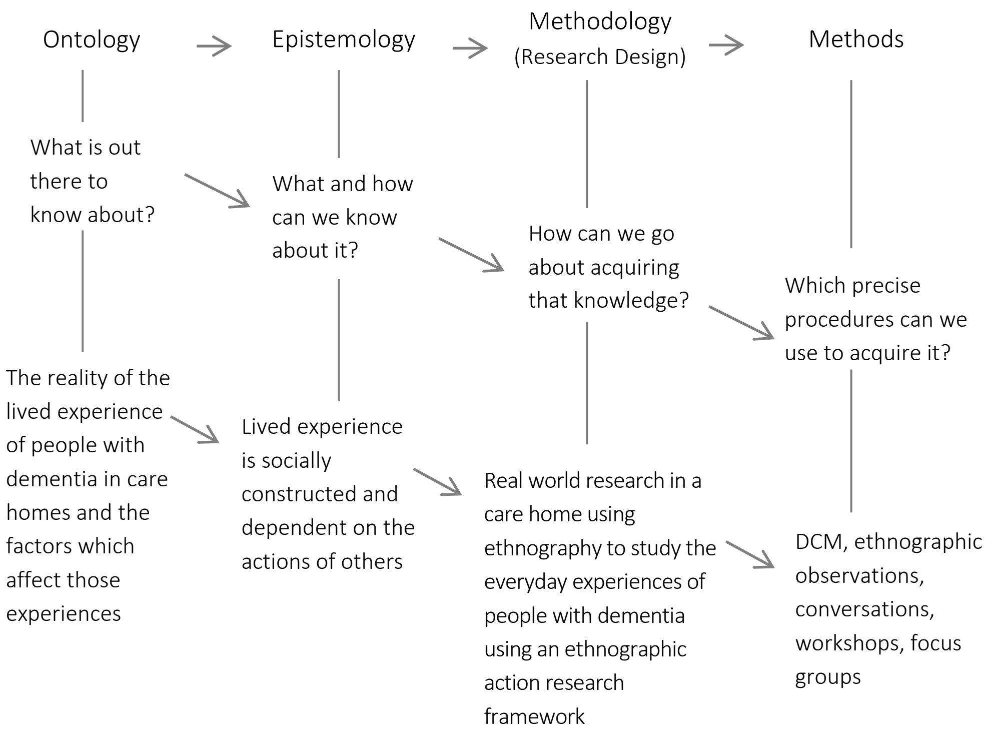
ONTOLOGICAL AND EPISTEMOLOGICAL PERSPECTIVES

The ontological and epistemological approach adopted within a study characterises the nature of that study and influences every element of it from the issue being researched to the methodology and methods used and the conclusions drawn from a set of findings. 'Ontology' refers to the characteristics of the social world and the views that individuals hold with regard to the nature of social reality (Ormston et al. 2014). This might represent the questions: 'What exists that we might acquire knowledge of?' (Hay 2002 p. 61). 'Underlying the broad concept of ontology are two basic positions; those of realism and idealism (Ormston et al. 2014). While members of the 'realism' school of thought regard the social world, like the natural world, as an objective reality made up of structures which are both constant and rigid, those who adopt idealism as an approach believe that the social world is constructed and shared by individuals (Ormston et al. 2014) and that human actions are motivated by their own values, beliefs and experience (Hammersley & Atkinson, 2007). Therefore, reality is dependent upon those subjective beliefs and understandings and may be constantly changing and evolving.

Epistemology considers the ways we can know about our world and what forms the basis of knowledge (Denscombe 2014; Ormston et al. 2014). Underlying the two broad ontological positions are the epistemologies of positivism or post positivism (underlying the 'realism' school of thought) and interpretivism and constructivism (underlying the 'idealism' school of thought). Within a positive approach, the nature of reality can be known about accurately using objective, unbiased (qualitative) observations such as measurement (Ormston et al. 2012). Within this paradigm, knowledge is objective, static and therefore unaffected by the research process (Blakie 2007). Taking an interpretive or constructivist approach however, acknowledges that knowledge is produced by exploring the social worlds of individuals and constructing meaning and interpretations from these individuals. Within this approach, the methodology and methods used to research natural science are inappropriate as the social world is not governed by natural law but ‘mediated through meaning and human agency’ (Ormston et al. 2014, p. 12). Therefore, research cannot successfully be conducted through a purely quantitative lens (Hammersley & Atkinson, 2007).

Within this research, an interpretive constructivist approach has been adopted to best fulfil the specific requirement of the research question. Both the experience of living with dementia and the lived experience in care homes are socially constructed phenomena (Harding and Palfrey 1997). Therefore, the response to the philosophical question ‘what exists that we might acquire knowledge of?’ (Hay 2002 p. 61) is that we can only know how different individuals and groups fashion their own social realities and seek to describe these differing realities. Therefore an interpretivist constructivist approach appears the most appropriate as it acknowledges the subjectivity inherent in the social worlds of individuals; social reality is understood as an entity that is continuously being constructed and reconstructed, shaped through individuals’ everyday actions, words and beliefs (Denscombe 2014). This approach has informed every element of the research from the initial decision about what should be researched to the research design, methods used and conclusions drawn from the findings. Figure One, shows the directional dependence between an ontological position and the methods used within a study. The approach adopted with this research is contextualised in this model.

Figure One - Ontology, Epistemology, Methodology and Methods: A directional dependence (Adapted from Hay 2002, p. 64)



SOCIAL CONSTRUCTIVISM

This thesis is grounded in the interpretivist approach of social constructivism. Such an approach has enabled an interpretation of the meaning of participants' experience and offered a comprehensive understanding of that lived experience in long-term care, with particular reference to the impact of engagement in activities and wellbeing. While there is no single agreed definition of 'social constructivism', it is a school of thought founded in the belief that an individual's reality is constructed over time in response to their own experiences as well as to wider social factors. Furthermore, personal experiences are interpreted through a range of historical and sociocultural factors (Burr 2015). Therefore, in line with an interpretivist epistemology, social constructivists would argue that within the study of the social word, objectivity is unattainable as social reality is formed by individuals' shared views and meanings and is therefore both relative and subjective (Harding and Palfrey 1997). Social constructivism may be described broadly as an approach that recognises one or more of the following fundamental assumptions:

- A critical view of knowledge that is considered to be taken-for-granted. Social constructivism challenges the view that 'knowledge' is founded upon unbiased objective observations and therefore argues against a positive epistemological approach to research that is typical of 'hard' sciences.
- That knowledge is historically and culturally specific. Therefore it is acknowledged within the approach that the way we understand the world is founded in culture and history. Within this context, the notion of good dementia care is recognised as being both historically and culturally specific as it has changed over time and is different across cultures.
- Knowledge is sustained by social processes and therefore is a construct between people or peoples. It is maintained by interactions and with social life and is consequently socially constructed. Within the context of this research, the way dementia is perceived in a society is based upon the construction of the condition within that society.
- Knowledge and action are interlinked and therefore different social constructions invite different human actions. Constructions of the social world are therefore bound up with power relationships that can influence the legitimate treatment of others. Within care homes, for example, the construction of dementia and the culture of care (as shared basic beliefs developed by a group of care staff that has an

influence upon the way that group works) will influence how individuals living with dementia are treated (Burr 2015).

This research is positioned within all of these assumptions since it assumes the social world to be fashioned by social, cultural and historical influences. Indeed, both the perception of dementia and shared assumptions about the appropriate ways to care for and support individuals living with the condition is a socially constructed phenomenon.

THE ROLE OF THE RESEARCHER WITHIN THIS FRAMEWORK

Within this study, the researcher interacted with people living with dementia to ascertain their activity preferences and their wish for engagement in the home. Using this information, the researcher worked with care workers at Forest View to support them to develop a strategy to improve opportunities for engagement amongst residents and therefore to act as agents for positive change. In this way, the research can loosely be described as a collaborative enquiry, whereby the research process was informed by the expressed needs of research participants (Burr 2015). In this way and within a social constructivist framework, this research was to an extent a democratised process in that the researcher was not perceived to be the 'expert' or in total control of the research. Within this approach therefore, the accounts of participants as to their lived experience were considered to be of equal value to the researcher's own observations and the chapters below, (particularly Chapter Six), includes verbatim accounts of participants' own experiences. Furthermore, the need for improved opportunities for engagement throughout the day was, to an extent, informed by residents' own reports of their need for activity and was part of the rationale for an action research approach (to create that positive change).

In addition, care workers were given control over the design of that positive change by being asked to create a strategy to improve opportunities for occupation. This approach acknowledged these care workers as experts in their field with a valuable contribution to make as to what might work in practice. In so doing, this research had the potential to be an empowering experience for both care worker participants and participants living with dementia. The ethos therefore was not one of the researcher doing research on the participants, but of working with them in a more collaborative way to fulfil an expressed need.

THE RESEARCHER'S VALUE BASE AND CORE BELIEFS

Within the context of interpretive research, it is understood that the researcher's own experiences and values can and do have a part to play in shaping research and as such the two cannot be separated (McNiff 2013). Research does not occur in a vacuum and the 'knowledge' gained by conducting a piece of research is constructed in the mind of the observer and therefore influenced by their own beliefs and values (Ormston et al. 2014). In addition, within action research, where the aim of the research is to actively change a situation for the better, those values motivating the researcher are an integral part of the process (Burr 2015).

Therefore, the researcher's core beliefs and values not only formed the motivation for undertaking a research project but were influential upon how the research was conducted as well as the conclusions drawn from the research. As a result, it is important that these are clearly articulated within this thesis (Nobel and Smith 2015). The values and core beliefs held by the researcher within the context of this research are that:

- Older people and people with a diagnosis of dementia remain valuable members of society and should be treated as such; advancing age and a diagnosis of dementia does not and should not denote declining worth.
- Every person living with dementia is a unique individual.
- People with dementia should be treated with dignity and respect.
- People living with dementia have the same psychosocial needs as other members of society. This includes the need for appropriate occupation and enjoyment.
- These needs do not diminish with increasing cognitive impairment but people living with dementia may need additional support to fulfil these needs; they have the right to quality support.
- People living with dementia retain a capacity for wellbeing and enjoyment. It is important to support people with dementia to live well in care homes.
- Engaging in a variety of activities is important to wellbeing.

These values have been shaped by both personal and professional encounters with individuals living with dementia and those who support them. The choice of study, research design, the research question, aims and objectives have been influenced by these core underlying beliefs as have the conclusions drawn from the findings.

Research design

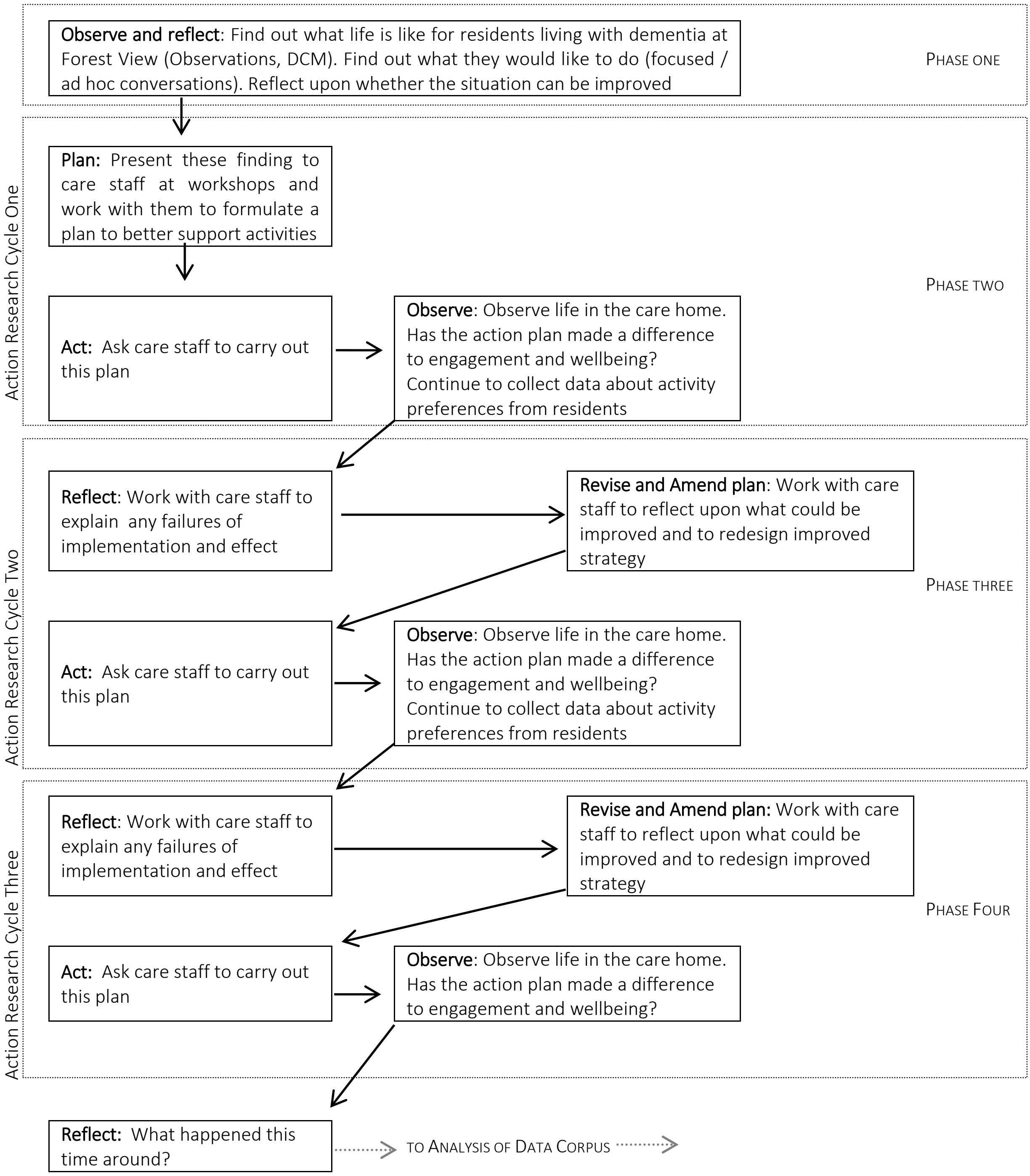
Due to the significant complexities of the research question, an approach was used that drew upon the research frameworks of ethnography and action research within the single study. This approach utilised the strength of both approaches with the intention of creating a fuller, more holistic understanding of the problems inherent in the research question. An ethnographic approach enabled a deep understanding of the lived experience of residents with dementia (Wolcott 2008; Fetterman 2010). Then, using action research, the researcher worked in partnership with staff at the care home with the purpose of developing a strategy to improve opportunities for engagement in a variety of activities. The intention was that this strategy was observed in practice and further refined by the researcher and care workers. This research was therefore designed to take place over four phases comprising three cycles of action research (Figure Two, p. 54). Encouraging positive change in this way, the research was designed not only to improve the lived experience of residents at Forest View but to create valuable knowledge about how to improve wellbeing amongst people living with dementia in care homes more generally (Brydon-Miller et al. 2003).

ETHNOGRAPHY

Ethnography seeks to understand the shared culture of a group through an in-depth investigation of a particular setting (Wolcott 2008), in this case a care home for people living with dementia. As such, it is a particular model of 'looking, listening and thinking about social phenomena' (Hammersley and Atkinson, 2007, p. 231). Ethnography is rooted in Western anthropology where it was used to explore the way of life amongst groups of people living beyond the Western world. However, ethnography is now used in a far broader field of study and concerns the understanding of the social worlds or cultures of a group of people (McNaughton et al. 2014). In this way, ethnography has become a well-established methodology in researching the social worlds of individuals living with dementia (Kelly 2010). It has been used to examine a variety of elements of their lived experience including the impact of creative interventions (Kelly 2010), the experience of hospital discharge (Poole et al. 2014), occupational patterns (Holthe et al. 2007) and experiences of healthcare (Prorok et al. 2013).

Figure Two - Study Design
(An adapted version of Lewin's model of action research in McNiff 2013, p. 61)

Idea: To study current levels of mood and engagement amongst people living with dementia in a care home and to discover the activities those individuals would like to engage in. To identify the factors that contribute to individuals' mood and engagement and to work with care staff to develop strategies to improve the current situation



Observe and reflect: Find out what life is like for residents living with dementia at Forest View (Observations, DCM). Find out what they would like to do (focused / ad hoc conversations). Reflect upon whether the situation can be improved

Plan: Present these finding to care staff at workshops and work with them to formulate a plan to better support activities

Act: Ask care staff to carry out this plan

Observe: Observe life in the care home. Has the action plan made a difference to engagement and wellbeing? Continue to collect data about activity preferences from residents

Reflect: Work with care staff to explain any failures of implementation and effect

Revise and Amend plan: Work with care staff to reflect upon what could be improved and to redesign improved strategy

Act: Ask care staff to carry out this plan

Observe: Observe life in the care home. Has the action plan made a difference to engagement and wellbeing? Continue to collect data about activity preferences from residents

Reflect: Work with care staff to explain any failures of implementation and effect

Revise and Amend plan: Work with care staff to reflect upon what could be improved and to redesign improved strategy

Act: Ask care staff to carry out this plan

Observe: Observe life in the care home. Has the action plan made a difference to engagement and wellbeing?

Reflect: What happened this time around?

The research framework acknowledges that individual and collective experience do not occur in isolation and are instead shaped by broader social, cultural and environmental factors (Fetterman 2010). Consequently, it corresponds to Kitwood's (1997a) model of understanding dementia, which highlights the role of the wider social environment upon the lived experience of people living with the condition.

Ethnography requires a researcher to spend time immersed in a group of people for an extended period of time (Wolcott 2008; Silverman 2011) with a view to documenting their distinctive social world to form an analytical understanding of individuals' activities and perspectives (Hammersley and Atkinson, 2007). It involves the researcher observing individuals (either overtly or covertly) in their own 'natural' physical and social environment (Fetterman 2010). As a methodology it is time consuming. Some authors advocate living with a group of people for a year or more in order to gather sufficient depth of data upon which to draw conclusions (Hammersley and Atkinson, 2007). However, there are no concrete rules on the length of time an ethnography should take (Wolcott 2008). Within the time limitations of a PhD, the ethnographic elements of this research were conducted over a period of 34 days; 27 days of observations, five days of focused conversations and a focus group and two days reviewing participants' formal records). This took place over a six month period. In addition, prior to this, the researcher had visited the home on a monthly basis and recorded reflections during these visits in a field diary.

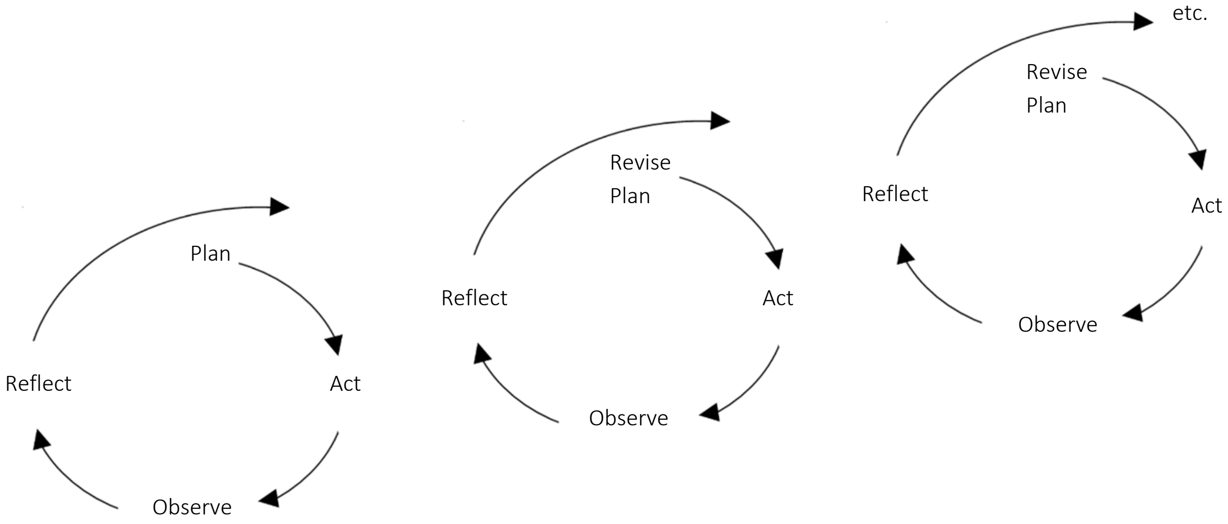
Unstructured observations remain the core method of ethnographic enquiry (Hammersley and Atkinson 2007; McNaughton et al. 2014). However, an ethnographic research design may also include unstructured or loosely structured interviews or conversations to add in-depth context to the findings (Hammersley and Atkinson 2007; Gray 2013). As such, it is similar to the methods that we, as human beings use to make sense of our own socially constructed surroundings. What differs in ethnography, is perhaps the systematic approach to data collection in which information is gathered, recorded and analysed to make sense of a specific research question (Hammersley and Atkinson 2007). Within this research, Dementia Care Mapping (DCM) and concurrent ethnographic observations of people living with dementia detailing their moment by moment lived experience were the principal methods employed. In addition, a systematic review of residents' care plans and activity logs, a focus group and both focused and spontaneous conversations with residents were part of the ethnographic element of this research. These methods were employed to gain an in-depth insight into the social worlds of people living with dementia and to ascertain their aspirations of engagement and interactions within the care home setting within a social constructivist approach.

However, despite its value, an ethnographic approach to research has been criticised for having limited impact (Hammersley and Atkinson 2007). As a research method, it is limited to the creation of knowledge and as such it is not a vehicle for constructive social or political change (Hammersley and Atkinson 2007). While the value of producing knowledge cannot be underestimated, encouraging positive change is imperative in improving the lived experience of individuals with dementia living in care homes. Therefore this study has been designed to combine ethnography with action research to attempt to provide an agent for that improvement.

Action Research

One of the aims of this research was to bring about positive change and to improve the lived experience of people with dementia in care homes. This was done by working with care and nursing staff to suggest an appropriate strategy to improve opportunities for positive engagement in activities. Of all the potential research tools, action research was selected as the most appropriate medium to facilitate this objective owing to the practical and solution driven focus of the framework. Action research is founded on the idea that change is positive and that fostering change may be valuable in knowledge creation (Brydon-Miller et al. 2003; Coghlan and Brannick 2014). In so doing, action research brings together the development of theoretical knowledge on the one hand and the means to influence change on the other; thus integrating theory and practice (Stringer 2013). Yet it also goes beyond this with a recognition that just as theory might inform practice, practice can generate theory (Brydon-Miller et al. 2003; Coghlan and Brannick 2014). The founder of action research, Kert Lewin, conceptualised action research as a cyclical process or an action–reflection cycle, through which a potential solution to a problem or set of problems is reached, delivered, critiqued and refined (Brydon-Miller et al. 2003). This approach was extended with the development of ongoing action–reflection cycles in which action research cycles were used sequentially to revise proposed change following a systematic pattern of plan, act, observe, reflect and revise (Figure Three). Therefore, the employment of critical self-reflection to enable the researcher to reflect upon and revise an approach, is central to action research (McNiff 2013).

Figure Three – The Spiral of Action Research Cycles
(Adapted from McNiff 2013, p.57)



Unlike other research frameworks, action research engages in the complexities of a social environment and uses this cycle of enquiry to formulate an effective resolution to problems experienced in the specific context (Stringer 2013). As such it is a practical research framework concerned with answering real world problems and focuses on an aspiration to effect positive change (Mcniff 2013). Consequently, those who work with action research often do so on a micro level by attempting to effect change in a specific and small scale context (in this case seeking an answer to the apparent limited opportunities that people living with dementia have to participate in daily activities within the context of care homes). Nevertheless, the knowledge generated from this change has the potential to act as a stimulus for positive change on a wider scale and therein lies its value (McNiff 2013). As a research tool, action research has gained credibility and popularity in social research over the past few decades with a dedicated peer reviewed journal to the methodology launched in 2003; *Action Research* (Brydon-Miller et al. 2003). With this rise in popularity, it has become an established research tool, contributing to the growing body of knowledge about good practice in supporting older individuals and people living with dementia. Indeed it has been used to explore a variety issues such as creating dementia friendly communities (Crampton and Eley 2013), improving nurses' understanding of geriatric care (Lea 2015) and changing attitudes to and social perceptions of dementia (O'Sullivan and Hocking 2013).

Within the context of this study, combined observational and interactional data gathered directly from people living with dementia in care homes identified a significant inconsistency between how these individuals were engaged throughout the day and how they reported that they would like to be engaged. Then care workers were asked to formulate, reflect upon and revise a strategy to better support their residents to engage in activities in a way that corresponded to the self-reported needs and desires of those residents. Care workers were chosen as they were considered to have expert knowledge of supporting people living with dementia and as they would be the key players in effecting positive change. The solution to the research problem was therefore reached with care practitioners (with input from people living with dementia) rather than by the researcher alone.

Working within an action research framework accepts the social constructivist perspective that reality is both subjective and relative and therefore socially constructed. Using this approach encourages a reflection upon how we, as human beings, might act in an informed and intelligent way to positively influence this socially constructed world (Reason and Bradbury 2001). In addition, asking care workers to devise a strategy to improve their practices for the better (rather than that strategy being researcher-led) has the potential to be an empowering experience and therefore enables a democratisation of the research process by shifting power away from the researcher and to care worker participants within the traditions of a social constructivist approach to research (Burr 2015).

Data Collection Methods

When selecting research methods it was imperative that the primary focus was on how to best accommodate the needs of the research question and underlying aims and objectives (Silverman 2011). Table One (p. 59), illustrates how the research frameworks and data collection methods were used to fulfil the aims and objectives of this study. The data collection methods used were selected on the basis that they were considered to be the best tools to answer the research question (Silverman 2011) and each method had a role to play in satisfying the individual aims of the study. A range of methods were used within this single study. Data Care Mapping (DCM), unstructured observations, a systematic review of care plans and activity logs, conversations (both focused and spontaneous) and a focus group were used to explore the lived experience of people with dementia with particular reference to their engagement in activities and their activity preferences. Within the action research element of this study, activity workshops with care staff were used to plan a strategy to improve opportunities for engagement amongst residents and then to reflect upon the success of that strategy in practice with a view to refining and improving it. The

Person-centred Care Assessment Tool (P-CAT, Edvaardsson et al. 2010a) also offered care workers the opportunity to reflect upon their own practices and to see how their perceptions of these practices altered over time. In addition, DCM and unstructured observations were used to observe how the strategy was put into action and the impact that this had upon resident wellbeing.

Table One – Linking the Research Aims and Objectives to the Research Framework and Methods

Research aim	Research objective	Research framework	Data collection methods
To consider engagement and wellbeing amongst people living with dementia in care homes.	To ascertain current levels of engagement and wellbeing amongst individuals living with dementia in care homes.	Ethnography	DCM, observations, care plans an activity log review
	To examine how activities are currently delivered in a care home environment.	Ethnography	DCM, observations, activity log review
	To determine the types of activities that individuals living with dementia value	Ethnography	DCM, observations, conversations, focus group
	To consider the relationship between engagement and wellbeing	Ethnography	DCM, observations
To explore ways in which engagement amongst people living with dementia in care homes might be improved	To explore factors contributing to levels of engagement amongst people living with dementia in care homes	Action research, ethnography	DCM, observations, conversations, focus group, workshops, P-CAT
	To work collaboratively with staff to identify how we might use this knowledge to develop a strategy for improved levels of engagement	Action research (informed by ethnography)	DCM, observations, workshops, P-CAT

DEMENTIA CARE MAPPING

Dementia Care Mapping is an internationally recognised and increasingly popular collection of observational tools used to evaluate the quality of long-term dementia care from the perspective of the individual living with dementia (Innes 2003; Brooker and Surr 2005; Barbosa et al. 2017). As such, it enables a microanalysis of care practices and moment by moment examination of the experiences of people living with dementia in care homes (Capstick 2003). The origins of DCM lie within the psychosocial theories of personhood and a person-centred approach to dementia care developed by Tom Kitwood (Kitwood 1993b; 1997a). Indeed, Kitwood himself originally developed the method through ethnographical observations in care homes (Kitwood and Bredin 1992a). Dementia Care Mapping emphasises the importance of quality interactions to the wellbeing of people living with dementia and therefore advocates a model of care based around the principles of person-centred care (Brooker 2003; Kitwood 1997). Thus, DCM acknowledges an individual's psychosocial environment as key to influencing their lived experiences (Brooker 2005) and therefore challenges the standard paradigm of traditional (task focused) care (Capstick 2003).

As the method seeks to evaluate care homes from the viewpoint of the person living with dementia, the observer is required to put themselves in the place of each individual being observed and is therefore consistent with a person centred approach to care (Brooker and Latham 2016). The original DCM manual states that:

> *Doing this involves a great deal more than simple observations. It requires the facility known as empathy; being able to put oneself, imaginatively, into the place of another person and sense what life may be like from within that person's frame of reference. (Bradford Dementia Group 1997, p. 5, quoted in Capstick 2003)*

Empathetic awareness is therefore a central element to the practice of DCM, with Kitwood describing the method as 'a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill' (Kitwood 1997a, p. 4).

The structured tool requires the observer (mapper) to observe up to five people living with dementia continuously for a period of time (usually more than four hours). Observations are broken down into five minute periods or 'time frames' and can only occur in communal areas of the care setting (Bradford Dementia Group 2005). Within the tool, four structured coding frameworks are used to record information. These are:

- Behaviour Category Codes (BCC). There are 24 of these in total and these can be used to code any behaviour an individual is engaged in such as sleep (N), receiving physical care (P) or engaged in an activity such as reading (I). One is coded for each five minute time frame during which a person is observed.
- Mood and Engagement Values (ME). These are six codes to choose from ranging from significant distress (-5) to significant joy, pleasure and sustained engagement (+5). One is coded for each five minute time frame during which a person is observed. Using this, an overall Well or Ill-being score, signifying individuals level of wellbeing for the duration of the observation can be calculated.

- Personal Detractions (PD). There are 17 possible PDs. These are based upon malignant social psychology and recorded when an incident is observed that might undermine the personhood of an individual.
- Personal Enhancers (PE). There are 17 possible PEs. These are based on Kitwood's concept of positive person work (Kitwood 1997a) and record instances when care staff have acted in a way to uphold an individual's personhood (Brooker and Surr 2005).

Updated editions of the tool are frequently introduced and DCM is currently in its eighth version (Brooker and Surr 2005), the edition used in this study.

At the end of each time frame the mapper is required to make a judgement about the behaviour that each participant was observed to be engaged in from a set of 23 Behaviour Category Codes (BCC, Table Two, p. 62). The selection of BCC is based upon the mapper's own observations and a set of operational rules to support the choice of code should more than one BCC occur in a given time frame (Appendix ii - *Dementia Care Mapping: Operational rules for recording Behaviour Category Codes*). These operational rules give preference to coding categories which have a greater potential for wellbeing (Broker and Surr 2005). Therefore, when using DCM, a 'best case' scenario is often presented in findings rather than an individual's true lived experience (Sloane et al. 2007). While this is not a criticism of the method, it must be taken into account when interpreting the findings. An example of this prioritisation of coding is evident in the following example:

> *Mollie is sitting in silence. A care worker passes. She says 'alright Mollie' and Mollie nods and smiles saying 'yes'. The interaction lasts a few seconds and the care worker moves away immediately. Mollie continues to sit in silence for the rest of the time frame (Field notes 16th June)*

In this time frame, the BCC coded for Mollie was 'Articulation' or (code A) indicating interaction, despite the fact that Mollie spent the majority of her time passively sitting in silence (code B). This type of interaction (an interaction of no more than a few seconds with the participant spending the rest of the time in a passive or withdrawn state) was frequent and therefore had the potential to distort the findings by showing participants interacting more than they actually were.

Table Two - Behaviour Category Codes (BCCs)
(Adapted from Bradford Dementia Group 2005 p. 17[1])

Code	Memory Cue	Appears in thesis as…	Description
Aa	*Articulation*	*Brief interaction*	*Interacting briefly with others verbally or otherwise with no obvious accompanying activity (a few seconds)*
Ab	*Articulation*	*Conversation*	*Engaging in a conversation with others verbally or otherwise with no obvious accompanying activity*
B	Borderline	Passive Engagement	Being engaged by passively watching surroundings
C	Cool	Disengaged / Withdrawn	Being disengaged and withdrawn
D	Doing for Self	Doing for self	Engaging in self-care such as putting on clothes, tying shoe laces or combing hair
E	Expressive	Expressive activity	Engaging in activities which have a clearly creative or expressive element such as arts and crafts
F	Food	Eating and Drinking	Included all aspects of eating or drinking
G	Going Back	Reminiscence	Reminiscence and life review activities in groups or one-to-one
I	Intellectual	Intellectual activity	Using intellectual abilities, for example reading the paper
J	Joints	Exercise	Activities which focus on physical exercise
Ka	*Kum and go*	*Walking in distress*	*Independently standing or walking in great distress*
Kb	*Kum and go*	*Walking from a-b*	*Independently standing or walking for the purpose of getting from one place to another*
Kc	*Kum and go*	*Walking as positive activity*	*Independently walking as a positive activity*
L	Leisure	Leisure activity	Activities which have a particular leisure fun or recreational component e.g. board games
N	Nod	Sleeping	Sleeping or dozing in communal areas
O	Objects	Interacting with objects	Showing attachment to an object such as a handbag, toy or doll
P	Physical	Physical Care	Receiving practical or physical care e.g. receiving assistance with walking, receiving medication
R	Religion	Religious activity	Spiritual or religious experiences or activities
S	Sexual	Sexual expression	Expression of a sexual nature
T	Timilation	Activities involving the senses	Activities which predominantly focus on stimulating the senses such as massage
U	Unresponded	Unattended distress	Making attempts to communicate (in distress) without receiving a response
V	Vocational	Work like activities	Work or work like activities for example watering plants, folding linen, handing round cake
W	Withstanding	Repetitive motion	Repetitive actions such as rubbing clothes or twisting hands
X	X-cretion	Not recorded	Relating to excretion
Y	Yourself	Interaction in the absence of others	Talking or interaction with oneself, an imagined person or the TV
Z	Zero	Other	None of the above

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[1] *Italics* indicate amendment to the original coding framework made by the author

Therefore, to mitigate this and in a slight variance to the traditional DCM framework, BCCs relating to interaction (A) were split into the sub categories of ‘Brief interaction’ (Aa) and ‘Conversation’ (Ab). ‘Brief interaction’ (Aa) were instances lasting no more than a few seconds, while ‘Conversation’ (Ab) represented a more sustained interaction. In addition, because walking appeared to be such a varied experience for residents, walking or standing independently (K) was also split into sub categories. These were ‘Walking in distress’ (Ka), ‘Walking from a-b’ (Kb) and ‘Walking as positive activity’ (Kc). The purpose of this was to give a better indication as to whether a behaviour related to a meaningful activity. These are defined here as those associated with positive social, recreational and vocational engagement and as such, distinct from care tasks, passivity and disengagement.

When used as a research tool, it is not uncommon to modify DCM slightly depending on the specific requirements of the research. Such modifications have included coding the predominant event rather than the ‘best event’ within the BCC framework to build a more accurate picture of the lived experience of individuals (Sloane et al. 2007). Grouping BCCs into large parent categories to give a more general overview of activities in a research setting has also been used (Chung 2004). Within this study, BCCs were grouped into three categories upon analysis of the data. These were passive engagement or disengagement, tasks necessary for physical care including minimal interaction and positive and meaningful activities (Table Three, p. 64).

Within this framework, passive engagement or disengagement refers to behaviours that involved an individual sitting alone and either passively watching their environment (B) or disengaged with it (C). This category included sleeping (N) and behaviours associated with distress, for example, unattended distress (U) and walking in distress (Ka). Tasks for care refers to those BCCs that were part of the task focused approach to care and physical maintenance of individual. These included brief interactions (Aa), eating and drinking (F), receiving personal care (P) and walking for the purposes of getting from one place to another (Kb). Within the context of these findings, positive and meaningful activities are considered to be those including a recreational, vocational, creative, leisure or social element. These were often delivered as part of the activities programme and appear to have had a positive effect upon residents’ levels of engagement and wellbeing (as defined within DCM).

Table Three - Overarching BCC Categories

Passive Engagement or Disengagement (including behaviours associated with distress)	**Tasks for Care and Physical Maintenance**	**Positive and Meaningful Engagement**
Passive Engagement (B) Disengaged/ Withdrawn (C) Walking in Distress (Ka) Sleeping (N) Unattended Distress (U) Repetitive Motion (W) Interaction in the Absence of Others (Y)	Brief Interaction (Aa) Eating or Drinking (F) Walking Independently (Kb) Receiving Physical Care (P)	Conversation (Ab) Doing for Self (D) Self-Expression (E) Reminiscence (G) Intellectual Activities (I) Exercise (J) Walking as an Activity (Kc) Leisure Activities (L) Interacting with Objects (O) Religious Activity (R) Sexual Expression (S) Activities Involving the Senses (T) Work like Activities (V)

Dementia Care Mapping also captures the state of mood and the level of engagement of each participant during each time frame by recording one of six Mood and Engagement (ME) values. The ME values range from +5 indicating high positive mood and sustained engagement to -5 representing significant distress (Table Four, below).

Table Four – Mood and Engagement Values
(Bradford Dementia Group 2005 p. 12)

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

Mood and Engagement values were always coded within the context of the accompanying BCC (Bradford Dementia Group, 2005) and in accordance with operational rules (Appendix ii - *Dementia Care Mapping: Operational rules for recording Behaviour Category Codes*). The information recorded using the BCC and ME frameworks was logged in real time onto raw

DCM data sheets (Appendix iii - *Dementia Care Mapping: Raw data sheet example*) and this data was analysed using a purpose built Excel spreadsheet developed by Bradford Dementia Group. This spreadsheet automatically calculated the percentage of time each participant and participants as a group spent observed in BCC and each ME value. To assess levels of mood, the researcher used Kitwood's original work which outlines 12 indicators of positive mood (Kitwood and Bredin 1992a, p 281-282). This has since been refined within DCM to include indicators of negative mood (Table Five). Judging positive or negative mood when a resident was in a state of passivity showing no overt signs of well or ill-being was a complex task. However, in-depth knowledge of the individual and the context of the observation often gave some clue to an individual's underlying mood (Capstick 2003; Brooker Surr 2005).

Table Five – Indicators of Well and Ill-Being in Dementia Care Mapping
(Brooker and Surr 2005 p. 39)

Indicators of Wellbeing	Indicators of Ill being
Assertiveness	Unattended despair
Bodily relaxation	Intense anger
Sensitivity to the needs of others	Unattended grief
Responding to and use of humour	Anxiety
Creative self-expression	Fear
Showing pleasure	Boredom
Helpfulness	Physical discomfort
Initiating social contact	Bodily tension
Showing affection	Agitation
Signs of self-respect	Apathy
Expressing a range of emotions	Withdrawal
	Cultural alienation
	Difficulty withstanding powerful others

Well or ill-being however, is more than levels of mood and engagement during a single time frame. Experiencing wellbeing is about the predominance of a positive over negative mood state during a period of time. Therefore at the end of each observation, it was possible to draw together Mood and Engagement data to enable an assessment of each individual's or a group of participants' overall well or ill-being during that observation. This interpreted data is reflected in a Well or Ill-being (WIB) score depicting a participant's or group's level of mood and engagement, on average, over an observational period (Appendix iv - *Dementia Care Mapping: Calculating Well and Ill-Being (WIB) Scores*). These scores could be compared by person or over a period of time to assess any overall improvements (or otherwise) to wellbeing.

The third and fourth coding frameworks concern episodes of positive and negative interaction between staff and residents that have a potential to either uphold or damage the personhood of the individual living with dementia (Bradford Dementia Group 2005). The third framework records instances of ‘malignant social psychology’ which might undermine personhood. In DCM these episodes are called Personal Detractions (PD). The fourth framework records occasions when staff were observed to have used an interaction to support the personhood of an individual or to have engaged in positive person work. These are called Personal Enhancers (PE). In these instances staff are psychologically available to residents and their interactions fulfil one or more of the five psychological needs of these individuals. There are 17 PEs and 17 PDs which might be recorded and are similar to Kitwood’s examples of positive person work (see p. 30) and malignant social psychology (see p. 28). They are directly linked to the psychosocial needs of individuals; those of comfort, identity, attachment, occupation and inclusion (Appendix v - *Dementia Care Mapping: Personal enhancers and personal detractions*).

Using these four coding frameworks, it is possible to build up a detailed evaluation of the quality of care delivered over a period of time. It is also possible to make an informed assessment about the types of engagement and relative state of well or ill-being experienced by an individual or group of individuals living with dementia in a care setting. This assessment can be fed back to care staff during designated feedback sessions and used to encourage positive developments to practice so as to improve the lived experience of residents (Innes 2003). It is a particularly useful way of presenting information to care staff since it is possible to synthesise the data into a succinct and comprehensible format, which can act as a starting point for a discussion about what potential improvements might look like.

As well as being a common tool for evaluating care homes, DCM has become a popular research tool amongst academics (Brooker and Surr 2005; Slone et al. 2007), enabling researchers to capture in-the-moment behaviours and wellbeing, as well as how those behaviour and wellbeing patterns change over a period of time. In addition, research has demonstrated the psychometric properties of DCM, establishing that Well and Ill-Being scores correlate with informant-related quality of life measurements and that the tool has achieved good test-retest reliability and high levels of inter-rater agreement (Fossey et al. 2002). The usefulness of DCM in assessing quality of life means that it appears to work well in longitudinal intervention evaluations (Fossey et al. 2002; Gigiotti et al. 2004; Hall et al.

2018) and in developmental evaluations (Wylie et al. 2002, Yasuda and Sakakibara 2017). It has also been used to examine wellbeing (Innes and Surr 2001) and quality of life (Fossey et al. 2002) in care homes. Most recently it is has been used to evaluate the impact of interventions such as life story books (Crook et al. 2016), live music (Richardson et al. 2015) and horticulture (Hall et al. 2018) upon the wellbeing of people living with dementia as well as the impact of staff training upon the delivery of person-centred care (Yasuda and Sakakibara 2017).

While the data gathered using DCM can be both rich and useful (Kuhn et al. 2002), those currently managing the tool advise careful consideration in deciding whether DCM is the best method for an investigation (Brooker and Surr 2005). As a research method it is both time-consuming (Fossey et al. 2002) and requires specialist training to use (Brooker and Surr 2005). Furthermore, there are limits to assessing wellbeing and quality of life using a single method and therefore employing additional methods may be expedient (Kuhn et al. 2002; Innes and Kelly 2007). Additional methods of assessing wellbeing such as interviews and focus groups with people living with dementia can add depth to this data (Kuhn et al. 2002; Brooker and Surr 2005). Therefore, adopting an approach that is not limited to DCM as the sole tool for data collection enables a fuller picture of a care setting beyond the limitations of the coding frameworks (Innes and Kelly 2007). This study is designed to accommodate such an approach.

UNSTRUCTURED OBSERVATIONS

Within this research project, Dementia Care Mapping was complemented by concurrent, unstructured or ethnographic observations. Observations have been formative in the development of ethnography and the two terms are often used interchangeably, with observations placed as the core method in ethnographic enquiry (Hammersley and Atkinson 2006; McNaughton et al. 2014). Data is usually collected using an unstructured approach by means of thick descriptive field notes (Hammersley and Atkinson 2007), which are used to record information and reflections upon a number of different aspects. In the context of this study, observations were used to consider elements that DCM failed to capture, including:

- The physical setting – the architectural and interior design of the care home including resources for activities.

- The social setting – the psychosocial environment; the actions, appearance and behaviour of individuals and how they change over time.
- The organisation's setting – this could include the way that work was organised and how staff were supported within that organisation. It also considered how resources were organised.

As a result, these unstructured observations added richness and depth to the data collected and analysed using DCM and provided a way to capture data that might otherwise be lost within the prescribed frameworks of that tool.

Therefore, while DCM looked at the specific behaviours an individual was engaged in and their levels of mood and engagement, rich ethnographic data sought to add meaning to the underlying raw figures (DCM, see pp. 115-117 for an example of how unstructured observations were used to add depth to the DCM data). The field notes recorded were often orientated towards the objectives of the research, focusing on resident engagement and their interactions with others. They also sought to document as much as possible and were rich with description. In addition, the notes captured the content of conversations (either verbatim or summarised) between staff and residents and perhaps most importantly between residents and the researcher, which might otherwise have been lost since the operational rules of DCM require the mapper to suspend mapping if their presence contaminates their research setting by interacting with participants. These resident / researcher interactions often yielded important and relevant information about activity preferences and the meaning of activity for residents. In addition to unstructured observations and DCM, a separate field diary was kept to record subjective daily reflections.

A SYSTEMATIC REVIEW OF INDIVIDUALS' CARE PLANS AND ACTIVITY LOGS

Each resident had a care plan detailing personal details about the individual as well as a brief section about their life history. Care plans were a written document detailing areas of care such as oral care, personal hygiene, mobility, falls prevention and communication. They were designed as a guide so that any member of staff could provide tailored person-centred care to any resident. Individuals living with dementia also had a section detailing an assessment made under the Mental Capacity Act (UK Government 2005). This assessment was considered when making a decision about whether an individual was able to give informed consent to participate in the research. If this was no possible, an appropriate individual with an interest in the resident's welfare (such as a family member) needed to be identified to advise as to whether the person should take part in the research project.

Individuals at Forest View also had an activity log that was created and maintained by the activities staff. Each log contained an A4 page, briefly detailing the person's past experiences and their activity preferences. Following this, the individual's participation in the formal programme of activities was logged alongside a few sentences about their engagement. A review of the participants' care plans and their activity logs was conducted prior to the first phase of data collection with specific reference to the individual's past lived experience and previous leisure activities or hobbies. In addition, the activity logs were studied to assess each participant's level of engagement in the six months prior to the first observations. The intention was to review these plans again at the end of the field research (November / December 2015). However, owing to inaccuracies in recording within these documents this did not take place (see p. 102, below).

CONVERSATIONS WITH PEOPLE LIVING WITH DEMENTIA

Additional data collection methods can be used to elaborate upon or explain observational material (Innes and Kelly 2007). Within this thesis, conversations and a focus group with people living with dementia were used to gain a greater insight into their unique activity preferences and the *meaning* that participation in activities held for them. When exploring the lived experience of people with dementia, evidence has often been sought from family members or care staff instead of from the individuals themselves (Hubbard et al. 2003). This is problematic, since proxy accounts have been shown to be less reliable than accounts from people living with dementia (Harmer and Orrell 2008). In line with the development of social philosophies of personhood (Kitwood 1992), citizenship (Gilmour and Brannelly 2010; Bartlett 2014), equality (Dewing, 2002) and social inclusion (Cantley and Bowes 2004), individuals with dementia are beginning to play a more active role in research (Robinson 2002; McKewown et al. 2010). The argument for the inclusion of people with dementia in research about their subjective experiences has been well made (Wilkinson 2002; Hubbard et al. 2003); listening to their voices enables us to create a more comprehensive understanding of their subjective experience.

Therefore, to successfully capture information about the activity preferences of people living with dementia and what activities might mean to them, it was important to employ methods to effectively capture their voice. Focused conversations (a less formal approach than an interview) and spontaneous conversations were used to achieve this. The value of these methods is embedded in the understanding that individuals are in the best position to communicate their own views through a group or one-to-one interaction (Finch et al. 2014). For this reason, interviews or focused conversations are an effective tool for ethnography (Yeo et al. 2014). Conversations have become an increasingly popular method among researchers working with people living with dementia (Wilkinson 2002; McKillop and Wilkinson 2004). When considering the cohort of participants, conversations are judged to be preferable to a more formal interview since they enable interaction in a way that is more fluid and therefore less structured. As any individual may feel under pressure when asked a direct question, those experienced in doing research with people living with dementia stress the importance of a conversational rather than questioning style of approach and therefore advocate a structure that is discursive rather than interrogative (Pratt 2002; Murphy 2007). Focused conversations took place in the lounge area of the care home or in an individual’s own room depending on the individual’s expressed preference. These focused conversations were audio recorded and later transcribed.

During the initial phase of the data collection however, it became clear that focused conversations were not the most appropriate method to use with a number of the participants and they were somewhat ineffective in yielding data relevant to the aims and objectives of this study. In some instances, focused conversations would last a considerable period of time (up to an hour) during which little relevant data was recorded and on some occasions the participants appeared disinclined to talk (although they may have been conversational in their natural surroundings). If this was the case, the interview was terminated. Throughout the research, ad hoc or spontaneous conversations proved to be a more successful way to gather appropriate information. These conversations were always initiated by the participant during moments of increased lucidity and when they felt they wanted to talk. This was most common when an individual was already engaged in an activity. This highlights the importance of adapting methods to suit the abilities of individuals (Pratt 2002). By encouraging and recording spontaneous conversations, the researcher was able to overcome the difficulties experienced during focused conversations and to maximise the strengths and abilities of the participant. When a participant spoke to the researcher about activities, other observations were suspended immediately and the conversation documented verbatim in the field notes. These conversations were captured in the field notes during unstructured observations.

A FOCUS GROUP WITH RESIDENTS

A focus group with residents and family members took place during the third phase of the field research. This was also useful in gathering data about activity preferences and barriers to engagement from the perspective of residents living with dementia. Focus groups are designed to generate interaction around a specific point (Bamford 2002) and as such have become a well-established and valuable social research method (Finch et al. 2014). They have been shown to be successful in research seeking the perspectives of people living with dementia in care homes and a complementary method to use alongside resident interviews or conversations (Milte et al. 2016). However, unlike a traditional interview, the focus group uses data generated through interactions between participants rather than between a participant and the researcher (Finch et al. 2014).

All eight participants were asked if they would like to attend the focus group[2], which was presented as an afternoon tea party in an attempt to make it less formal and potentially more engaging for these individuals. In this way, the group environment was distinct from usual activities in the home while also offering a sense of familiarity and continuity (as advocated in Bamford 2002). The particular purpose of this group was to identify the type of activities that residents would like to do and the meaning of activity to these individuals. This information (along with information from focused and ad hoc conversations) was used to inform the staff workshops. To this end, the researcher, with support from a family member, attempted to steer the conversation towards activity preferences as much as possible while allowing participants the flexibility to direct the discussion.

The group was conducted following guidelines set out by Finch, Lewis and Turley (2014) who suggest the importance of setting the scene, laying down ground rules and performing introductions before introducing the topic to be discussed. The main part of the focus group was a discussion of key issues by the participants before the researcher brought the group to an end by summing up the main points from the discussion (Finch et al. 2014). The result was a lively and wide ranging discussion about activities, reminiscence about past hobbies and aspirations for future engagement. Family members, who had extensive knowledge about their relative's past experiences, were particularly successful in generating discussion. This discussion were audio recorded and transcribed by the researcher. In addition, detailed notes were made during the session.

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[2] By the third phase five participants had withdrawn from the research

While activity preferences were expressed clearly during interactions, the meaning behind engagement in activity was less apparent in the first instance as it was expressed on a much more latent level during the focus group and in conversation (Braun and Clarke 2006). Individuals could say what they might like to do but appeared less able to say why they wanted to do it. Yet the meaning of activity was important as the observational data showed that the type of activity was less important than the fact that an individual was engaging in something. Analysis of interactional data combined with rich data from ethnographic observations however revealed why engaging in activities was important for residents living with dementia. This point illustrates the value of an approach using more than one method of data collection.

WORKSHOPS WITH CARE WORKERS

Nine activities workshops with care workers and nurses were planned to take place. Three at the beginning of the second, third and fourth phases of the research. Each session was 90 minutes long and designed to involve up to eight members of staff. It was intended that those staff involved would attend one workshop during each of the three phases so that they could design and develop a strategy to better support residents in activities while considering current limitations (involving a total of 24 staff). The workshops were run in partnership with the in-house training and development manager and served several purposes. First, they provided an opportunity to present a brief analysis of the observational (DCM and unstructured observations) and interactional (conversations and focus group) data to care staff and offered them a space to discuss these preliminary findings. Secondly, using the combined data about levels of engagement and wellbeing amongst residents, staff were asked about how it might be possible to improve engagement amongst residents in line with their expressed wishes for activity. This also lead to important conversations about what care workers regarded as the barriers to increasing opportunities for engagement amongst residents. This was important in understanding the specific factors influencing engagement in care homes.

It was critical to work directly with care staff in this way; they had the professional expertise and experience of working in the care home and were therefore best placed to develop strategies to better engage people living with dementia in activities and in quality interactions. They were also in a position to suggest what might work best in practice as they knew the factors that were preventative to their engaging residents. In addition, as care workers were asked to be the agents of change by altering their practices to better accommodate activity, it was important to give them ownership over that change by co-creating a strategy. These sessions were audio recorded and transcribed by the researcher. In addition, reflections from the workshops were recorded in a reflective field diary. These workshops represented the ‘plan’, ‘reflect’, ‘revise plan’ and ‘amend plan’ sections of the action research design (Figure Three, p. 57, above) and provided a co-created strategy to enable care workers to ‘act’ to better support residents with activities.

THE PERSON-CENTRED CARE ASSESSMENT TOOL

The Person-Centred Care Assessment Tool (P-CAT, Edvardsson et al. 2010a) was completed anonymously by care workers at the beginning of each activity workshop. The P-CAT is a research tool designed to measure the extent to which care and nursing staff working in care homes feel their practices and the practices of the organisation in which they work to be person-centred (Edvardsson et al. 2010a). It captures the informal discourse about person-centred care within a care environment as well as the extent to which this discourse has been formalised in operational processes and translated into care practice (Edvardsson at al. 2010a). This self-reported assessment tool is deeply embedded in the principles of personhood and person-centred care (Kitwood 1997a, Edvardsson et al. 2010a). It is made up of 13 statements against which staff can rate their level of agreement within a five point Likert-scale rating from ‘disagree completely’ to ‘agree completely’ (Appendix vi - *Person-Centred Care Assessment Tool*).

The 13 statements are grouped into three categories representing three facets of person-centred care. These are: personalising care which represents care workers’ own care practices, organisational support, which refers to the leadership of the care home, and environmental accessibility referring to the physical environment. Answers are scored between 1 and 5, generating a total score of between 13 and 65 per questionnaire with higher scores indicative of higher levels (as perceived by staff) of person-centeredness (Appendix vii - *Person-centred Care Assessment Tool: Scoring notes*). Data collected using the tool was synthesised to create an overall picture of how they perceived their own care practices as a group. The intention was to see if the cohort of care workers attending the workshops changed their perception of their practices over the course of the research. In reality, different carers attended the workshops during different phases so this comparison was not possible. What was feasible however, was to create a picture of how carers overall perceived their care practices.

A TOOL KIT APPROACH TO DATA COLLECTION

Employing a range of methods was of great value to a study (Hammersley and Atkinson 2007). Advocates of a mixed methods approach note the significant complexities within health and social research and consider the use of a single method inadequate to address these (Tashakkori and Creswell 2007; Moyle 2010; Creswell 2015). Therefore, mixing methods can broaden the scope of a study, thereby permitting a more robust analysis (Morse 2003) and enabling a more extensive understanding (Moyle 2010; Mayoh et al. 2012). Indeed, a mixed methods approach is not uncommon within the field of dementia and wellbeing (Hall et al. 2018; Windle et al. 2016). Within psychosocial dementia research specifically, authors note the need to adopt a research design which is robust enough to measure the specific impact of an intervention while also being able to capture complex and subtle information:

> *A major challenge for dementia research is measuring the impact of psychosocial interventions. A number of standardised and validated measures exist, some we incorporate into our protocol. However, the extent to which the measures are sensitive enough to capture change in relation to a complex intervention such as a visual arts intervention are unclear. In recognising these challenges at the outset, the mixed-methods approach will enable qualitative exploration which may reveal more subtle impact and experiences to be identified* (Windle et al. 2016 p. 9).

Indeed, within this research, while DCM was the primary method used for collecting data about engagement and wellbeing amongst residents, there was great value in combining this with other methods to create a richer picture of the care setting and of individuals' lived experience. Within the context of service evaluation, this has been referred to as a 'tool kit' approach (Innes and Kelly 2007). The value of such an approach is that it creates the opportunity for the researcher to select the tools or techniques that are considered to be most appropriate for that service evaluation (Innes and Kelly 2007) or in this case the research.

PREPARING FOR THE RESEARCH

In preparation for this research, the researcher attended a four day Dementia Care Mapping course at Bradford University (in November 2013) to gain the necessary knowledge and skills required to use this method in practice and had the opportunity to practise mapping during a separate research project at Bournemouth University. In addition, ethical approval was sought and obtained from Bournemouth University's ethics committee prior to the commencement of the research and appropriate information sheets and consent forms developed.

The researcher also visited the care home on a monthly basis between March 2014 and May 2015. Initially, these visits helped to shape the research questions and enabled orientation and familiarisation with the research setting and potential participants; an essential part of ethnography (Hammersley and Atkinson 2006; McNaughton et al. 2014). The researcher spoke informally to residents and observed the daily routine in the home. The researcher's initial reflections were recorded in a field diary kept during this time. These initial observations and conversations with the residents indicated an inconsistency between individuals' level of engagement in activity and their desire for daily occupation; residents reported that they wanted to be involved in activities but were observed to be passive for much of the time. As part of the initial contact with the home, the researcher attended a Residents and Relatives Meeting organised by the care home to discuss the background to the project and to ask for any initial feedback. A reflective diary written immediately following this meeting notes that a number of relatives attending this meeting reported that they felt there was a lack of opportunity for residents to participate in activities and expressed concerns at the lack of engagement they observed in the home. Ethical approval for these initial visits was sought and obtained from Bournemouth University's Ethics Committee in February 2013.

Ethical Considerations

The process of gaining formal ethical approval acts as a valuable prompt to ensure a rigorous ethical approach to research. It highlights the need to ensure the physical and psychological safety of both the participants and the researcher as well as confirming appropriate processes are put into place for gaining informed consent, protecting participant anonymity and confidentiality and storing sensitive data. The key ethical considerations within the application for ethical approval were to:

- Ensure the anonymity of participants and to protect confidentiality,
- To make sure that participants and other individuals living in the home experienced no harm as a result of the research,
- To ensure that each participant had given informed consent to participate in the research or that an individual with an interest in the welfare of the person with dementia had been consulted to give advice regarding whether the person lacking capacity should take part (Bartlett and Martin 2002; Sherratt et al. 2007; Heggestad et al. 2013).

Ethical approval to conduct this research was granted from Bournemouth University's Ethics Committee in May 2015. However, although the Ethics Panel did approve this research, the researcher was not advised to apply for ethical approval from a Research Ethics Committee recognised by the Secretary of State such as NHS ethics approval. Such approval is a requirement of the Mental Capacity Act (UK Government 2005) since the research involved individuals who were unable to give their informed consent due to their cognitive impairment. The need for additional ethical approval was brought to the researcher's attention after the completion of this doctoral research and this raises questions regarding what material may be published from the research.

PROTECTING ANONYMITY AND CONFIDENTIALITY

During the field research and writing up this project, every effort was made to protect the privacy and confidentiality of any personal information relating to the participants or members of staff. Due to the nature of this research, any data collected was likely to be sensitive as this research was designed to explore the social worlds of people living with dementia through observations and conversations. Resident care plans were also reviewed and these contained highly confidential information including residents' personal details, their medical history and information about their family and life history. It was imperative therefore to work in a way that ensured the confidentiality and anonymity of participants (Sherratt et al. 2007). Researchers in the UK are governed by the Data Protection Act of 2018, which regulates how data is stored and processed (UK Government, 2018). In practice, this necessitates careful consideration to data collection and storage. During this research and when the data was written up, strict protocols were adhered to in order to protect individuals' data and to ensure that individuals remained anonymous.

To protect anonymity during data collection, resident participants were identified using a two digit number and during workshops staff participants were given a letter of the alphabet. When the data was written up, each resident participant was given a pseudonym. In addition, no data has been included within this thesis (or in any other document produced as part of this research project) if, despite being anonymised, that data may have enabled the identification of an individual. To further protect anonymity, the home is referred to the pseudonym 'Forest View' and details (such as the location of the home and the management company responsible for it) have been excluded from this thesis. To protect confidentiality, any sensitive information relating to residents was stored securely, access to the raw data was restricted to the researcher and their supervisors and no data was collected that was not directly relevant to this project.

MITIGATING POTENTIAL HARM TO RESIDENTS

Within the ethical framework, it was important that no harm came to participants or to any other individual as a result of the field research within 'the ethical principles of beneficence and non-maleficence' (Bartlett and Martin 2002, p. 49). This research had the potential to deliver therapeutic benefits to participants (increasing opportunities for participation in activities and thereby potentially improving wellbeing). Yet, while there was little inherent risk within the design of this research, it is acknowledged that any research has the potential to cause psychological or physical harm. Initially, discussions with care and nursing staff and with participants' family members were used to identify any situation that were likely to incur more than a negligible risk to a participant's physical or psychological health and strategies were sought to mitigate any potential risk. For example, care workers knew that Margaret often became distressed when talking about her past and therefore the researcher did not attempt to speak to her about her life history. There was also a need to consider those residents who were not participants of this study as the researcher's presence in the home may have had an impact upon them. While the researcher did not attempt to observe non-participants, they were naturally in communal areas while the research was taking place. Therefore, prior to the research, the researcher visited the home on a monthly basis for fifteen months to enable residents to become familiar and comfortable with her presence.

Working with human participants is likely to incur unexpected situations which have not been considered prior to research, as human beings can be unpredictable (Heggestad et al. 2013). Furthermore, there is no way to ensure that every moral and ethical question has a satisfactory conclusion (Heggestad et al. 2013). It was therefore imperative that the researcher adopted an approach of moral sensitivity throughout the research. This required the researcher to consider the moral values in any contentious situation and to judge each situation in a moral and ethical way (Heggestad et al. 2013 p. 32). Therefore, if any resident became distressed during observations, conversations or the focus group, the researcher planned to stop data collecting immediately and attempt to soothe the individual. The approach taken was in line with the provisions of the Mental Capacity Act (UK Government 2005) designed to mitigate harm to participants. These state that the research process may not interfere with an individual's freedom or privacy in a significant way or be unduly invasive. The act also asserts that nothing may be done to an individual to which they appear to object and that the interests of the individual must outweigh those of the research. All of these points were considerations during the field research.

ENSURING CONSENT TO PARTICIPATE IN THE RESEARCH

Gaining informed consent is an important part of any research project involving human participants. However, it is a process that becomes complex when involving individuals living with dementia who may not be able to give their consent to participate in research in a way that can truly be considered to be 'informed' (Hellström et al. 2007; McKeown et al. 2010; Sherratt et al. 2007). Despite this, there is a growing body of research that suggests that these individuals should be afforded an opportunity to take part in research (Keys et al. 2014). This necessitates more creative ways to seek informed consent in a moral and ethical way (Cubit 2020; Murray 2013) in which the consent process is tailored to cognitive abilities of the individual living with dementia (Heggestad et al. 2013). This was achieved, in part, by appropriate construction of information literature and consent forms (Appendix viii.i - *Information Sheet for Residents Living with Dementia* and Appendix viii.ii - *Consent Form for Residents Living with Dementia*) which were written in line with design guidelines and used accessible language and large print (Murphy 2007; Dementia Engagement and Empowerment Project 2013). These were accompanied with face-to-face conversations to explain the research and the implications of participation (Dewing 2002, Meulenbroek et al. 2010).

Within the ethical approval it was agreed that an assessment would be made of each resident regarding whether they could give informed consent or whether the researcher needed to consult with an appropriate family member who could advise upon that individual's wishes regarding participation in the research. Each resident with dementia had a formal assessment under the Mental Capacity Act (UK Government 2005) and this was kept in their care plan. Decisions as to whether an individual was able to give informed consent was based on this assessment as well as with guidance from the lead mental health nurse at the home.

In a majority of instances, the individual living with dementia was not able to give ethically robust, informed consent to participate in the research. In these instances, the Mental Capacity Act (UK Government 2005) states that a researcher should identify a person to act as a personal consultee for that individual. A personal consultee is a person who was has an interest in the individual's welfare such as a close family member, and who is prepared to be consulted by the researcher concerning that individual's wishes regarding their participation in the research (NHS Health Research Authority 2018). Therefore, during this research, if gaining informed consent was not possible, the researcher sought the views of a family member (usually a child of the resident) to advise them on whether the resident should participate in the project. This decision was based upon what the family members felt the resident's wishes and feelings about taking part in the project would be likely to be if that individual had the capacity to decide. It was also informed by the relatives' own feelings regarding the research and whether or not they felt that the person living with dementia would benefit from participating. Due to the nature of this study (in that it was designed to provide therapeutic effects by improving opportunities for meaningful engagement) most family members agreed that the person living with dementia should take part. Indeed, in many instances, family members discussed the project face-to-face with the resident to seek their views before advising the researcher. Family members were offered an information sheet about the project (Appendix viii.iii - *Information Sheet for Relatives*) and were asked to sign a form to indicate that they agreed to a resident's participation in the research.

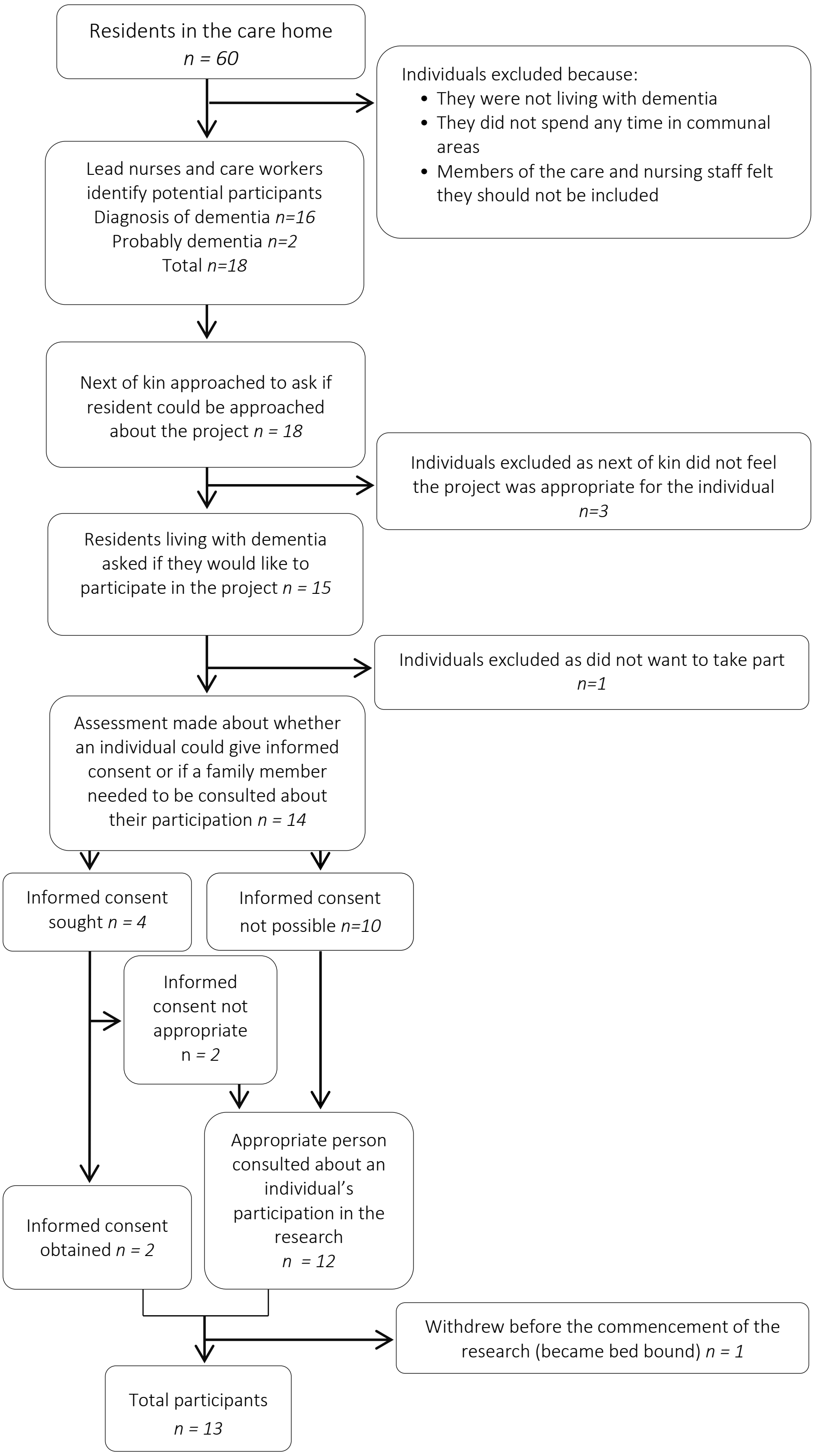
In addition, family members were often present during the data collection and would on occasion, discuss the field research with the resident. Upon reflection however, it is acknowledged that it may have been appropriate to have adopted a more formal approach to engagement with family members to discuss their views on the continued participation of individuals. Regular and formal contact with family members would have enabled the researcher to periodically seek and record their opinion about individual participation. That said, during the data collection there was no evidence of any participant wishing to withdraw from the project. Had there been, this issue would have been immediately addressed by the researcher. Throughout the data collection informed consent or advice from personal consultees regarding an individual's willingness to participate was not regarded as an end to the discussion surrounding consent. Consent to participate was assessed by the researcher at the beginning of each day and in each moment using a method of 'process consent' (Dewing 2007).

Informed consent was also sought from staff members who participated in the workshops during this research and relevant information sheets and consent forms were developed to facilitate this (see Appendix viii.iv - *Information Sheet for Staff Members* and Appendix viii.v - *Consent Form for Staff Members*). The information sheets developed as part of this research made it clear that consent must be given freely and willingly (Bartlett and Martin 2002) and that an individual's care provision (for resident participants) or job (for staff participants) would not be affected if they chose not to take part.

Identifying Participants and Obtaining Consent

Potential participants were identified in partnership between the researcher and the care and nursing staff at Forest View. Of the 60 residents in the home, 18 individuals were identified as potential participants. Of these, informed consent to participate was given by 2 residents. Where informed consent was not possible, an appropriate family member was asked for advice as to whether a resident should participate, this occurred in 12 cases. One individual withdrew before the commencement of the project upon becoming unwell, therefore, in total, 13 residents took part in this research (Figure Four, p. 81). In addition, 20 members of the care team were recruited to participate in activities workshops and each gave their written consent to do so. These participants were invited to participate by the training and development manager and were selected upon her assessment of the person-centred nature of their care.

Figure Four - The Process of Identifying Participants and Gaining Consent



IDENTIFYING RESIDENT PARTICIPANTS

Residents living in Forest View were considered as potential participants if:

- They had a diagnosis of dementia or if the qualified mental health nurse working at the home thought it likely that they had dementia, even if there was no formal diagnosis. This approach was used to accommodate the fact that not all individuals living with dementia in the UK have a formal diagnosis (NHS England 2017).
- They spent some of their time in communal areas of the care home. This was because observations could only take place in these communal areas. Therefore if an individual was bedbound or chose to spend their time in their own room, they were excluded from participation.
- The individual was able to give informed consent to take part in the research or there was an appropriate person with an interest in the welfare of the individual living with dementia who could be consulted as to whether they should participate.

While the inclusion criteria was broad, not every resident with dementia who spent time in communal areas was approached to participate in this study. Care workers and unit nurses acted as gatekeepers to those who could be included. By request of the management, they selected participants that the researcher was then permitted to approach. Their own inclusion criteria was unclear. However, they appeared to choose residents who engaged more with the formal programme of activities and those who had relatives who were more positive about the care home. A verbatim conversation between a unit nurse and a carer discussing potential participants was included in a reflective field diary and may facilitate an understanding of how staff decided upon which residents might be approached to participate:

> *Care worker: 'Why doesn't she ask X?'*
> *Nurse: 'No, X's family are sometimes funny aren't they, they sometimes complain and stuff.'*
> *Care worker: 'OK yeah not her then.'*
> *Nurse: 'Yeah, I don't want you to approach X's family really.' (Extract from reflective diary, May 2015)*

Interestingly, during the residents and relatives meeting attended by the researcher, X's relatives had been vocal about the fact that X did not have enough to stimulate her in the care home. They also often brought this up with care workers during observations. Indeed, it appears to be for this reason that the nurse felt X should be excluded from participation in the research. In addition, it is possible that they chose the most socially active residents to participate because these individuals were more likely to give a more positive picture of the home. Indeed, there was evidence that the residents who participated in the study were more likely to engage in activities run by the activity staff (this was noted in the reflective field diary kept by the researcher). While it is possible that this had a negative impact on the project for not presenting a full picture of the lived experience of all residents, it was important to work closely with these gatekeepers who managed access to potential participants. The nurses identified 16 residents with a diagnosis of dementia and two further individuals who she believed likely to have dementia but who did not have a formal diagnosis, making a total of 18 potential participants (Figure Four, p. 81).

Eight potential participants lived on the ground floor, six on the first floor and four on the second floor. The home was organised by level of need with those with the lowest level of need on the ground floor and highest on the top floor. The fact that most participants were chosen from the ground floor could be an indication of the fact that the home wished to show the most positive picture in the research. However, it could also be because more residents on the top floor were bedbound and were therefore excluded from the study. As the researcher was unable to access data from non-participants it was impossible to discover the number of people on each floor that may have met the inclusion criteria compared to the number of people offered to the researcher as potential participants.

OBTAINING CONSENT

The researcher had felt it appropriate to approach people living with dementia in the first instance about their willingness to participate in the project and this was agreed by the ethics panel at Bournemouth University. However, in line with the wishes of the care home, the next of kin of each resident, regardless of that individual’s ability to give informed consent, was approached first to ask if the researcher could approach the resident about potential participation. When approached, some relatives felt it was inappropriate for their family member to take part in the research as a result of their diagnosis of dementia. One family member declined saying:

> *'Dad's got dementia you know so he's not appropriate for your study. No I don't think you should ask him.' (Conversation with son of a potential participant - reflective diary, May)*

Three family members asked that their relative was not approached. The family members of the remaining appeared happy for their relative to be involved. For example:

> *'That's a great idea. Mum really doesn't have enough to do in [the care home].' (Conversation with Edith's daughter – reflective diary, May)*

Therefore following these initial conversations, 15 residents were approached and asked if they would like to take part. At this point, only one resident refused to take part, the remaining 14 residents appeared happy to participate. For example when May was asked she replied:

> *"Yes I'll do it if you think it would help [...] I would like to help you if I can dear" (Conversation with May – reflective diary, June)*

The lead nurses of each floor made a decision as to whether it was possible to gain informed consent from an individual or whether a family member with an interest in the welfare of the individual needed to be approached to provide guidance as to whether that individual should participate in the research (in line with guidance set out in the Mental Capacity Act, 2005). This decision was based upon the nurses' in-depth knowledge of each individual's capacity and the resident's mental capacity assessment. Within this process it was important that capacity was assumed unless otherwise stated. Four individuals living with dementia were asked to give informed consent to participate in the research, however after conversations with these individuals the researcher decided that only two could give ethically robust informed consent. An appropriate family member of each of the remaining 12 individuals was approached to give advice as to whether the resident should take part in the research. If the family member felt a resident should take part, this was formally captured with a signature using a consent from.

THE PROCESS OF ENSURING CONTINUED CONSENT

Beyond the establishment of informed consent and consultation with appropriate family members, a practice of process consent was adopted. Using this approach, consent was considered as an ongoing process throughout data collection rather than a one off event prior to the commencement of the research (Dewing 2002; Hellström et al. 2007; Murphy 2007). This process was used to ensure that initial informed consent was reviewed and re-established not only on a day-to-day basis but moment-by-moment depending on individuals' inclination to participate (Dewing 2002; 2007). Therefore, participants were able to dip in and out of participation in the project as they wished and their willingness (or not) to participate was judged continuously through listening to them and observing their body language. In addition, in line with guidance set out in the Mental Capacity Act (UK Government 2005), family members were made aware that residents could withdraw from the research at any time if they wished to do so.

To ensure residents' continued assent to participate in the field research, the researcher introduced herself and asked for the participant's agreement to conduct observations before the beginning of each day. In addition, explicit verbal consent was sought before engaging participants in focused conversations or the focus group. In this way, in line with ethnographic principles (Hammersley and Atkinson 2006) and the principles of best practice in conducting research with people living with dementia (Dewing 2002; 2007), permission to participate was continually renegotiated. For example:

> *I have asked Mollie and Audrey if I can observe their day. Audrey nods assent and Mollie said 'Ok dearie, anything you like. Do you need me to do anything?' I assure her she doesn't need to do anything. (Field notes, 16th June)*

In addition, following the ethical principles of avoiding the harm or distress to participants (Bartlett and Martin 2002), observations or conversations were suspended if a participant appeared to become upset or seemed as though they did not to wish to take part. On the same day for example, Mollie began to question the presence of the researcher:

> *Mollie and Audrey are sitting side-by-side. They're talking about me. 'Do you know her? I thought she was your sister, is she your sister. What's she doing there then?' (Field notes, 16th June)*

As a result, observation was suspended temporarily while the researcher spoke to the two women to explain the reason for the observations and to ensure that they were happy for the observations to continue:

> *I ceased mapping temporarily to explain what I am doing. I ask if it is OK to carry on. Mollie says 'Yes that's fine, you go ahead'. (Field notes, 16th June)*

On every occasion residents agreed to be observed.

IDENTIFYING PARTICIPANT CARE WORKER AND GAINING THEIR CONSENT

Care workers who attended the staff workshops were also considered to be participants of this study. They were key in the action research element of the research design by facilitating the development of a strategy to better improve opportunities for engagement amongst individuals living with dementia. While all care and nursing staff in the care home were made aware of the research taking place, those at the workshops were given a more detailed overview of the research and asked to formally consent to participate. Attendance at the workshops was by invitation only and the training and development manager was responsible for inviting individual care workers. She chose those members of staff who already showed a propensity towards delivering person-centred care as she felt that these individuals would be most interested in improving wellbeing amongst residents and might therefore be the most engaged in the process of developing a strategy to do so. Twenty members of staff were asked to take part in the workshops and each one agreed to participate in the research.

Data Construction and Analysis

The different methods used to collect data yielded several different data sets for analysis. These included rich ethnographic field notes, raw DCM data, notes and audio recordings from focused conversations and the focus group, notes and audio recordings from the workshops with care workers and raw P-CAT questionnaires. The first step in thematically analysing this data corpus was to sort and process the data sets (Braun and Clarke 2006).

THE CONSTRUCTION OF DATA

Field notes recorded during observations formed the bulk of the data collected. These provided a rich ethnographic description of what was observed in the care home with specific attention to engagement in activities and interactions. They also focused on factors that appeared to influence that engagement as the focus of the study. These field notes provided a moment-by-moment account of 206 hours of observations spanning 27 days. At the end of each phase, the raw notes were typed up using a separate document for each day. To ensure the field notes were as authentic as possible, no attempt to alter or edit them was made in any way with the exception that participants' numbers (used thus far to identity individuals) were substituted for chosen pseudonyms (Appendix ix - *Extract from Raw Field Notes*).

Data gathered using DCM however, required more extensive processing. Raw data from daily observations using the Behaviour Category Code (BCC) and Mood and Engagement (ME) frameworks was entered into a purpose built Excel template created by the Bradford Dementia Group. This spreadsheet calculated the number of time frames and percentage of time that an individual spent in each BCC and the number of time frames and percentage of time that they spent in each of the six ME values. Daily Well or Ill-being (WIB) scores were calculated for each person within this tool. In addition, the programme calculated group BCC, ME and WIB profiles for each day. In total, 27 group sheets were completed (one per day of observation) and an additional 108 individual sheets (one per person per day of observation). This data was then analysed by hand into the four phases and combined to give an overview of BCCs and ME values for the whole data collection period. Following guidelines set out in *Dementia Care Mapping: Principles and Practice* (Brooker and Surr 2005), data gathered using the four DCM frameworks was systematically synthesised into 108 Individual Care Summaries (Appendix x - *Individual Care Summary Example*) and 27 Group Care Summaries (Appendix xi - *Group Care Summary Example*). Each Summary included an overview of the day, overall Well and Ill-being (WIB) scores, overall engagement (using the BCC framework) and a list of positive and negative interactions observed between care workers and residents. They also presented a summary of the general points noted during the day and recommendations detailing how care practices may be altered to improve resident engagement and wellbeing. Again, at this point pseudonyms replaced resident initials.

The audio recorded material (from focused conversations, the focus group and activities workshops) was transcribed by the researcher and the notes taken during these events were typed up. Care workers who attended the workshops were given an initial (A-T) to protect their anonymity (while those who were just part of the DCM or unstructured observational data were referred to in the field notes as 'carer' or 'care worker'). The data obtained using the P-CAT was analysed to show the extent to which care workers felt their own practices to be person-centred. The data sets from each of the four phases were reviewed alongside the observational data and four reflective pieces were constructed. Processing the separate data sets and reflecting upon them in this way enabled a greater level of familiarisation with the data, essential to thematic analysis (Braun and Clarke 2006). This eventual data corpus offered a significant amount of information upon which to examine the levels of engagement and wellbeing amongst people living with dementia in care homes and to analyse the factors affecting their lived experience.

THEMATIC ANALYSIS

Thematic analysis is a widely used method for categorising, examining and reporting themes in data (Braun and Clarke 2006; Spencer et al. 2014). Consequently, this type of analysis is useful in highlighting the most significant patterns present within a body of data, with reference to the focus of a study (Joffe 2012). As a method of analysis it offers the researcher many advantages as it is flexible and can be used to summarise the salient points of a large data set while facilitating a richness and depth within those findings (Braun and Clarke 2006). Within an ethnographic framework, data analysis is centred upon the interpretation of human interactions and how these actions influence the wider social context (Hammersley and Atkinson 2007). Using thematic analysis requires the researcher to produce an initial set of codes from their knowledge of the raw data and in the context of the specific demands of the research topic. Within this framework, a predominantly inductive approach to analysis was employed in that no prescribed codes or themes were prepared prior to the analysis of the data. Instead they began to emerge as the researcher transcribed, read and reread the data corpus (see Braun and Clarke 2006). However, the data analysis also had a deductive element as it was driven specifically by the theoretical position and the aims underpinning this study. Therefore, the themes identified specifically address the research question while the coding framework was flexible enough to allow themes to emerge naturally during analysis. By working though data using a systematic approach, themes were identified that referred to a particular meaning found within the data corpus (Joffe 2012). From this point it was possible to begin to map how certain codes and themes relate and interrelate to one another and to begin to build up a relationship between them (Braun and Clarke 2006; Spencer 2014). During the process of writing up the findings chapters (Chapters Four to Seven, pp. 91-186) the data collected was further refined to create a coherent and interlinking analysis.

Two key themes emerged from the data corresponding to the two aims underlying the research question. The first theme, relating to the first aim was centred within the ethnographic framework and considered current levels of mood and engagement and the self-reported wish for engagement amongst residents living with dementia. The second theme, relating to the second aim concerned the specific factors that influenced engagement in activity and interaction amongst residents living with dementia. This theme also considered how care staff might mitigate some of these factors to offer better opportunities for engagement amongst residents. This theme was informed by both the ethnographic and action research elements of this study. Underlying each theme were a number of codes to which relevant data (extracts from the field notes and verbatim interactions) was allocated. This coding framework formed the basis of the thematic analysis

DEMONSTRATING RIGOUR

Research with a qualitative element is sometimes criticised for a lack of scientific rigour (Noble and Smith 2015). However, by using a systematic approach to data collection and analysis it is possible to find out about the lived experience of individuals in a reliable and rigorous (all be it subjective and relative) way (Hanson 2008; Ormston et al. 2014). Despite this, there remains no consensus regarding how rigour may be judged within a qualitative approach to data (Rolfe 2006). Noble and Smith (2015) have therefore developed a strategy by which researchers using qualitative methods might ensure credibility and rigour in their research. This strategy highlights the importance of acknowledging personal bias (see also Braun and Clarke 2006) and a bias in sampling, which may influence the findings. Detailed record keeping, demonstrating a clear decision trail and thought processes during the data analysis and representing all aspects of the data and including rich verbatim notes is also imperative as is engaging with other researchers and participants to validate findings (Nobel and Smith p. 2). Within this study, this strategy was followed as far as was possible. A further analysis of how this strategy was applied during the research process is offered within the discussion of this thesis (p. 191).

Summary

To facilitate an answer to the research question: ‘Can we improve wellbeing for people living with dementia in care homes by increasing their opportunities for engagement in positive and meaningful activities?’, a research design was adopted that drew upon the approaches of ethnography and action research. Ethnography was used to explore the lived experience of residents living with dementia in a care homes environment with particular reference to their activity preferences, the *meaning* they placed on engagement and the factors that contributed to that engagement. Action research was employed to facilitate the design of a strategy to improve the opportunities for these individuals to engage in activities. This strategy was co-created with care workers at Forest View as they were acknowledged to be the experts in care and therefore best placed to know what might work in practice regarding increasing opportunities for engagement. This study was designed to include three cycles of action research, set over four phases and was conducted in a care home environment in line with the principles of ethnography, which involves observing individuals in their own natural physical and social surroundings.

Within this research framework, a 'tool kit' approach was used to data collection. Dementia Care Mapping, unstructured observations, a review of individuals' care plans and activity logs, conversations, a focus group, staff workshops and the P-CAT were employed to gather rich data regarding the lived experience of people living with dementia and to create a strategy to have a positive impact upon that lived experience. The data sets were synthesised and processed before being thematically analysed. The following four chapters of this thesis detail the findings gathered during this research and present these using rich verbatim extracts from field notes and from interactions with people living with dementia and care workers at Forest View.

Chapter Four - Introducing Forest View and the Participants of this Study

Forest View was a private, purpose built care home situated near a large town on the South Coast of England. Set over four floors and with the capacity to house up to 60 residents, the home was designed to accommodate the needs of older adults and specialised in residential, nursing and dementia care. In total, 13 individuals living with dementia or who showed signs of cognitive impairment took part in this research. These individuals lived on three of the four floors of the care home: the ground, first and second floor. This chapter briefly describes the care home, members of staff and the daily routine at Forest View as well as the programme of activities offered at the home. Following this, the participants are introduced using data gathered during in-depth ethnographic observations, systematic review of their care plans and activity logs and conversations with them, their family members and care staff.

The Care Home

Completed in 2013, Forest View was in its infancy during the design and data collection phases of the research project. Pitched at the top end of the care home market, the home's management company expressed an aspiration for it to become the best in its class in the local area, both in terms of the physical building and quality of care delivery. The care philosophy at Forest View emphasised the importance of person-centred care, supporting residents to engage in activities and offering residents an experience that was as close to home life as possible. To facilitate this approach, residents' history and their personal preferences were logged in their individualised care plans and their preference for and participation in activities were recorded in personal activity logs by dedicated activities staff. In addition, the home itself was designed to be both enabling and as home like as possible.

THE PHYSICAL ENVIRONMENT

Forest View was a large, impressive and modern building. It could easily have be mistaken for a luxury block of apartments or quality hotel. To the front of the home was a small car park flanked by well-maintained flower borders. Beyond this was an enclosed garden comprising a small lawn encircled by a block-paved path wide enough to accommodate a wheelchair. A gazebo lay at the far end of this garden and there were a number of raised flower beds to enable individuals to easily participate in gardening activities. There was abundant seating to allow people to sit and rest in the garden. The garden appeared to have been created as an important feature of the care home and was designed in such a way as to maximise resident participation within it. However, the garden was essentially inaccessible to residents. As the home was built over four floors which, remained locked at all times, residents had no access to the garden space without being accompanied by a family or staff member. In addition, the garden itself was only accessible through a set of doors on the lower ground floor which were kept locked at all times.

The care home was accessed through the main entrance on the lower ground floor. This entrance led to a reception area and two small offices. A small display stand here held greetings cards for sale that the residents had made during activity sessions. On this floor, there were a small number of residents' bedrooms, a lounge, a dining area and a small hair salon which opened once a week. The remainder of the floor was dedicated to the home's utility areas. These were not accessible to residents or their relatives. Three more floors, each acting as a separate locked unit were accessible by one of the two staircases to the east and west wings of the building or by lifts located in the central part of the building. Pin activated door locks enabled staff and visitors to move freely between the floors while preventing residents from doing so without being accompanied. This research took place on the top three floors of the building: the ground floor, first floor and second floor, which were almost identical in their layout and design. Each floor had a central communal area with a large lounge, a small kitchen dining room and a nurses' station in the centre of a long wide corridor spanning the length of the building. To the east the corridor led to nine resident bedrooms, a small store room and a communal bathroom with accessible bath tub. To the west were eight more resident bedrooms and a smaller room designed for relatives to stay in but which was used as a store room.

It was evident that Forest View had been designed and built with the needs of older adults and those with complex health conditions as a fundamental guiding principle. The corridors, for example, were light and spacious, wide enough to enable two large wheelchairs to pass and had handrails down either side to support residents to move independently around the home. In addition, chairs were placed along the corridors to allow residents to sit and rest should they need to do so. To add interest, inspire reminiscence, aid wayfinding and to encourage residents to develop a deeper engagement with their surroundings, each corridor had a unique theme created using pictures and objects. On the movie themed corridor for example, cinema posters from the 1940's and 50's adorned the walls alongside reels of film. On the sports themed corridor were pictures of sporting activities as well as old fashioned sporting paraphernalia such as football boots and a wooden lacrosse stick. To further aid wayfinding and to give the residents' rooms a more personal feel, each bedroom door was a different style and colour and designed to look like a traditional front door with residents' artwork fixed to them. Like the corridors, the bedrooms were spacious, light and airy. Furthermore, in acknowledgement of the fact that older adults, particularly those living with dementia or sight loss, require good lighting, each room had a large window to optimise levels of natural light. The rooms were large with ample room to manoeuvre a hoist or a wheelchair and also big enough for residents to bring their own furniture and other effects to personalise the space. Each bedroom had an en suite bathroom with a toilet, basin and walk-in shower. There was also a buzzer system in each bedroom which was connected to the nurses' station so that residents could contact care and nursing staff immediately should they require assistance.

The communal areas that opened out from the corridor had also been designed to feel roomy, light and homely. The residents' lounges were painted a light cream colour and full length windows spanned the south facing wall contributing to the feeling of light and space. A large TV was mounted on one wall and acted as a focal point of each room with comfortable sofas and armchairs placed in a u-shape around it. This was often where residents spent the majority of their time when in the lounge. In the rest of the room, chairs and coffee tables were arranged in intimate pairs or threes to create a more homely atmosphere and there were some enclosed corners for residents who wished to have a quieter and more private space. There was also a small dining table and chairs at the back of the room for people who wished to participate in activities such as jigsaw puzzles, art work or crosswords. To encourage curiosity and investigation and to stimulate conversation and reminiscence there were a number of potentially familiar items including a tailor's mannequin, an old sewing machine, a typewriter and a gramophone in each lounge. Residents' art and craft work was also displayed and this acted as an aid to conversation as well as being an evident source of pride for some individuals. In one corner of each lounge was a sink and cupboards storing a variety of resources for different types of activities including art and craft materials, games, musical instruments and jigsaws puzzles. It was evident therefore that the lounge was designed to maximise the opportunities for residents to engage in different activities.

On the other side of the corridor was the residents' dining room. The partition between this room and the lounge was almost entirely glazed. The room overlooked an area of woodland and was also light, airy and spacious. Rather than having one long institutional style dining table as is common in many care homes, there were several small tables to allow for a more intimate and family-like dining experience. Kitchen units in the corner of each room contained crockery, cutlery, glasses and tea making equipment. In addition, there was a sink, kettle, toaster and microwave in the room making it possible for residents to participate in basic kitchen activities with encouragement and support. Attached to each dining room was a smaller room intended to be a private dining room with the capacity to seat six to eight people so that residents and their families could have intimate family meals together thus, in some ways contributing to the normalisation of the care experience. However, these spaces were not used for this purpose. On one floor the small room had been turned into a training room and on another it was being used as a staff office.

Nevertheless, it was clear that a great amount of thought had gone into the design and layout of the physical space and that it had been created to be both interesting and engaging for the residents by giving them a number of opportunities for participation in activities, particularly those considered to be 'normalising' or 'activities of daily living', that is those that an individual may have carried out on a day to day basis when they lived in their own home such as gardening, engaging in conversation and working in the kitchen. In addition, the architecture and interior design of the space facilitated care tasks by supporting the use of specialist equipment (such as wheelchairs and hoists) and maximised resident safety and independence by ensuring good natural light, providing appropriate tools (such as grab rails) and using features that supported wayfinding. Although the home was large, encouraging individuals to bring their own furniture, the creation of cosy and intimate corners in the lounge, the provision of small family-style dining tables and access to kitchen facilities all helped to create a homely environment for residents.

STAFF

Forest View employed care and nursing staff as well as a number of ancillary staff to facilitate the operation of the home including chefs, kitchen porters, laundry workers, maintenance staff, cleaners, receptionists and an administrative assistant. There was also a training and development manager who developed and delivered regular bespoke training including a two day induction programme for all new members of staff. While the majority of these supporting staff tended to work in a separate part of the building, their different roles did necessitate their interaction with residents to varying degrees and are therefore not excluded from these chapters. There was also a registered care home manager and deputy manager to oversee operations in the home and two activities staff: an activity coordinator to design and facilitate a programme of activities and an activities assistant to support the programme.

Forest View appeared to have a generous quota of care staff; during the day shift (8am – 8pm) there was a registered nurse on each of the four floors who acted as the unit manager and who, in addition to her nursing duties was responsible for organising care on the floor. Working alongside her (for the nurses were all female) was a team of care workers. These care workers came from a variety of different backgrounds and appeared to have very different motivations for working in care. The majority were female (over 90%), yet they were diverse in age, ethnic background and previous work experience. While some came from non-care professions such as retail, others had extensive experience of care work spanning many years and others appeared to have come straight from school or college. In acknowledgement of the fact that the morning was the busiest time of the day, there were five care workers on the floor during the first half of the shift, reducing to four after 2pm. This is the equivalent to one care worker for every 3.4 residents in the morning and one for every 4.25 during the afternoon. The permanent members of the care team appeared to be genuinely attached to their residents, treating them with dignity and a great deal of respect, genuine affection and even love. And, in recognition of the importance of the continuity of staff within dementia care, each care worker and nurse was assigned to a particular floor where they predominantly worked. This arrangement gave both staff and resident the opportunity to get to know one another well and to forge positive relationships. Despite this, the care home often appeared to be short of staff and there was a heavy reliance on temporary care workers from agencies.

During early visits to the care home (between March 2014 and May 2015) and during the first two phases of data collection (June to August 2015) it was noted that the home routinely employed temporary (agency) care and nursing staff to fill gaps in the weekly rota. These staff shortages appeared to be caused by high levels of staff attrition combined with difficulties in recruiting new members of staff. During the first and second phases of data collection for example, the field notes detail the use of agency staff almost every day and note that, on occasion, there were more agency than permanent members of staff on shift. This was particularly the case during the night shifts which was predominantly staffed by agency staff. It is acknowledged that the use of agency staff may be a temporary necessity to cover staff illness or holidays but using them routinely in this way often proved problematic as they did not appear to have the same positive relationship with the residents or an emotional investment in the residents' wellbeing. During the final stages of data collection (phase four, November 2015) however, the reliance on agency staff reduced to some extent due to the successful recruitment of new care staff although they still remained a common feature of the night shift.

Staff turnover was evidently problematic as both new staff and agency staff were less familiar with the routines in the home and therefore often less efficient, requiring help and support from other more experienced members of the team. It was noted that on occasions when a significant proportion of the care staff were from agencies, the quality of the care and consequential resident wellbeing was reduced. Conversely, when a floor was staffed entirely by permanent members of staff, resident engagement and wellbeing appeared to improve. High staff turnover was not exclusive to care and nursing staff however. A reflective field diary kept during the initial visits to the care home noted that in the 15 months from March 2014 to May 2015, the activity coordinator changed four times. Perhaps more problematic, was the fact that during this period the home was run by five different managers (three full time and two interim managers) who were supported by several deputy managers. In addition, the management company responsible for the organisation and consequently the senior management team behind the home, changed three times. This is of note since such a change in management is likely to have had a significant impact on staff and therefore also upon the resident experience.

THE CARE ROUTINE

The daily routine in the care home essentially remained the same throughout the data collection. In a 24 hour period there were two shifts: a day shift from 8am to 8pm and a night shift from 8pm until 8am. Between these shifts was a brief handover period when departing staff passed relevant information onto those arriving for their shift. During this research project only the day shifts were formally observed and documented using Dementia Care Mapping (DCM) and ethnographic observations as there were rarely any residents in the lounge during the night. However, the researcher had a presence on the floor during some of the night shifts. This was captured in a reflective diary and included in the data analysis. At the beginning of the day shift, care workers supported residents to get out of bed, washed and dressed and to have their breakfast. A selection of hot and cold dishes were served in a buffet style so that residents had choice and control over what they had to eat. However, out of necessity the majority of individuals breakfasted in their own rooms as care workers were often unable to get every resident out of bed and dressed before the arrival of lunch at noon. Care workers were at their busiest during the morning and were rarely seen in communal areas except to support a resident from their own room to the lounge. These findings raise questions about the extent of the person-centred nature of the care being provided as given the choice it is probable that residents would not choose to stay in bed until noon. This point was raised by family members in conversation with the researcher and was also reported by the Care Quality Commission (CQC) in a report written following an inspection of the home that occurred during data collection for this research. The CQC report concluded that residents were not always supported in a timely manner and suggested that this was an area that should be improved. In addition, the observations showed that care workers did not appear to have time to spend interacting with residents beyond what was necessary to carry out care tasks (see *Chapter Five - Engagement and Wellbeing* and *Chapter Seven - Factors Affecting Engagement and a Strategy for Promoting Activity in Care homes*).

In the morning (usually between 10.00 and 11.30) was the first of two daily activity sessions run by the activities staff. At noon, lunch was brought to the floor on a heated trolley and the residents were given the opportunity to decide what they wanted to eat from a choice of at least two hot options, soup or sandwiches. Shortly after the arrival of the trolley, care workers supported residents into the dining room. Again, lunchtime was fairly busy as the care staff attempted to serve all 17 residents, some in the dining room and some in their own rooms simultaneously. As a result, the interactions that were observed between staff and residents were often limited and task focused. Directly following lunch, care staff spent time supporting residents to the toilet or engaging them in other personal care tasks and filling in mandatory paperwork. At 2pm one member of the team finished their shift leaving four care workers on the floor for the remainder of the day. In the afternoon, a second activity session was scheduled. This lasted for between 30 and 90 minutes depending on the activity being offered; a keep fit session, for example, lasted for half an hour while a trip to the local pub was considerably longer. Afternoon activity sessions often engaged larger groups of residents and were frequently delivered by an external professional with support from the activities staff. After this, tea and cakes were served followed by supper at 5pm. At the conclusion of the evening meal a number of the residents chose to go directly to their rooms and care workers began to support these individuals to get ready for bed. Others chose to stay in the lounge. From 7.30pm until the end of the shift was often the most relaxed and quiet time of the day and was when care workers appeared to have more time to spend interacting with their residents.

The Activity Programme

In recognition of the importance of supporting residents to participate in positive and meaningful activities, there was a rich and varied programme of activities at Forest View offering residents the opportunities to participate in a diverse range of group and one-to-one activities. Acknowledging the uniqueness of each individual, this programme included activities pitched at varying levels of intellectual and physical ability and endeavoured to ensure that there were elements to suit the personal preferences of each resident.

THE WEEKLY ACTIVITY PROGRAMME

Within the formal programme, two different activities were planned each day; one in the morning and one in the afternoon. Table Six (p. 99), is an example of such an activity programme and illustrates the diversity of activities offered within the activities programme during one week. Activities offered within this formal activity plan were delivered in three ways, small one-to-one or one-to-two activities, small group activities (usually floor based) and large group activities open to the whole home (Smith et al. 2009). One-to-one or one-to-two activities took place between the activities staff and one or two residents and were usually brief conversations but could also include singing, dancing, engaging in crafts, reading and reminiscence. They often took place in individuals' own rooms or in the communal areas of the home and were often scheduled during the morning activity session. Small floor based group activities occurred in the communal areas of a floor and were often quite low key, including just the residents living on that particular floor. Small group activities included intellectually stimulating games (such as word searches, hangman and quizzes), physical games or sensory games and arts and crafts. Like one-to-one activities they usually happened during the morning. The third way that activities were delivered was in large home-wide groups when residents from all floors were invited to one area of the home to participate in an activity such as a singalong group, keep fit session or baking group. These activities, were often facilitated by external professionals and usually took place in the afternoon.

Table Six - An Example of a Weekly Activity Programme

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Morning (10.30 am - noon)	Reading the paper *(One-to-one)*	PAT dog visit *(One-to-one)*	Quiz *(Small group)*	Chats *(One-to-one)*	Not recorded	Chats *(One-to-one)*	Quiz *(Small group)*
Afternoon (2pm onwards)	Film hour *(Small group)*	Keep fit session *(Large group)*	Baking group *(Large group)*	Entertain-ment *(Large group)*	Not recorded	Entertain-ment *(Large group)*	Group social *(Large group)*

OBSERVED ACTIVITIES

Table Seven (p. 100), details the activities directly observed by the researcher during the data collection phase and offers a brief description of each one as well as an idea of how residents may have engaged with that activity.

Table Seven - Observed Activities

Activity	Brief description
Animals	The care home kept hens in the garden, there was also a resident cat and a tank of fish on the lower ground floor. On occasion Pets As Therapy (PAT) animals visited the home and interacted with the residents. These included a pony, owls and a dog. Only one instant of a PAT animal visiting the home was observed. During this visit none of the participants were seen interacting with the animal in a positive way.
Arts and Crafts	One participant was observed making Christmas decorations and two participants made cards during the data collection. The Christmas decoration making was a largely passive activity with the coordinator making the decoration under instruction of the resident. Card making was a simpler and more participatory event but lasted no more than 15 minutes. The cards made by the residents were sold in the reception area of the home to generate funds for the activity programme. There was evidence of other arts and crafts around the home such as personalised door signs, paintings and decorated bird boxes but no other arts or crafts were observed within the research.
Baking	Three participants were observed participating in a baking group on the lower ground floor. They made cupcakes by mixing readymade sponge mix and water and adding dried fruit. When the cakes were baked they decorated them with icing, helped to tidy up and had a tea party with some members of the care team. This activity enabled some of the residents to reminisce together about baking at home as well as about other elements of homemaking. This appeared to be a highly positive experience. The session lasted for 90 minutes.
Chats	One-to-one chats were often part of the Programme. The activities staff spent this time talking to individuals who could not leave their room and were also observed engaging in chats with participants in the lounge. As the activities staff had to engage with a large number of residents in a relatively short period of time, chats were usually quite short lasting no longer than a few minutes.
The Daily Sparkle *(Daily Paper)*	The home subscribed to a speciality daily reminiscence newspaper *The Daily Sparkle.* Copies of the paper were placed around the lounge each morning to be used as a conversational or reminiscence tool or simply read by residents. Some residents spontaneously engaged with the paper and the activities staff sometimes used it to engage the participants in reading reminiscence and the daily quiz. This usually lasted no more than a few minutes.
Entertainment	Entertainment was by far the most popular and regular activity on the activities programme. The home engaged a number of entertainment professionals to deliver music based entertainment. These sessions varied depending on the specific artist employed and included highly participatory singalong sessions as well as more passive concert type performances. Entertainment sessions typically lasted for approximately 60 minutes and engaged between 9 and 27 residents.
Exercise	The home employed an external individual to run a simple keep fit session for the residents, this was a well patronised event with up to 16 attendees. The session involved simple seated exercises set to music which were demonstrated by the instructor and copied by the residents. The instructor was able to skilfully tailor the exercises to the ability of the individuals in the group. The session lasted 30 minutes.

Film Hour	During Film Hour the activity coordinator put an old film on the TV and offered the residents a selection of cinema style snacks. Although the residents sat in front of the film there was very little evidence that many of them engaged in watching it for a prolonged period of time.
Games (intellectual)	Intellectually stimulating games included personal word searches, crosswords, group quizzes, games of hangman and other word and puzzle games. These could be group activities (such as hangman) or one to one pursuits (word searches). Participants engaged in these activities in different ways depending on their intellectual abilities.
Games (physical)	Despite the fact that the home had a number of good quality resources to facilitate physical games, only one example of a physical game was observed. This was when a group of scouts visited the home and two of the scouts played a balloon game with two participants.
Games (sensory)	Once a game of 'mystery objects' was observed. This involved asking residents to identify an object in a cloth bag using touch alone. This activity sparked social engagement as it appeared to draw much interest and excitement from other residents.
Pampering	On occasion, the activities staff engaged female residents by doing their make up or painting their nails. These interventions were often approximately 15 minutes long.
Pub visit	On two occasions residents visited the pub which was conveniently situated next door to the care home. During pub visits, residents were able to choose their own drinks and the activities staff brought along a pub quiz for them to try. Up to ten residents attended the pub visit at any one time and it appeared to be both a sociable and an enjoyable experience. Pub visits usually lasted around 90 minutes.
Social Group / Party	There were ladies' and gents' social events as well as social events for the whole home. The social event observed was a drinks party when residents gathered together and were offered their choice of an alcoholic drink, tea or coffee. They played simple games and chatted together. This lasted 60 minutes.

Due to the researcher's decision to remain with the majority of participants at all times, on the occasion when the participants within a group split (if some participants chose to attend a group in another part of the home while others stayed on the floor) the researcher would remain with the largest group. This meant that not all of the activities that took place during the data collection were witnessed. For example, on one occasion one of five participants visited the pub, however as four remained in the lounge the researcher remained there as well. The activities observed appeared rich and varied with opportunities for residents to try a number of different things including singing, engaging with animals, baking and exercise classes. In addition to this programme, there were a number of resources including books, resident animals, a working kitchen and craft materials. These were used to facilitate the activities delivered by activities staff as well as spontaneous, self-initiated activities amongst residents and activities supported by care staff.

RECORDS OF PARTICIPATION

Residents' participation in activities was routinely documented in their own activity log. These briefly outlined their activity preferences as well as logging their participation in activities delivered within the formal activities programme. An analysis of each participant's activity log shows that in the six months to June 2015 participants, on average, engaged in an activity 3.2 times a week (approximately every other day) and that entertainment sessions were the most frequently engaged in activity by the group as a whole with some residents attending an entertainment session at least once a week. Chats and intellectual activities were also some of the most common activities. A systematic review of individuals' activity logs showed that overall there were 229 instances of participation in an entertainment session (an average participation of 0.8 times per person per week), 198 instances of one-to-one chats (an average of 0.6 times per person per week) and 99 instances recorded of an individual engaging in an intellectual game (an average of 0.3 times per person per week), other types of engagement were less frequent.

During the course of the research however, it became clear that the recording of participation was often inaccurate as well as being optimistic. An example of this is on an occasion when the Pet as Therapy (PAT) dog came into the home. Dorothy was recorded as having enjoyed interacting with the dog despite the fact she was not given the opportunity to do so:

> *Lilly the PAT dog is in the lounge and engaging with another resident. Dorothy is holding out her hand to the dog trying to get her attention. The activity coordinator and Lilly's handler are talking together and don't notice Dorothy's attempts to interact with the dog. After a few moments the activity coordinator mentioned that they should go and visit people in their own rooms and she and the PAT dog leave. Dorothy looks dejected. (Field notes, 24th August)*

Later that afternoon, the activity coordinator recorded that Dorothy had participated in the activity in her activity log:

> *The activity coordinator gets the activity logs to record participation. She records that Dorothy engaged with the dog and enjoyed doing so. Yet the observations reveal that despite evidently wishing to engage with the animal Dorothy was not given the opportunity and faced ill-being as a result of being ignored. The activity logs are clearly*

> *an inaccurate and optimistic account of what actually happened. (Field notes, 24th August)*

Indeed, it appears likely that in recording participation there was sometimes no discrimination between real engagement and enjoyment and a resident simply being in the room while an activity was taking place. This was also recorded during 'film hour' when residents were recorded not only as having watched but liked the film shown when independent observations paint a different picture.

Engagement was over reported in other ways. On another occasion for example, the activities assistant recorded that she had engaged two residents on the ground floor in conversations despite the fact that these lasted no more than half a minute. It is therefore questionable as to whether this brief interaction counts as a 'conversation' (rather than just a brief exchange). In addition, activities facilitated by care and nursing staff and those initiated by the residents themselves were not noted in the log. Due to these inconsistencies and inaccuracies, the activity logs were not considered again during the research. Ethnographic observations and DCM were considered more accurate tools in gauging levels of participation amongst participants.

The Participants

Thirteen individuals were recruited to take part in this study. Of these, six lived on the ground floor, five on the first floor and three on the second floor. In line with the concept of grouping people with similar needs and abilities in one area, residents were allocated to a floor corresponding to their unique cognitive or physical needs. Corresponding to the overall demographic of the care home and the demographics of care homes generally (for the majority of care and nursing home residents are female and over the age of 80, Kilich-Heartt 2017), eleven participants were female and ten were over the age of 80. Every participant was of white British origin and from a middle socioeconomic background.

PARTICIPANTS ON THE GROUND FLOOR

Freda, Dorothy, Norma, Margret, Eleanor and Edith lived on the ground floor. Of the three floors, the ground floor was for individuals who had the lowest levels of physical care needs.

The majority of residents living on this floor were able to move independently and spent most of their day in the communal areas of the home and as a result the lounge was often full. This was the only floor to have a large south facing balcony overlooking the garden and field beyond. This balcony was accessible via large patio doors (however, despite the fact that a number of residents reported their love of being outside, this asset seemed somewhat underutilised). The ground floor lounge was often where large multi-floor activities took place such as keep fit sessions and entertainment and in one corner most of the care home's activity resources were stored.

Freda was in her late 80s and had a diagnosis of Alzheimer's disease. She rarely communicated verbally and she also had limited mobility which became more pronounced during the course of the data collection. Freda liked the company of others and would always choose to sit amongst other residents. She appeared to be content most of the time but was often left alone for long periods of time since she could not get up independently. She did not have her life story or activity preferences recorded in her care plan and although her activities folder reported that she enjoyed having her nails painted it did not suggest any other activities she may have enjoyed. However, it was clear from observing Freda that she took pleasure in a variety of different activities and particularly liked participating in the entertainment sessions and playing ball games. However, she would never initiate an activity of her own accord.

Dorothy was 78 and had a diagnosis of Alzheimer's disease. She had six children, many of whom lived close by and came to visit her regularly. Dorothy kept an album with photographs of her husband beside her bed and would look through it when she was missing him. Occasionally (often in the afternoons) Dorothy became distressed as she waited for her children and husband to return from school and work. During these periods she would plead to be let out of the home so that she could go and search for them and became increasingly distressed when she was unable to do so. When she was younger she taught PE in a secondary school and reported taking great pleasure in physical activity. Her activity log stated that she enjoyed attending entertainment sessions, art and crafts, talking about her family and being pampered.

Aged 93, **Norma** had a number of complex health needs including a diagnosis of vascular dementia. She evidently experienced great pain, particularly in her legs. This caused her great distress and consequently had a significantly negative impact on her wellbeing. Norma found it difficult to engage in conversation or initiate interaction and as a result she was often overlooked by care staff and spent much of her time sitting alone and in silence in the lounge. Norma's daughter felt that she needed more stimulation and suggested involving her in simple board games such as cards or dominoes. She also felt that Norma would benefit from being given the opportunity to do arts, crafts, gardening or reminiscence. Norma remained proud of the contribution she made during the Second World War when she worked for the Royal Air Force. Her activity log says that she enjoys being pampered and watching entertainment. Norma passed away midway through the field research.

Although **Margaret**, who was 81, did not have a formal diagnosis of dementia, she was chosen to be part of the research project as the lead nurse on the ground floor believed it was likely that she did have a type of dementia. Margaret used a wheelchair but otherwise did not have any significant physical health problems. She was a quiet lady who enjoyed her own company. Her care plan noted that she had asked not to complete a life story as she did not wish to recall the past and also suggested that care workers did not attempt reminiscence work with her. Margaret expressed a love of dressmaking, knitting and watching soap operas. Her activity log also recorded that she liked physical activity, art and craft and having her nails painted. However, her greatest pleasure appeared to be reading and she would often spend hours sitting in the lounge engaged with a book or the newspaper. Margaret passed away after the first phase of data collection.

Edith was 84 and had a diagnosis of vascular dementia and Alzheimer's disease. She was otherwise physically fit and healthy. She moved into Forest View when her daughter felt that she could no longer care for her safely in her own home. Edith was a sociable and good humoured woman and enjoyed interacting with others. However, she was hard of hearing and care staff were rarely able to get her hearing aid working. Therefore conversation was often difficult. During her working life Edith was a bookkeeper and also undertook a lot of voluntary work. Edith's activity log recorded that she enjoyed watching entertainment and having her nails painted. Her daughter reported that she had had a number of highly creative hobbies such as flower arranging, ballroom dancing, gardening and cross stitch. She also said that she felt her mother was not sufficiently stimulated in the home. Edith spent a significant proportion of her time sitting or walking along the corridors in silence and occasionally became distressed and confused when she found she was unable to leave the floor.

Eleanor was 84 and had a diagnosis of vascular dementia. She was physically mobile but struggled to find her way around the care home and so never walked around the home without the support of a care worker or nurse. She was sociable and good humoured and enjoyed interacting with other residents, their visitors and members of staff. Born and raised in Scotland, she had a great fondness for her own country. Upon leaving school she trained as a nurse and had had an exciting and varied career living for a period of time in Africa. She remained very caring and continued to employ her nursing skills on other residents. For example, on one occasion when a resident became unwell, Eleanor felt her brow to check her temperature and took her pulse. She also raised her concerns with the nurse on duty. Eleanor's activity log reported that she enjoyed having a chat, going on outings and watching entertainment.

PARTICIPANTS ON THE FIRST FLOOR

The individuals on the first floor had greater levels of physical need than those on the floor below and many of the residents required two-to-one support and the aid of a hoist. It is perhaps as a result of this that care workers appeared to be a lot busier on this floor compared to the others with one reporting that she felt so busy that she barely had time to think during a twelve hour shift. Meal times too seemed more chaotic here as a number of the residents required significant support to eat their meals. Despite this, the first floor often felt like a lively place to be and there was evidence of close friendships between the residents and signs of genuine warmth and affection between residents and staff. Stanley, Bill, May, Peggy and Vera lived on the first floor.

Stanley was 79 and had a diagnosis of Alzheimer's disease. He moved into the care home when his daughter felt that he could no longer be cared for safely in his own home although he remained physically fit and healthy. He was born and raised in the local area and had spent his working life as a small shopkeeper. Stanley spent much of his time walking around on the first floor and also liked to travel between the floors, occasionally accompanying the activity coordinator around the home or into the garden to feed the hens. He enjoyed being involved in all of the activities on offer in the home and appeared particularly happy when he had the opportunity to engage in music based activities by singing, dancing or playing his bells. His activity log documented his love of group entertainment as well as his fondness for gardening, playing games, football (he was a lifelong fan of the local team) and having a chat.

Bill was also 79 and had a diagnosis of Alzheimer's disease. He used a wheelchair and required the use of a hoist to transfer him from his chair to a comfortable seat in the lounge. His wife, who also had a diagnosis of dementia and who was also a participant of this study, lived in the care home on the second floor. Bill often sat on his own in the lounge and enjoyed reading magazines or the Sun newspaper which was delivered to him daily. When Bill was younger he bred pedigree dogs, he fondly remembered raising puppies and lamented that those days were behind him. Although a PAT dog visited the home on occasion, Bill said that this was not the same as having his own dogs. During conversation Bill also said that he enjoyed football, dominoes and cards (he used to play cribbage on his lunch breaks at work) and described himself as a 'proud bugger' and an 'independent so and so'.

May was 87 and had a diagnosis of Alzheimer's disease. She was a highly educated woman and worked as a pharmacist before she retired. She was quiet and thoughtful and although her verbal communication skills were excellent, she often said very little. She did however, enjoy spending time with Peggy and the two women spent the majority of their time sitting together in the lounge engaged in intermittent conversation. May was acutely aware of and sensitive to being patronised and infantilised and became upset if she was offered an activity that she felt was too easy. May's activities log documented that she enjoyed singing, being pampered and having a chat. Observations of her actions around the home also showed that she liked to help out around the home for example by drawing the curtains as it got dark.

Peggy was 88 and did not have an official diagnosis of dementia, however the lead mental health nurse and the care and nursing staff who worked with Peggy felt certain that she had some form of dementia. Like May, Peggy was quiet and used few words. Despite this she enjoyed company and always chose to sit next to May in the lounge. She liked looking at and handling pretty objects such as costume jewellery and feather boas. She also had fun dressing up in jewellery, boas and hats. Her activity log said that she loved singing and dancing as well as chatting, taking part in arts and crafts and being pampered.

Vera was 91 and had a diagnosis of vascular dementia. She used a wheelchair and required a hoist to move her from the chair to her bed. She reported feeling lonely in the care home and said that there was no one that she wanted to talk to. It was perhaps for this reason that she chose to spend much of her time in her own room and therefore she was included in little of the observational data. Vera was very fond of her family and enjoyed looking at their photos and talking about them. She was also a very fine artist and had some of her work displayed in her bedroom and around the care home. However, she felt that she could no longer engage in art owing to her arthritis. When Vera was in the lounge she often spent her time sitting alone looking out of the window. She reported enjoying gardening and baking but she rarely had the opportunity to engage in these activities. Vera became ill after the first phase of the field research and thenceforth remained in her room.

PARTICIPANTS ON THE SECOND FLOOR

On the second floor, at the furthest part of the home from the main reception area lived, the individuals who were assessed as having the highest level of need with each resident receiving some form of nursing care. As many of the residents on this floor rarely left their own bedrooms there were often few people in the lounge. That said, the second floor was far from calm owing to the complex psychological needs of residents and it sometimes felt like an upsetting place to be. Despite this, staff on the floor appeared to be highly skilled in supporting the residents and often had more time to spend with them than on other floors. Mollie and Audrey lived on the second floor.

Mollie was 83 and had a diagnosis of Alzheimer’s disease. She was a friendly woman who enjoyed interacting with others. When her family came to visit they always took her down to sit in the garden as Mollie adored being outside and remained a keen gardener. She also liked feeling close to others and often sought physical and emotional interactions such as cuddles and chats. Many of the care staff appeared to be genuinely attached to Mollie and treated her with a great deal of affection which, made her smile. When Mollie was alone however, she often became distressed. Mollie took great delight in simple things such as seeing the sun and had a great affection for children and animals, including her toy dogs that she liked to cuddle. Before the data collection began, Mollie broke her hip and although she was present in the lounge during the first day of data collection, she chose to remain in her room thereafter. She was therefore only observed for a short period of time.

As well as a diagnosis of dementia **Audrey** who was 80, had a number of underlying mental health problems and occasionally became deeply and inconsolably distressed. She was the only participant of this study to be prescribed psychotropic medication. Audrey’s family and her psychiatrist had asked care staff not to approach her when she was experiencing high levels distress and this was difficult to observe. When Audrey was well she was a sociable and caring woman and attempted to care for the other residents by stroking their hands and offering them cushions. She enjoyed interacting with others and often sought companionship. She also liked having her hair, make-up and nails done as it was important to her to look neat and tidy. Audrey's husband also lived in the care home and although the pair rarely had contact she often asked after him. Audrey passed away after the third phase of the field research.

Summary

Forest View was a care home specialising in dementia and nursing care for older adults. Of the 60 residents, 13 people with a diagnosis of dementia or who probably had dementia were recruited into this study. This sample did not include every person living with dementia in the care home but those who spent time in communal areas, who the care and nursing staff agreed could be approached and who agreed to participate. The philosophy at the care home emphasised the importance of creating a home like environment, providing person-centred care and supporting residents to engage in activities. The home was designed in such a way as to maximise resident ability and their engagement with the environment. In addition, there was an extensive activity programme that was designed to give residents the opportunity to engage in a variety of different activities. Nevertheless, extensive observations of the 13 participants indicated that despite this, residents living with dementia in Forest View spent long periods of time sitting alone and in silence, unengaged with their surroundings or in any form of positive activity.

Chapter Five – Engagement and Wellbeing amongst Residents Living with Dementia

Empirical data gathered using Dementia Care Mapping (DCM) and concurrent in-depth ethnographic observations form the backbone of this research project. These research tools were used to gather information about how residents living with dementia spent their day-to-day lives in the care settings with particular emphasis on engagement and wellbeing. This chapter begins with a summary of the DCM data collected during the field research. Then the findings of the overall levels of engagement and wellbeing are presented. Qualitative extracts from the ethnographic observations (field notes) are used to provide richness and depth to these raw figures. In total, between June 2015 and November 2015, structured observations (DCM) and simultaneous minute-by-minute descriptive ethnographic observations were conducted over 27 days for a total of 206 hours. Data gathered during these observations show that participants spent a significant proportion of their time in behaviours associated with passivity, showing limited signs of wellbeing and engagement during their day-to-day lives.

Dementia Care Mapping Data

Table Eight (p. 111) shows the number of hours spent conducting observations on each floor during each phase. The total number of hours spent on each floor loosely corresponds to the number of participants living on the floor. As the majority of participants lived on the ground floor for example, the majority of time was spent there. Participants were observed when they spent time in communal areas of the care home, such as the lounge, dining room or corridors. Out of respect for privacy and in line with DCM guidelines, participants were not observed in private spaces such as their own rooms or bathrooms. Therefore the duration of time that each participant was observed varied greatly depending on how much of their day they chose to spend in communal spaces and no participant was observed for the entire observational period as residents moved about the home and so in and out of the researcher's field of vision. In addition, Mapping data was discarded if a participant interacted with the mapper as this was considered to be a contamination of the data. However, these instances were still logged in the field notes.

Table Eight – Hours Spent Conducting Observations on Each Floor

Floor	**Phase 1** June-July 2015	**Phase 2** Aug 2015	**Phase 3** Sept-Oct 2015	**Phase 4** Nov 2015	**Total**
Ground	17	24	27.5	24	**92.5**
First	13.5	17	23.5	38	**92**
Second	12.5	9	/	/	**21.5**
Total	**43**	**50**	**51**	**62**	**206**

Table Nine (below) presents the total number of time frames recorded for each participant over the duration of the field research and the equivalent number of hours. In total, 7,465 time frames were recorded; the equivalent of 622 hours of data.

Table Nine – Dementia Care Mapping per Participant: Total time frames and equivalent hours

Participant	**Phase 1** June-July 2015	**Phase 2** Aug 2015	**Phase 3** Sept-Oct 2015	**Phase 4** Nov 2015	**Total Time frames**	**Total Hours and Mins**
Mollie	34	/	/	/	58	4hrs 50
Audrey	111	87	/	/	198	16 hrs 30
Stanley	149	174	232	312	867	72hrs 15
Bill	132	108	202	282	724	60hrs 20
Peggy	167	189	274	340	970	80hrs 50
May	78	136	219	218	651	54hrs 15
Vera	26	/	/	/	50	4hrs 10
Norma	133	100	/	/	233	19hrs 30
Freda	158	229	291	306	984	82hrs
Dorothy	183	262	275	307	1027	85hrs 35
Edith	107	119	240	300	766	63hrs 50
Eleanor	138	145	265	254	802	66hrs 50
Margaret	135	/	/	/	135	11hrs 15
Total	**1,551**	**1,549**	**1,998**	**2,319**	**7,465**	**622hrs 10**

The number of hours during which an individual was observed varied greatly, from four hours and ten minutes (Vera) to eighty-two hours (Freda) depending on how much time residents spent in communal areas of the home and whether they withdrew before the completion of the field research. Of the 13 participants who were recruited into the study, three individuals withdrew before the commencement of the second phase and a further two prior to the third phase. This was for reasons of ill health requiring palliative care, an admission to hospital or death. The remaining eight participants were 'Mapped' for an average of 849 time frames each, the equivalent of 70 hours 44 minutes in total.

The duration of daily observations varied from four hours (16th June) to 11 hours (25th August and 16th November) and the average length of time spent conducting observations was 7.63 hours; approximately seven hours and 40 minutes per day. To capture different periods of the daily care routine, observations began and ended at different times of the day. Although it was initially intended to begin some observations at the start of the day shift (8am) this did not occur as there were rarely any participants in communal spaces at this time. As a result of this, no observations began before 8.30am and Mapping often began a lot later than planned. For example on the second floor on 17th June, observations were due to begin at 7am but did not start until two hours later when the first participant entered the lounge:

> *08.15 - There are still no residents in the lounge. I decided to leave the floor again and return later. (Field notes, 17th June)*

And again on the first floor on 26th August:

> *09.00 – Arrive on the floor but no one is up and about, occasionally care workers can be seen along the corridor or in the dining room preparing breakfast but they are mostly supporting people in their own bedrooms. I can't start mapping. (Field notes, 26th August)*

On this day observations did not begin until 10am when one participant walked independently into the lounge. In the evening, Mapping usually ended no later than 8pm although on one occasion participants were observed until 8.45pm. Again, this was because most, if not all of the participants left the communal areas of the home and were in their own rooms by this time of the day. If all the participants had left, all of the communal areas for the evening observations on that day came to an end, for example:

> *19.57 – […] the care worker takes Audrey by the hand and walks with her towards her room to get her ready for bed. 19.58 – Today's mapping session ends. (Field notes 16th June)*

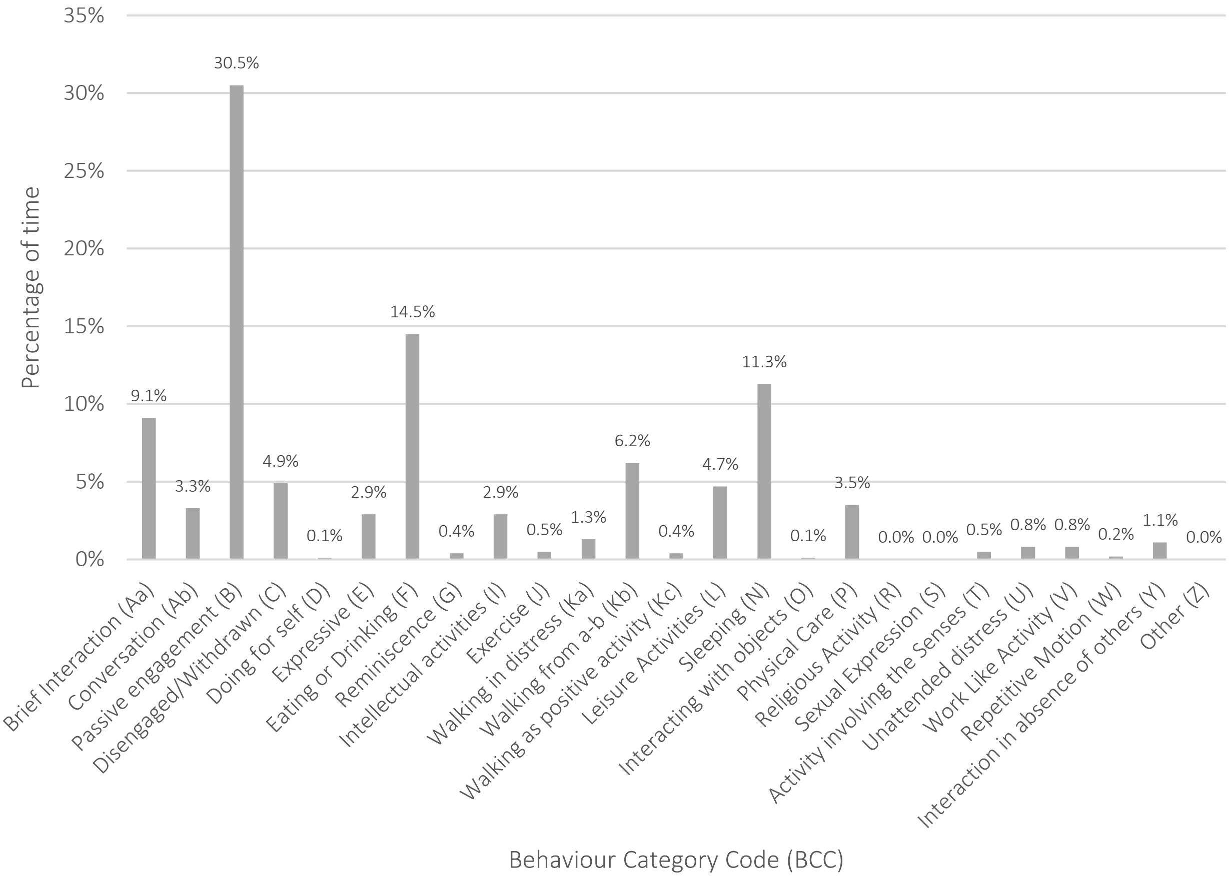
THE IMPACT OF MAPPING

As part of DCM it was important to be as unobtrusive as possible and to try and limit the impact of the presence of the researcher. This was not always possible. While the researcher aimed to be as unobtrusive and as out of view as possible, residents often seemed eager for conversation and sought out interactions. As it remained important not to act in a way that might undermine the personhood of an individual (by ignoring a request for interaction for example), the researcher would always engage with a person if a direct verbal or nonverbal request was made. During these periods Mapping was temporally suspended so that the researcher limited their impact on this data. However, conversations were often captured in field notes, particularly if they were about activity preferences or opportunities for engagement in the care home. In line with the guidelines set out in *Dementia Care Mapping: Principles and Practice* (Brooker and Surr 2005) if the researcher did impact upon the setting then the Mapping data gathered during those time frames was disregarded. However, it is possible that the researcher impacted the research setting in more subtle ways. Care workers knew that the researcher was observing their practices and therefore may have altered their approach during periods of observation either consciously or unconsciously. It is possible for example that they became more mindful of positive engagement as a result of the observations. However, as data was only collected when the researcher was in the home, no comparison can be made to evidence the impact of the researcher's presence.

Behaviour Category Codes

The data gathered using the Behaviour Category (BCC) and Mood and Engagement (ME) coding frameworks shows that despite Forest View's aspirations, residents spent a significant amount of their time sitting alone, either displaying passive behaviours or those associated with disengagement and in a fairly neutral mood. Figure Five (p. 114) is a synthesis of the total data collected using the BCC coding framework and included data gathered during 7,465 five minute time frames, the duration of the research project. During each of the data collection phases and in total, the Behaviour Category Code 'B' was the most frequently recorded of the 25 possible category codes, signifying passive engagement (for example sitting in silence and watching the surroundings but not actively engaged in any additional activity). In total, participants spent almost a third of their time (30.5%) in this category. Eating or drinking (F) was the second most frequent behaviour category coded (14.5%) followed by sleeping (N = 11.3%), brief interactions (Aa = 9.1%) and walking independently from one place to another (Kb = 6.2%). The data shows that participants spent their time in similar ways throughout the four data collection phases as these five behaviour categories were the most coded categories during each phase with the exception of phase three when leisure activities appeared as the fourth most engaged in activity (Appendix xii - *Behaviour Category Codes: A breakdown by phases one to four*).

Figure Five - Behaviour Category Codes (BCC) Results



EXAMPLES OF BEHAVIOUR CATEGORY CODES

The field notes taken alongside DCM detailed real examples of the behaviours observed during this research project. The examples below relate to the five most prevalent BCCs recorded in the home, which together accounted for 71.6% of the participants' total time in communal areas (B, F, N, Aa and Kb).

Passive Engagement (B) usually occurred when there was no external stimulation for residents and consequently they sat in silence only passively engaged with their surroundings. For example:

> *Edith is sitting on a dining chair in the corridor, she is alone and sits in silence looking into the middle distance. A care worker passes her and she looks up briefly, she then looks down at her hands in her lap. After a few moments she glances up again momentarily. (Field notes, 27th September)*

There is evidence from the DCM and the field notes that individuals often spent prolonged periods of time in the category:

> *There is very little to note. Freda has not moved or spoken to anyone for 75 minutes. The only thing to show that she might be engaged with her surroundings is an occasional glance upwards to the direction of the TV, otherwise she has been sitting motionless and in silence. (Field notes, 24th August)*

In line with the operational rules of DCM, passive engagement was only recorded in the absence of any other behaviour with the exception of complete disengagement or withdrawal (C), sleeping (N), asking for support with no response (U) and repetitive movement (W). Therefore, if any other behaviour was observed during the time frame, that behaviour was coded instead.

Eating and drinking (F) also made up a significant proportion of the participants' days. This included mealtimes and ad hoc refreshments served in the lounge. As discussed, the tables in the dining room were small and intimate to facilitate conversation between residents and foster a family like atmosphere. However, the field notes show that mealtimes were rarely a positive and fulfilling event for residents:

> *May and Peggy sit in silence. Peggy eats her sandwich and chews mechanically looking into the middle distance as she does so with a glazed expression. May takes intermittent*

> *sips of soup. She too looks glazed and her movements appear mechanical. Neither speak and neither show sign of well or ill-being. (Field notes, 17th November)*

In line with the operational rules of DCM coding eating or drinking took priority over other categories, therefore participants would be coded with 'F' if, during a five minute time frame, they took a sip of tea even though they may have been sitting withdrawn for the majority of the frame. For example:

> *Bill has been sitting with his eyes closed, now he reaches out and takes a brief sip of tea before closing his eyes again. He spends the rest of the time frame with his eyes closed. (Field notes, 3rd October)*

Sleep (N) was the third most prevalent BCC although some residents slept more than others. Participants would often fall asleep after prolonged periods of inactivity when there was little to engage and stimulate them. On 19th June Dorothy and Norma appeared withdrawn and slept for 47% and 56% of the observation respectively:

> *Both Dorothy and Norma have been asleep for 2 hours, they appear peaceful. (Field notes, 19th June)*

While sleep was mostly peaceful, it could also appear uncomfortable particularly if the individual was distressed in their sleep or in an awkward position.

> *Stanley is asleep in a dining chair, he is slumped forward with this head below his knees and he looks as though he might topple out of it. He is murmuring in his sleep and seems unhappy and uncomfortable. (Field notes, 28th August)*

Sleeping was only recorded if the participant remained asleep for the entirety of the time frame, if the participant woke for any length of time then an appropriate alternative code was recorded instead, in line with the operational rules.

Brief interactions (Aa) were interactions that lasted for no more than a few seconds. These were the most common type of interaction observed between residents and care staff. For example, on one occasion Norma had been sitting alone in the lounge for several time frames:

> *A care worker walks past Norma and says 'Alright Norma?' Norma looks up briefly and acknowledges the care worker without speaking. Norma spends the rest of the time frame in silence. (Field notes, 28th August)*

Brief interactions also occurred between residents. For example, May and Peggy often sat together on the sofa with cups of tea in front of them.

> *May turns to Peggy and says 'Is that my tea', Peggy says 'Don't know' without looking up. The two women sit in silence for the rest of the time frame. (Field notes, 19th June)*

In both of these examples, participants spent the majority of the time frame sitting in silence.

Although not all residents could move independently around the home the code relating to moving independently with the explicit purpose of getting from one place to another or **Walking from a-b** was the fifth most frequently coded category. For example:

> *The lunch trolley arrives on the floor, Stanley immediately rises and walks independently into the dining room. (Field notes, 17th November)*

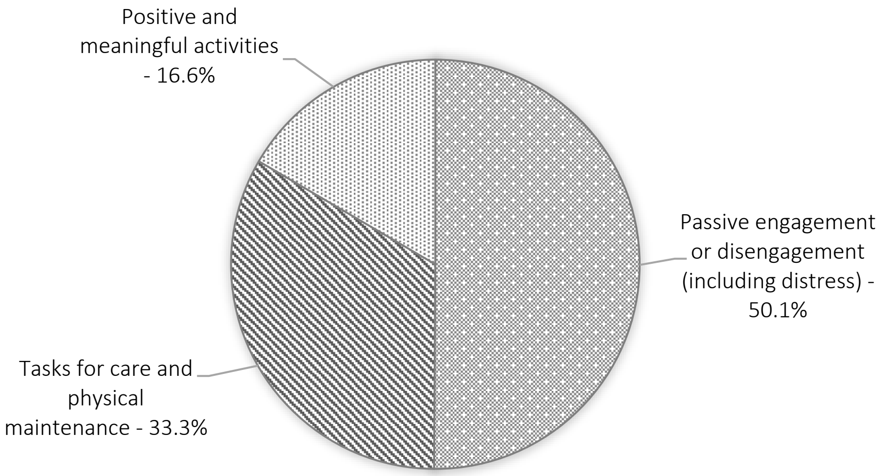
If an individual required support to walk or moved around the home in a wheelchair this was coded as 'P' signifying the receipt of personal care.

GROUPING BEHAVIOUR CATEGORIES

During analysis, Behaviour Category Codes were grouped into three overarching categories. These were: passive engagement and disengagement (including behaviours associated with distress), tasks for care and physical maintenance and positive and meaningful engagement (Table Three, p. 64). Grouping the individual BCCs in this way presents a clear picture of how participants spent their day. As a group, participants spent 50.1% of their time sitting in silence in communal areas either passively watching their surroundings or completely disengaged from them. They spent 33.3% of their time engaged in tasks for care or physical maintenance and 16.6% of their time engaged in positive and meaningful activity. For the purposes of this research these were considered to be activities that had a social, vocational or leisure element and were distinct from disengagement, passivity and tasks necessary for physical care (Figure Six, p. 118).

During an average observational period of approximately 7 hours and 40 minutes, this equated to 3 hours and 50 minutes spent in passive engagement or disengagement, 2 hours and 35 minutes engaged in tasks for care and 1 hour 15 minutes engaged in positive and meaningful activity. This latter category includes episodes where staff or a family member engaged a participant in an activity, a participant engaged themselves in an activity as well as when a participant was engaged in the formal activity programme facilitated by the activities staff. However, engagement varied from day to day. It was not unusual for some individuals to spend up to 82% of an observational period in BCCs associated with passivity or disengagement (including behaviour associated with distress) and no time engaged in positive and meaningful activities. This was particularly the case if an individual appeared unable to independently initiate their own engagement and on days when there was limited support from care, nursing and activities staff to engage in activities. Alternatively, on one occasion, residents were observed to engage in BCCs associated with positive and meaningful activity for up to 37% of their time. The reasons for this variation in engagement levels are multidimensional and complex. Findings relating to the factors affecting levels of engagement amongst residents living with dementia are discussed in greater detail in Chapter Seven.

Figure Six - Proportion of Time Spent in Each Overarching BCC Category



SELF-REPORTED ENGAGEMENT

There was a marked discrepancy between the ways participants reported they spent their day and how they actually did so. Therefore, one of the strengths of DCM was that it did not rely on individuals' recollection. For example, in the hours prior to Bill's interview the researcher had observed him sitting in his chair either asleep or awake and unengaged. However, during his interview when he was asked what he had been doing he replied:

> *'Well I went for a walk this morning you know'. (Focused conversation with Bill)*

On another occasion when Eleanor's daughter sat beside her and asked her 'So Mum, what have you been up to today?' Eleanor replied:

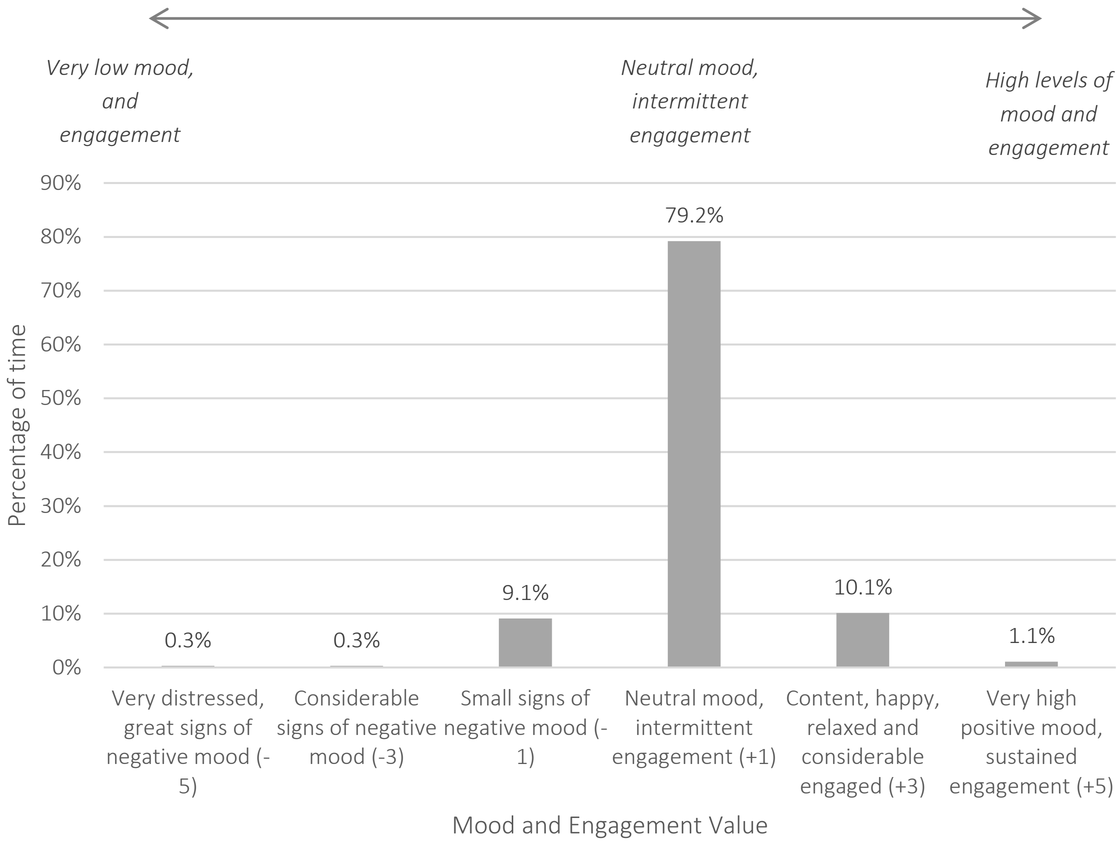
> *'Well really dear, I've been terribly terribly busy with things this morning.' (Field notes 23rd August)*

Yet, in this instance, she had been observed sitting in silence for a prolonged period of time and not engaged in any activity. These examples indicate a definite disparity between the DCM data and individuals' recollection of their own day and makes the case for the use of the tool despite its limitations. Dementia Care Mapping was effective in building up a picture of an individual's daily engagement, which may not be presented through self-reported accounts or even proxy reports.

Mood, Engagement and Wellbeing

During Mapping the observer made a judgement about individuals' state of mood and engagement during each time frame using the Mood and Engagement framework and recorded a value beside each BCC code accordingly. Within this six point scale, -5 signified extreme distress and great signs of negative mood while +5 was representative of significant and sustained positive mood and engagement and +1 signified a neutral mood and intermittent engagement. Figure Seven (p. 120) is an amalgamation of the Mood and Engagement (ME) values during data phases one to four and includes data from 7,465 five minute time frames. It shows that participants spent a significant majority of their time displaying no signs of positive or negative mood and either passively engaged or intermittently engaged with their surroundings or in an activity. In total, participants spent 11.2% of their time showing signs of wellbeing and considerable engagement in activity (values +3 and +5) and 9.7% of their time showing a degree of ill-being (-1, -3, -5). A neutral mood (+1) accounted for 79.2% of the participants' time as a group. While this might be seen as a positive outcome since instances of ill-being appeared relatively rare, there was also an opportunity to improve wellbeing amongst the participants. Recorded ME values remained similar throughout the four data collection phases but during the third and fourth phases there were no instances of a -5 value recorded (Appendix xiii - *Mood and Engagement Values: A breakdown by phases one to four*).

Figure Seven – Mood and Engagement (ME) Value Results



EXAMPLES OF MOOD AND ENGAGEMENT VALUES

The field notes can be used to add depth and context to the figures presented above and the examples given below illustrate the reality behind the six different ME values. The value -5 was coded when a participant appeared very distressed and showed significant signs of inconsolable negative mood. During one afternoon for example, Dorothy, who had been restless for much of the day, became increasingly distressed as the evening approached:

> *Dorothy continues to walk along the corridor and appears greatly agitated, she is crying. A care worker asks her if she is ok, she replies that her children haven't come home from school or her husband from work, she knows that it is dark outside now and is worried for their safety. She goes to the door that leads to the stairwell and begs to be let out to search for them. When the care workers refuse she screams in despair and hits out at another resident with her stick in frustration. [During this time frame Dorothy was coded Ka -5] (Field notes, 13th November)*

The ME value -3 was recorded when a participant showed considerable signs of negative mood that was less severe than that experienced in -5. For example, on one occasion Audrey was sitting crying in the lounge:

> *Now she holds out her hands to a passing care worker for support. The care worker is too busy to stop for her and Audrey's cries turn into a wail. She continues to sob for the remainder of the time frame looking around her as though for support which is not forthcoming. [During this time frame Audrey was coded U -3] (Field notes, 17th June)*

These ME values were only rarely observed, accounting for just 0.6% of the participants' time. The value -1 signifying a slight negative mood was more often observed but again this was not a regular occurrence. This value was recorded in the absence of any activity, for example where the individual was completely withdrawn or disengaged with their surroundings (C), for example:

> *Bill has spent the whole time frame staring at the table in front of him. His has not looked up or made any move to suggest that he might be engaged in his surroundings. He appears completely withdrawn. [During this time frame Bill was coded C -1] (Field notes, 3rd October)*

This value was also recorded when a participant was engaged in a more active behaviour category but that engagement was negative. On one occasion Mollie, who had broken her hip, had to be transferred from a chair to a wheelchair using the hoist. She found this an uncomfortable experience.

> *Mollie tells the nurse that the hoist hurts her. The nurse speaks to her gently telling her that she understands that the hoist is uncomfortable for her and must be scary. Mollie agrees to be hoisted, the care workers are gentle and supportive but she winces in pain as she is lifted out of her chair. [During this time frame Mollie was coded P -1] (Field notes, 16th June)*

The most commonly recorded ME value was +1 signifying a neutral mood and intermittent engagement in activity. This value was almost always recorded simultaneously with the Behaviour Category Code 'B' but was also coded when an individual was intermittently engaged in an activity and showing no signs of positive or negative mood. For example:

> *Bill is glancing at his magazine, he opens it and looks at one of the pages briefly before looking around the room. Bill continues to look at his magazine intermittently showing*

> *no signs of well or ill-being. [During this time frame Bill was coded I +1] (Field notes, 15th November)*

When participants appeared to be content, happy or relaxed and considerably engaged in their surroundings +3 was recorded. This value accounted for 10.1% of resident time. Instances of +3 most often occurred when a participant was engaged in an activity delivered by the activities staff but this value was also occasionally coded outside of these structured activities. On one occasion, for example, Edith and Eleanor were sitting together in the lounge talking and appeared to be enjoying their conversation.

> *Both women seem happy and relaxed and engaged in the conversation. Edith is talking about putting her tea cup on the table saying 'I put that there because I thought it would be better' and laughing, Eleanor agrees with her. The women chat together for the whole time frame. [During this time frame both women were coded Ab +3] (Field notes, 19th June)*

The value +5 was only coded when a participant appeared to be in an extremely positive mood and deeply engrossed in activity. This value was only ever observed during an activity session and particularly during sessions involving music participation. During one sing-along group for example:

> *Stanley is really enjoying this session, a care worker encourages him to dance with her. The two move together for a few moments before she gives Stanley his bells. He walks around the audience shaking them and smiling happily, he is considerably engrossed in this. Stanley then stands beside the entertainer and provides percussion with the bells. His eyes are closed. He is completely engaged and could not be happier. [During this time frame Stanley was coded E +5] (Field notes, 28th August)*

The value +5 was observed during 1.1% of the data collection phase. The examples given by no means include the full extent of scenarios observed in the care home but provide a flavour of life in the care home beyond the bare statistics.

WELL AND ILL-BEING (WIB) SCORES

In recognition of the fact that the experience of wellbeing is about the prevalence of positive states of mood and engagement over negative ones, an overall wellbeing profile can be drawn from the data. The Mood and Engagement data recorded during the observations represents an individual's moment-by-moment mood and engagement. However, by taking an average of each ME value, an overall Well and Ill-being (WIB) score can be calculated which depicts a group or individual's well or ill-being during a prolonged period of time (Appendix iv – *Dementia Care Mapping: Calculating Well and Ill-being (WIB) Scores*). The overall WIB score for the duration of this study was +1, indicating a situation where neither positive nor negative mood states were prevalent over the other. Each of the four phases of data collection had a similar overall WIB value (p1 - +0.98; p2 - +0.94; p3 - +1.07; p4 - +0.94, Appendix xiii - *Mood and Engagement Values: A breakdown by phases one to four*). This is an important point to consider as one of the intentions of this project was to work with care staff to devise strategies to improve the engagement and wellbeing of residents. Strategies were formulated (Table Sixteen, p. 182 and Table Seventeen, p. 183, below), but the results of DCM indicate that they were either not put into practice or that they were introduced but not successfully. Therefore they appeared to have had no overall impact on engagement and wellbeing.

WELL AND ILL-BEING (WIB) BY PERSON

Well and Ill-being (WIB) profiles differed by person. Table Ten (p. 124) shows individuals' WIB scores for the duration of the observations alongside a brief statement about their personality, abilities to independently engage in activities and the extent to which care staff interacted with them beyond the delivery of personal care. Margaret and May had the highest WIB scores of +1.4 and +1.3 respectively and Norma had the lowest at -0.4, although this may be considered to be a slight anomaly in the data as, for much of the time she was severely ill and this had a significant impact on her wellbeing. Excluding Norma, overall WIB scores range from +1.3 to +0.6.

The factors that contributed to an individual's overall state of well or ill-being were complex. They included elements of the individual's own unique personality and abilities as well as the ways that care staff interacted with them. An individual's ability to independently initiate activity appears to have positively impacted upon their wellbeing with those who more regularly engaged in self-directed, independent activity having higher WIB scores overall. May (+1.3) and Peggy (+1.2), for example, always sat together and engaged one another in conversation. Eleanor (+1.2) also initiated conversation with other residents and care staff while Margaret (+1.4) was engaged in reading for a significant proportion of her day. What is also interesting to note is that care staff appeared more likely to interact with residents who appeared more socially skilled resulting in some residents receiving more quality interactions than others.

Table Ten – Well and Ill-Being Scores by Person

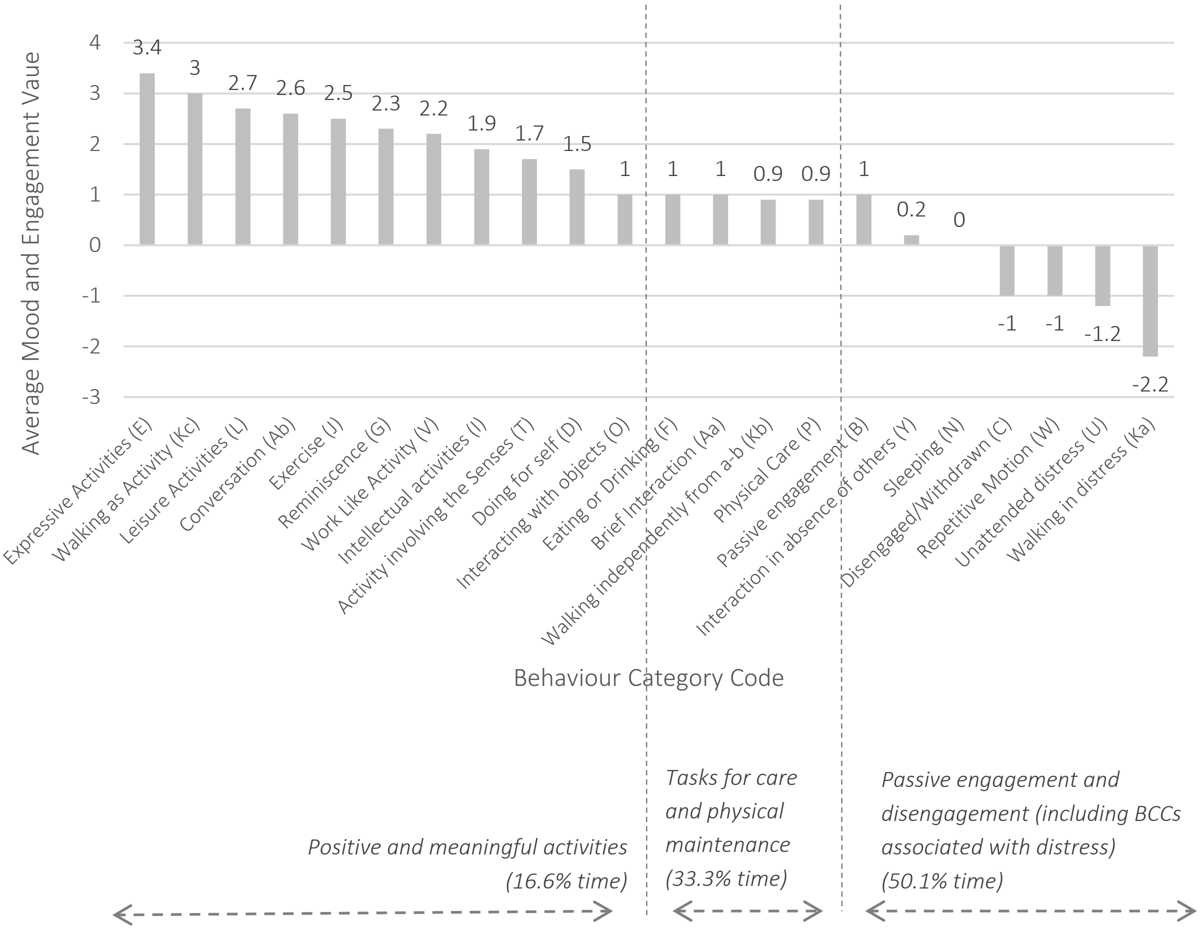
Participant	Av. WIB score	Description
Mollie	+0.7	Mollie enjoyed the company of others but often sat alone, unengaged in activity. She had recently broken her hip that hurt her causing periods of ill-being.
Audrey	+0.6	Audrey often attempted to initiate interaction with others and although she was often ignored there was evidence of staff spending long periods of time with her. Audrey had periods of significant wellbeing as well as times when she was extremely distressed owing to complex mental health issues.
Stanley	+1.0	Stanley rarely initiated activity but enjoyed engaging in activities and interaction. Care staff appear to interact with him more than they did with other participants. Stanley experienced periods of great joy when he was engaged in a group activities and often slight distress when he was alone.
Bill	+0.9	Bill occasionally read intermittently. Care staff rarely interacted with him beyond what was necessary to provide personal care. He often became withdrawn but rarely appeared distressed, he rarely had periods of heightened wellbeing.
Peggy	+1.2	Peggy rarely initiated activity herself but enjoyed participating in activities when encouraged to do so. She often interacted with May and sometimes with the care staff. She rarely appeared to experience negative mood.
May	+1.3	May occasionally initiated her own activity and enjoyed engaging in activity when encouraged to do so. She often chatted to Peggy and care staff sometimes interacted with her. She never became distressed and rarely showed signs of disengagement or ill-being.
Vera	+0.7	Vera never initiated conversation or activity and staff rarely engaged with her beyond care tasks. She occasionally became withdrawn but otherwise never appeared distressed, nor did she appear to display signs of positive mood.
Norma	-0.4	Norma never initiated conversation or activity. During the study she became unwell and deeply distressed which had a significant negative impact upon her wellbeing.
Freda	+0.9	Freda never initiated conversation or activity and staff rarely engaged with her beyond care tasks. She often sat alone in silence and occasionally appeared withdrawn but rarely showed signs of being unhappy or distressed.
Dorothy	+0.8	Dorothy rarely initiated her own activity but occasionally tried to start a conversation. She enjoyed participating in activities when given the opportunity to do so. During periods of inactivity she sometimes fell asleep or became distressed.
Edith	+1.0	Edith occasionally read and walked around, she also enjoyed participating in the activity programme. Staff rarely interacted with her beyond care tasks and she occasionally became distressed.
Eleanor	+1.2	Eleanor often attempted to start a conversation with other residents and staff. She was sociable and staff often engaged her in conversation. She rarely became withdrawn or unhappy and enjoyed participating in activities.
Margaret	+1.4	Margaret initiated her own activity by reading a lot. Staff rarely interacted with her but she never appeared to become withdrawn or distressed.

Well or ill-being was also affected by an individual's tendency to become distressed or withdrawn (and consequently experience negative ME values); while May (1+3), Margaret (+1.4), Peggy (+1.2) and Eleanor (+1.2) rarely showed signs of negative mood, Dorothy (+0.9) and Audrey (+0.7) sometimes showed significant distress and negative mood, while Edith (+1.0) and Stanley (+1.0) occasionally appeared to be in a negative mood state. Freda (+0.9) and Bill (+0.9) however, although occasionally withdrawn, rarely showed any signs that they were experiencing negative mood but also seldom experienced heightened states of wellbeing. Physical illness was also a cause of ill-being as both Mollie (+0.6) and Norma (-0.4) appeared to be significantly distressed as a result of illness and injury, although in Mollie's case there were also periods of considerable positive mood due to positive staff interactions. Indeed, it was evident that the regularity and quality of staff interactions had a pronounced effect upon resident wellbeing, this was clear within the field notes and is discussed in greater detail in Chapter Seven.

THE RELATIONSHIP BETWEEN ENGAGEMENT AND WELLBEING

The data showed a link between engagement in activities and wellbeing. Figure Eight (p. 126), shows each of the 22 BCCs observed and the average ME value for each. The BCCs within these figures are grouped into the three overarching categories: passive engagement or disengagement, tasks necessary for care and physical maintenance and positive and meaningful activities. The figure illustrates the Behaviour Categories that had the highest and lowest potentials for wellbeing. Those associated with positive and meaningful activity tended to occasion the highest levels of wellbeing (as indicated by the average well and ill-being scores experienced by participants). Activities with an element of self-expression or creative expression appeared to cause the deepest levels of engagement and greatest wellbeing (+3.4), followed by walking as an activity (+3). Behaviours categorised as tasks for care and physical maintenance affected less positive mood and those associated with passivity, disengagement and distress caused the lowest levels of mood and engagement; walking in distress appeared to affect the greatest levels of ill-being (-2.2) followed by unattended distress (-1.2) With this evidence it is possible to strengthen the case for increasing opportunities for engagement in positive and meaningful activities in care homes as a means to improving levels of wellbeing amongst residents.

Figure Eight - Wellbeing by Behaviour Category Code



Most residents had the opportunity to engage in some type of positive and meaningful activities on most of the days, either by participating in the formal programme of activities, being supported by staff to engage in activities or engaging in self-directed activities. On days when residents were observed to spend more time engaged in activities categorised as positive and meaningful, they experienced higher levels of overall wellbeing as indicated by their overall WIB scores. During one observational period for example, May and Peggy spent 45% and 39% respectively of their time engaged in a variety of activities including conversation, creative expression, reading, leisure activities, sensory activities and work-like activities. They appeared to experience significantly higher levels of overall wellbeing throughout the day as a result of this engagement and their overall WIB scores during this period were both recorded as being + 2.0. Conversely, if residents were observed to spend a significant majority of their time in BCCs associated with passivity, disengagement or distress their overall WIB score appeared substantially lower. For example, during one observational period, Dorothy and Freda spent 81% and 82% respectively in a withdrawn or passive state. At no point were they engaged in positive activity or interaction beyond those necessary for physical maintenance. As a result of this lack of interaction and activity neither woman experienced any level of wellbeing or sustained engagement during the day. Their overall WIB scores on this occasion were +0.5.

Summary

Using data from DCM and concurrent ethnographic observations collected over a period of six months (during 27 days or 206 hours in total), it has been possible to gain a clear understanding of how residents spent their time in the care home. The data shows that people living with dementia spent half of their time (50.1%) engaged in behaviours associated with passivity, disengagement or distress. Tasks associated with physical care were observed for a significant proportion of time (33.3%). Engagement in positive and meaningful activities appeared limited (16.6%) despite the rich and varied activity plan and the fact that residents expressed a wish to engage more in activities. The qualitative element of the observations paints the picture behind the figures.

There appeared to be a clear relationship between participation in positive and meaningful activities or engagement in positive interactions and increased levels of wellbeing. Levels of mood and engagement (as defined within the DCM framework) almost always increased with engagement in positive and meaningful activities. This supports the tacit assumption underpinning the research question that a lack of opportunity to engage in activities contributes to poorer outcomes for people living with dementia in care. Correspondingly, it reinforces the argument that to promote wellbeing in care homes, residents need to be given the opportunity to engage in positive and meaningful activities and interactions. This point is central to the philosophical foundations of this study.

Chapter Six - Self-Reported Activity Preferences and the Meaning of Activity for People Living with Dementia

This research began with the principle that people living with dementia should be afforded choice and control over their care and this principle extends to choice over participation in activities. In this chapter, data collected during observations, interviews, spontaneous conversations and a resident focus group is used to construct a thematic analysis of residents' self-reported activities preferences and to identify the types of activities participants might like to do. These included outdoor and physical activities, creative or expressive activities, fun and games, normalising activities and social activities. This data was also used to identify the underlying factors which might create meaning in activity for residents. While participants were clear about the types of activities they wanted to do, establishing the meaning behind engagement was a more complex task. However, six interlinking themes emerged. These were (i) supporting a sense of purpose and enabling an individual to contribute to life in the care home, (ii) enabling personal achievement, (iii) supporting a sense of self and identity, (iv) fulfilling a need for inclusion and belonging, (v) creating enjoyment and pleasure and (vi) enabling an individual to keep busy.

Engagement in activity almost universally had a positive effect on the mood and wellbeing of participants (see *Chapter Five: Mood and Engagement*). Yet there were a few examples of activities leading to poorer outcomes if they were delivered in a way that did not take into account the unique physical and intellectual abilities of an individual. If an activity was too complex for example, it could lead to disengagement, frustration or anxiety. If it was too simple there was evidence that residents felt patronised or infantilised. Therefore while the type of activity might not be significant in supporting wellbeing, it is important that the activity be delivered in a person-centred way and tailored to the individuals' needs and abilities.

Self-Reported Activity Preferences

The results from Dementia Care Mapping (DCM) demonstrate that residents living with dementia spent a significant amount of time withdrawn from their surroundings or in a state of passive engagement (see Chapter Five – *Engagement and Wellbeing*). This should not, however, be taken as an indication that residents were unwilling to participate in activities as they were keen to be involved in activities when opportunities for engagement arose. In addition, their engagement in activities appears to have had a positive impact upon their wellbeing. When asked about the type of activities they might like to do, participants were often able to clearly articulate their preferences. While focused conversations proved to be largely ineffective in gathering information about activity preferences, spontaneous or ad hoc conversations during observations and conversations during the focus group were more successful.

GATHERING INFORMATION ABOUT ACTIVITY PREFERENCES: WHAT WORKED?

The researcher initially intended to ask participants about their activity preferences using one to one focused conversations. Themes from these conversations were to be synthesised and discussed during a focus group with participants that took place during the third phase of data collection. One to one focused conversations in this instance however appeared to be a wholly unsuccessful way of collecting information about activity preferences. Participants often appeared to struggle to recall the things they enjoyed doing in the moment of the conversation despite the researcher's attempt to use audio and visual prompts and to ensure sufficient time was given to the interview. Of the 13 focused conversations attempted, only three were successful in gathering data about activity preferences. What transpired to be a more effective way of collecting data and far more enlightening to resident preferences was to make detailed recordings of ad hoc comments made by residents during every day observations and outside the confines of an interview (or focused conversation) situation and recording the types of activities they appeared to enjoy. For example, during a focused conversation with Mollie, the researcher asked her what activities she used to enjoy doing before moving to the care home:

> *Researcher: 'What did you like to do before you lived here?'*
> *Mollie: [pause] 'Well I don't know love.' [pause]*
> *Researcher: 'You have said before that you like having your hair done.'*
> *Mollie: 'No.'*
> *Researcher: 'Your hair is looking lovely now.' [pause]*
> *Researcher: 'You also like dogs don't you' [indicating Mollie's toy dog that she has with her].*
> *Mollie: 'I don't know.' (Extract from focused conversation with Mollie)*

However, during an unplanned conversation Mollie seemed more loquacious and keen to talk about activities. For example, during an observation Mollie invited the researcher to sit with her:

> *She talks good humouredly: 'Come here, come and say 'ello to Frank [Frank was Mollie's toy dog]. Hello Frankie boy'. She kisses him on the nose 'Isn't he a lovely boy?' I ask her if she likes dogs and she says that she loves dogs. She continues to cuddle and kiss Frank. (Field notes, 16th June 2015)*

On another occasion Mollie was in her wheelchair being taken to the pub and the researcher was walking beside. Being outside triggered Mollie's memories about her love of the outdoors and particularly of the seaside and she struck up a spontaneous conversation with the researcher saying:

> *'Oooh I love to be out and about. Do you know what I'd like more than anything else? To go to the seaside and have fish and chips. Wouldn't that be lovely!' (Field notes, 8th July)*

The focus group was also a more useful exercise than one to one interviews as some participants were prompted by family members who knew them well and were able to bounce ideas off one another in conversation. Reflective notes written directly after the focus group record:

> *The [focus] group was a fruitful exercise. In conversation with one another and with family members, residents were able to share ideas and elaborate on ideas made by others. Working as a team they came up with many ideas of the things they would like to do and what is clear is the appetite for engagement here and the enthusiasm to try out new activities. (Reflective notes, September 2015)*

While focused conversations were largely unsuccessful in gaining information about activity preferences in all but three instances, the information was obtainable through adapting the data collection methods to suit the individual participants.

TYPES OF ACTIVITY

The activities that participants expressed a preference for fell under five board headings; (i) physical activities and being outdoors, (ii) creative and self-expressive activities, (iii) playfulness, fun and games (iv) normalising activities, including activities of daily living and (v) social activities (Table Eleven, these categories are similar to those laid out in a study by Tak et al. 2015).

Table Eleven - Self-Reported Activity Preferences

Activity Theme	Activities Suggested by Participants
Outdoor and physical activities	Gardening and visiting a garden centre Keep fit classes A residents sports day with fun / silly activities Visiting a football stadium Going to a park Going to the seaside
Creative activities	Painting Doing adult colouring books Small DIY or woodwork projects Making pompoms Making lavender bags Joining a singing group or creating a care home choir Learning an instrument
Playfulness, fun and games	Board games and card games Jigsaw puzzles Quizzes A residents sports day with fun / silly activities A music based entertainment session
Normalising activities	Helping around the home, for example by tidying or cleaning Cooking or baking Helping to make tea Interacting with animals (mostly dogs) Having a chat Reading Small DIY or woodwork projects Listening to music Folding laundry Shopping for food
Social activities	Coffee mornings and ‘get togethers’ Going into the community, for example to cafes or to the pub Going to the theatre to see a play or a musical event

Physical activities and being outdoors referred to activities that would usually be undertaken outside such as gardening or team sports but also included a desire to keep fit, healthy and active for example by participating in an exercise class. Creative activities included those with a primary focus on creative expression for example by engaging in music making, making art or craft activities. Playfulness, fun and games involved intellectual, physical and sensory games such as playing a board game or engaging with a word search. Normalising activities referred to those activities that individuals might have undertaken in their daily life before moving to Forest View for example cooking and reading the paper. They included activities relating to leisure and hobbies as well as those involving an element of work or work-like occupation. While many of the activities within these categories may also be considered social, social activities emerged as a distinct and separate theme and referred to those activities where the opportunity to socialise was the predominant focus of the activity such as attending coffee mornings or trips to the pub.

PHYSICAL ACTIVITIES AND BEING OUTDOORS

There was a clear love of being outdoors expressed amongst residents. During the focus group and spontaneous conversations, a love of gardening was mentioned by 11 of the 13 participants. Individuals spoke warmly about their enjoyment of looking after their own garden before moving into the care home and also of the memories they had made in their gardens. For example, Edith explained:

> *'I loved my little garden. We had roses you know and the smell. Well it was wonderful. And I liked going to choose the plants you know in that place where you buy them from. That was always a treat.' (Edith: Focus group)*

Participants' love of gardening became clear early on in the research. During initial visits to the care home, the researcher took Dorothy into the garden upon her request:

> *Dorothy enjoyed being out in the garden. She kept saying: 'it's nice to be outside'. She told me what she would do if she owned this garden and which flowers she would plant where. She liked daffodils and I picked one for each of us. Later when I went to see her in her bedroom she still had a daffodil in her hand. The residents appear to get so much pleasure from the garden when they do visit it but few appear to do so unless their family members take them. (Extract from reflective diary, March 2014)*

Within these interactions it became clear that gardening was something that was strongly rooted in individuals' sense of self and had often been a pleasurable part of their lives. However, the observational data shows that residents were unable to access the dementia friendly garden in the home as the locked floors prevented them from going outside without the support of a family member or member of staff and that support to do so was rarely forthcoming. These field notes record just two instances of a participant accessing the garden space.

Participants also wanted to go further afield and to connect with a wider environment. They discussed their love of visiting garden centres, the park and the seaside and suggested these as possible options. Again, these were often deeply rooted in their past and encouraged a great deal of reminiscence within the group. For example:

> *'I used to take the children to that park when they were small. Oh the fun we had.' (Dorothy: Focus Group)*

Physical activities and sports were also discussed. During the focus group participants expressed a wish to organise a home wide sports day with silly activities as a way to bring people together but also to encourage physical activity. Despite limiting physical abilities, participants seemed to value the opportunity for physical activity as a means to keep healthy and well:

> *'I was a PE teacher you know and I know it is important to keep yourself moving. Keep fit you know. Yes we definitely need to do more about keeping fit in here. Lots of people just sitting about.' (Dorothy: Focus Group)*

Again, they appreciated the opportunity to take part in keep fit classes. These were well attended by residents and appeared to be enjoyed by the majority of attendees. For example, after the keep fit session Edith was overheard saying to a care worker:

> *Oooh that was fun. I can feel it in my whole body. I've been working hard [she laughs]. (Field notes, 24th August)*

The opportunities to take part in physical activity or to venture outside were observed to be significantly limited however. This is to be regretted since they might have had a positive impact on engagement and wellbeing in the care home.

CREATIVE ACTIVITIES

More than any other types of activity, creative and expressive activities appeared to generate the greatest levels of wellbeing amongst residents. As many of the female participants had engaged in arts and crafts before moving to Forest View, many of these activities appeared familiar and stirred positive memories. In addition, the process of making something tangible also led to feelings of pride and pleasure. During this research a number of participants expressed an interest in participating in arts and crafts and reported an aptitude for this type of activity often having examples of their own handiwork on display in their rooms. In Edith's room, for example, there were small frames encasing samples of intricate cross stitch and embroidery. She reported that she was good at 'finger things' (from the context of the conversation and her hand gestures this was taken to mean delicate crafts) such as sculpting minute sugar flowers and making her own greetings cards. She also had a talent for flower arranging and dressmaking; she used to provide arrangements for the local church and Women's Institute and often made her own clothes and clothes for her children.

Dorothy, who was a mother of six, also explained how she used to knit and sew clothes for her children and recalled the memories fondly:

> Dorothy: '*I knitted them little things, lovely little things you know for the little ones and it was cold and you could whoosh wrap them up. Cosy. Yes knitted a lot for those children. […] dinky little girl's things you know. It was so lovely. And one with a fat pink ball, you see on the top of her head on her hat I suppose, it looked so fun and we laughed about it.'* [Dorothy laughs at the memory]. *(Field notes, 19th June)*

For these women, arts and crafts were not merely a pastime but deeply entrenched in their self and identity and part of that character as a homemaker. In a spontaneous conversation with the researcher about her mother's past Edith's daughter described how creative crafts were a big part of her Edith's life before she moved into Forest View. In addition, for Vera, who was an accomplished fine artist, art and painting appeared to be an integral part of her identity and a source of great joy:

> *Vera: 'But you know, you've probably noticed in the dining room there's one of mine hanging there and it's worth a lot of money* [referring to one of her paintings] […] *I really enjoyed it in that old house painting you know my father was there and in that old sideboard you know the one, well the drawers were filled with painting that I've done*

> *and they were all spilling out everywhere* [she makes arm gestures simulating the paintings spilling out of the drawers and laughs]. *Well some of them were not half bad, no not bad at all.' (Focused conversation with Vera)*

An interest in creative expression through interacting with music was also mentioned in focused and spontaneous conversation, although it was discussed less often than might have been expected considering the high levels of engagement and wellbeing observed during participatory music sessions. For Stanley however, the opportunity to engage in self-expression in music was of paramount importance. He expressed his enjoyment in making music during a non-verbal interaction:

> *When I ask Stanley what sort of things he would like to do he rises and takes me by the hand. He leads me to his room and then over to a chest of drawers. He opens the top drawer and gets out a set of handheld sleigh bells. He shakes these. He offers them to me and gestures to me to shake them, which I do. He holds out his hands and takes them back. He shakes them again and smiles broadly as he does so. (Focused conversation with Stanley)*

Stanley enjoyed shaking these bells during entertainment sessions in the home and these participatory entertainment sessions seemed to be a favourite amongst residents. During one session for example the entertainer sang a number of familiar songs and encouraged his audience to sing along and join in by dancing, providing percussion with maracas and waving cheerleading pompoms and flags:

> *[The entertainer] stands on a table and encourages the residents to wave the flags/pompoms/maracas. […] Most of them know all of the words to the chorus and sing with great enthusiasm as they wave their flags. Stanley is happier than I have ever seen him, he is waving his flag furiously and singing smiling all the while. He seems to be having a wonderful time. The residents look at one another as they sing, the session seems to be facilitating an air of inclusion and belonging as well as being good fun. (Field notes, 18th June)*

During this session, mood and engagement appeared considerably elevated as residents were given the opportunity for creative self-expression in singing and movement.

PLAYFULNESS, FUN AND GAMES

Fun and games included activities with a competitive or pseudo competitive element and fell into three sub categories of intellectual, physical and sensory activities. Intellectual games were those with an intellectual element, for example a word search or quiz; physical games were those with a physical element such as throwing and catching or hitting a target; and sensory games primarily engaged taste, smell or touch. Playfulness was a key element of fun and games. Of all the activity types, fun and games were perhaps the least discussed at the focus group. Bill was one of the only residents who spoke about games; he remembered playing cribbage and dominoes during his lunch breaks at work:

> *'Yeah. When I was work. Well yeah you know when you're at work you're not working all the time. We had a lot of time on our hands. Yeah I can play most of those games, cribbage and dominoes and all that.' (Focused conversation with Bill)*

However, although few people spoke about a desire to participate in games (beyond the idea of a home sports day), observations showed that physical games had the potential to affect high levels of wellbeing amongst some participants. On one occasion a group of scouts visited the care home and engaged Stanley and Freda in a physical game involving hitting a balloon between them. During this interaction, Freda was more engaged and appeared to experience a greater level of wellbeing than she had during any other observation:

> *Both Freda and Stanley are smiling and laughing and appear to be greatly enjoying the game and deeply engaged in it. The atmosphere (there are care workers and other residents watching) is fun and exciting as those around them cheer and clap. [Both Freda and Stanley are scored at +5 for the duration of the game]. (Field notes, 27th September)*

The musical entertainment sessions were also instrumental in fostering a sense of fun amongst participants. This was particularly the case if the entertainer and members of staff encouraged active participation such as singing, dancing and music making or if the songs were upbeat and familiar.

> *The entertainer has sung* Doing the Lambeth Walk *some of the residents join in singing this song and all of them join in with 'oi!' at the end of the chorus. They look around as they sing and I see Peggy and May giggle to each other with delight. […] There is a great sense of fun and energy in the room and levels of engagement and wellbeing appear high as the residents laugh and join in. (Field notes, 18th June)*

Instances of playfulness and fun often heightened mood as observed within the DCM framework and created sustained engagement amongst participants.

NORMALISING ACTIVITIES

Normalising activities was the category with the widest scope since most activities might be seen as normalising if they were activities that residents had undertaken around the home before moving into care. Normalising activities encompass a breadth of activity including home making activities as well as traditional hobbies such as reading and interacting with pets. Within the focus groups there was significant discussion surrounding traditional home making roles and many of the female participants expressed a wish to continue to perform home making tasks such as baking or tidying:

> *Dorothy: 'Oh yes I was in the kitchen all the time, there were lots of children you know. They are always hungry.'*
> *May: 'Well I used to like baking.'*
> *Facilitator: 'Would you like to try baking while you are here.'*
> *May: 'Yes I suppose so love. If it would help you.'*
> *Dorothy: 'Yes I think that would be good. Because we used to do it a lot you see.' (Focus Group)*

In this extract, Dorothy has highlighted that she used to engage in baking before moving into care and May expressed a wish to use home making activities as a way to help out around the home. During the focus group, Stanley said that he would like to be given the opportunity to help with maintenance in the care home. These appear to have been central to their identity before moving into the care home. For example:

> *'I used to do DIY, you know. And I think I'd still like to do that. It's what I used to do. On a Sunday I'd do a bit here and there. It's just what you did.' (Stanley, Focus group)*

Engaging with animals was also a normalising experience and a popular theme amongst residents. When Bill was asked what he most enjoyed in his life he replied:

> *Bill: 'Well I only had one love and that was dogs. Yes that was what I really loved. […] We had 14 pups at one time and well, they was everywhere. You know your house suddenly didn't belong to you no more. And there was dogs all over place. Lovely time I thought. […] I'd like to do that again sometime. Yes I'd like to have dogs again.' (Focused conversation with Bill)*

Dorothy, Eleanor, Mollie and Edith also spoke of their love of animals, particularly dogs, and in spontaneous conversations with the researcher talked about times in their lives when they had owned a dog and remembered the joy that this had brought.

SOCIAL ACTIVITIES

As with normalising and outdoor activities, within the theme of social activities there seemed to be a strong desire to spend time engaging in the wider community, for example by visiting a local café or the nearby pub. However, social activities could also take place in the home for example by holding a coffee morning or a social group. What is perhaps interesting here is that despite the fact that residents sat together in the same room most of the day, they often did not interact with one another. However, within the context of a staff supported social group conversation was more common. During the focus group Edith said:

> *'This is nice isn't it, all sitting together having a talk with a cup of tea. That's lovely isn't it?' (Edith: Focus Group)*

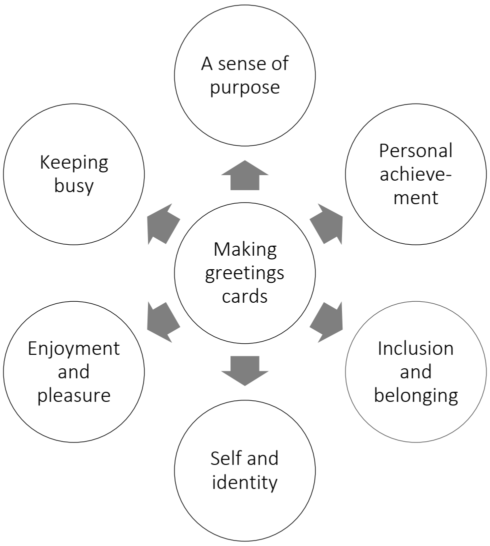
Yet, at the time, Edith was sitting with the same people she sat with in the ground floor lounge on a daily basis. While social groups and activities were rarely mentioned in conversation, interviews or during the focus groups they were a predominant feature of the activity programme in the home and the evidence from the DCM shows that residents enjoyed the opportunity to socialise either in large groups (for example during a trip to the pub) or within smaller situations (such as having a chat over a cup of tea).

The Meaning of Activity

Conversations with residents living with dementia demonstrate that despite cognitive decline and admission to an institutional care setting, the desire for regular participation in activities remained strong. Individuals were able to clearly present a picture of the types of activity they wished to engage in. By combining this interactional data with observational data, it was possible to begin to conceptualise the meaning behind engagement. A sense of purpose occurred when an individual had the opportunity to make a valuable contribution to life in the care home (linked to the idea of 'feeling useful'). Similarly, a sense of personal achievement was observed when they did something positive for themselves. Both making a contribution and personal achievement appeared to evoke feelings of pride amongst residents which lead to improvements in wellbeing. Identity and self were facilitated by enabling an individual to engage in a familiar activity or an activity that held deep meaning in their past. It was also supported by encouraging positive reminiscence. In both respects there was a need to create a continuity between an individual's current and past life. Fostering a sense of inclusion and belonging enabled an individual to connect deeply with their social environment. It differs from the category 'social activities' described above as it was concerned with the meaning of social connectedness rather than the *type* of activity that created social connection. Within this framework, activities held meaning if they provided enjoyment and pleasure to an individual. In addition, it was clear that individuals appreciated engagement for engagement's sake, as being engaged in activity was seen as preferable to a state of passivity or withdrawal. Indeed, this need for engagement as an end in itself was often of more importance than the *type* of activity that the individual was engaged in and whether it corresponded with their unique activity preferences.

These themes often overlap and may be embedded within different types of activity. A simple card making activity for example may provoke a sense of purpose and contribution to the care home since the cards were sold to raise money and a sense of personal achievement as the residents made something tangible. This simple craft activity may have been familiar to some and therefore facilitated a sense of identity. In addition, if the card making took place in a group environment, individuals may have felt a sense of inclusion. The activity may also provoke enjoyment and pleasure and support an individual to keep busy (Figure Nine).

Figure Nine – The Meaning behind an Activity: An example of card making



Similarly, other activities had the potential to fulfil more than one meaning simultaneously. The meaning behind activities was often dependent on how the activity was presented and the uniqueness of the individual engaged.

A SENSE OF PURPOSE (CONTRIBUTING TO LIFE IN THE CARE HOME)

Throughout the focus group there appeared to be an underlying feeling of regret amongst some participants that they no longer felt useful since they entered a care home. Although not explicitly articulated, this could feasibly be linked to individuals' feelings of pride, self-esteem or self-worth. Stanley particularly expressed regret that he did not feel useful, saying that he used to be constantly busy before coming to live at Forest View:

> *'People used to come to me with things you know to fix. If there was anything to fix they used to say "give it to Stanley". Yes I used to do that.' (Stanley: Focus Group)*

And when he was asked what he would like to do he said again:

> *'I would like to feel useful, that's what I'd do. Yes to be useful around here, maybe I could do that. You know, do things around the home.' (Stanley: Focus Group)*

Stanley himself suggested that he could help out with some of the DIY jobs around the home, perhaps working along the maintenance man but also said he has happy to do simple things such as tidying up or dusting. Some of the women too reported that they no longer felt needed and spoke about times when, as a wife and mother, they were busy most of the time. Residents' desire to feel useful indicated a regret that their former roles had been removed upon their admittance to a care home. This is an important factor to take into account when supporting individuals to participate in an activity and yet these types of activities did not appear within the formal programme of activities in the home

Residents wanted to help. When asked by a care worker if she would like to 'do some cooking', Dorothy refused. However, a few moments later when a nurse asked her for help to bake a cake she agreed to participate:

> *[The nurse] kneels by Dorothy. She says: 'I wonder if you could help me Dorothy. Some people are making some cakes downstairs for our afternoon tea. Do you think you could come along and help? I am just really busy and I don't have the time'. Dorothy replies 'Yes I'd like to help you, yes' and goes down the stairs to engage in the baking group. (Field notes 27th September)*

Following a baking group Edith articulated her sense of wellbeing generated by utilising her skills as a baker. She smiled as she describes her experience:

> *She describes in detail how she made the cake by stirring the mixture and putting it into paper cases. The care worker listens with interest and congratulates her on her achievements saying the cake is delicious. Edith agrees that the cake is nice and says 'I have enjoyed baking it for you'. (Field notes, 27th September)*

In this example Edith showed her delight in making valuable contribution by doing something for the care worker when she says 'I have enjoyed baking it for you'.

For Stanley, remaining useful seemed important (his was the most powerful voice during the focus group asking to be supported to participate in activities which made a valuable contribution around the home). Stanley appeared to take pride in feeling that he was helping out around the home and was delighted to undertake little jobs. On one occasion when he returned to the first floor he described how he had helped the activity coordinator by feeding the hens:

> *'I've been helping to feed the chickens. I've been throwing them food and they've been going [he does a pecking motion with his hand]. The activity coordinator says 'Yes you've been really helpful today Stanley thank you' and Stanley beams with pride. He appears delighted that he was able to help out. (Field notes, 19th November)*

Participants were also observed experiencing wellbeing in making a valued contribution to the home during craft and music sessions. During one afternoon the activity coordinator supports Eleanor to make greetings cards, these are sold in the reception area to raise money for the activities programme. When Eleanor has finished her card she expressed pleasure in making a contribution to this endeavour saying:

> *'Is that what you wanted?' The activity coordinator says it looks great [...] Eleanor says 'I am glad I could help you dear, I'm really pleased'. (Field notes, 25th September)*

She expresses her desire to contribute further by saying:

> *'Let me know if you think there is anything more I can do, to help you you know. I'll do what I can.' (Field notes, 25th September)*

Perhaps the greatest example of an individual making a valued contribution was during an entertainment session when Stanley supported the entertainer to make music for the other residents by providing percussion with his bells. He stood at the front of the room next to the entertainer as he did so. At the end of the session the entertainer extended his hand to Stanley and thanked him:

> *'And thank you to my friend for helping me today' the residents clap and some of the care workers watching the group cheer and whistle for Stanley. Stanley is beaming, he appears delighted at the recognition from his audience, and he bows his head. His ME value has been at +5 for almost all of the session. (Field notes 28th September)*

It was evident that each participant had made a valuable contribution to their environment (either at home or in the wider community) in a number of different ways. Yet admission to a care home appears to have robbed them of an opportunity to contribute to a great extent. These examples show that the residents were able and willing to make a valuable contribution to life in the care home and that the opportunity to do so created meaning within the activity and had a positive effect on mood and feelings of self-worth.

A SENSE OF PERSONAL ACHIEVEMENT

A sense of personal achievement was also linked to feelings of pride and increased self-worth amongst participants who often expressed signs of shared celebration with others. Dorothy who had spent her working life as a teacher of physical education and continued to take a great interest in physical activity for example, took pride in her aptitude for exercise during a keep fit session at the home:

> *Dorothy is considerably engaged in the exercises. She is concentrating hard on copying the exact moves of the instructor and appears to be really enjoying herself. The instructor says 'Well done Dorothy, you are doing really well there' and smiles at her. Dorothy smiles back and seems proud of her accomplishments and at being able to demonstrate her skills. (Field notes 24th August)*

Within this interaction both the instructor and Dorothy showed pleasure in Dorothy's skills and achievements and celebrated these achievements together. Achievement and subsequent celebration was often observed during social activities and physical, sensory or intellectual games as these had an element of gentle competitiveness. For example, there was a quiz during the social group:

> *When a resident gets a question right the other residents and the staff facilitating the group celebrate their achievement. May gets a maths answer correct, it is a difficult question and the activity coordinator seems impressed 'Well done May, that was an incredibly difficult question, I didn't think anyone would get that' from across the room a care worker gives May a thumbs up and she smiles saying 'see I'm not daft'. (Field notes, 24th August)*

During a game of hangman Dorothy seemed proud when she got an answer right and celebrated the fact with the activities assistant:

> *The activities assistant congratulates her and celebrates her achievement 'That's right! Well done Dorothy.' Dorothy smiles with pride and says 'Thank you very much.' (Field notes, 24th August)*

When the game had finished, Dorothy remained proud of her achievement saying:

> *'I enjoyed that, I enjoyed that very much. I got one right didn't I?' The care worker acknowledged this achievement saying 'yes you did, well done Dorothy'. (Field notes, 24th August)*

During the baking group Edith also celebrated her achievement in removing a stain from a table:

> *Now the cakes are in the oven, Edith takes the cloth and begins to wipe down the table. She seems happy and engaged […] As she cleans she talks to others of her efforts 'look, I've got that stain off! I didn't think I would manage to get that stain off but it has come off hasn't it'. She seems proud of her efforts and the care worker congratulates her. (Field notes 27th September)*

These examples show how attaining a sense of purpose through personal achievement can encourage feelings of pride and wellbeing amongst individuals living with dementia. Activities that facilitate achievement should therefore be encouraged and supported.

SUPPORTING SELF AND IDENTITY (HABITUAL ACTIVITY)

Engaging in habitual activities was observed to support an individual's sense of self and identity. One of the most beautiful examples of this was on an occasion when Eleanor expressed her identity as a nurse. Eleanor always seemed concerned with the welfare of those around her. When Eleanor felt that one of her friends had become ill she employed her skills in an attempt to support them.

> *Eleanor gently holds P's hand and takes her pulse with two fingers. She feels P's forehead and asks her if she can open her eyes. She talks gently to P. She is displaying all the signs of an experienced nurse. (Field notes 11th November)*

Through her interaction with P, Eleanor was creating a link with her past identity. Indeed, she continued to identify herself as a nurse and when a care worker thanks her for her support she replied:

> *'Well I am a nurse aren't I? Is the poor wee lass alright now?' The care worker says yes and Eleanor replies 'well let me know if I can do any more.' (Field notes 11th November)*

In a similar way but on a separate occasion, Audrey supported individuals on the second floor by sitting beside them, holding their hands and talking to them gently. In this way she expressed a continuation of her former identity as a family carer. Throughout the observations were numerous examples of participants expressing their selfhood (Self 3) by exhibiting a variety of social identities (such as nurse, mother or homemaker) by performing familiar tasks.

Supporting Self and Identity (Remembering the positive past)

It was also possible to support identity and a sense of self through remembering the past. Although reminiscence was never observed to be part of the formal activities programme it did occur during some conversations and some activities provoked memories about the past. Engaging in normalising activities and particularly homemaking activities appeared to stimulate positive memories of the past and acted to connect residents through expressions of similar experiences. During the baking group Dorothy and Vera talked together about their children and the hard work that children bring, including long hours in the kitchen. The women were delighted to share these experiences with one another and in doing so enhanced their level of wellbeing and deepened their engagement in the activity:

> *Dorothy says: 'I was in the kitchen all the time. It was a big family. We didn't do cakes so much because it was a big family and we had to take what we could get but I was in the kitchen all of the time.' Vera replies: 'I remember mine, gosh they were hard work and always hungry, always in the kitchen. Under my feet.' She laughs and Dorothy nods her*

> *head in apparent agreement. Both women smile together at their memories. (Field notes 27th September)*

Reminiscence of past experiences with children appeared to create a bond of sympathy between the two women (who rarely came into contact with one another as they lived on different floors) as mothers and homemakers. This lasted until the end of the baking session. In addition, while the activities assistant supported Eleanor to read a piece in the paper about nursing she recounted her fond memories of the profession:

> '*Oh it was a wonderful time. Us nurses together you know. We had a lovely time looking after the people and making it all all right again.' She smiles as she recalls the memory. (Field notes, 19th June)*

Remembering the positive past seemed to enhance residents' overall enjoyment of an activity. Perhaps more importantly however, it enables individuals to articulate their identity and to connect with their social identity or sense of self. Such a connection helped to create a deeper meaning to engagement.

A FEELING OF INCLUSION AND BELONGING

To feel physically and psychologically included in a group was described by Kirwood (1997) as being one of five main psychological needs of people living with dementia. The evidence from this study indicates that people living with dementia experienced wellbeing as a result of feeling inclusion or belonging in a group environment. Social activities often created an environment of inclusion amongst participants who genuinely appeared to enjoy one another's company. Yet interestingly, while a sense of inclusion and belonging was not apparent in everyday care when residents were sat together in communal areas of the home, it was clear during facilitated social groups. For example, during one social activity, Vera, who rarely interacted with other residents, expressed her pleasure at being part of a group saying:

> *'It's so nice us all being here together isn't it. (Field notes, 24th August)*

And during a trip to the pub Eleanor expressed similar sentiments:

> *Eleanor has been looking around her and smiling. She says: 'It's good to be in this group'. She appeared happy and content in the company of the others. (Field notes, 8th July)*

Promoting feelings of inclusion and belonging were not unique to group activities and were also created when the activities staff spent time interacting with participants during one-to-one or one-to-two conversations. For example, on one occasion the activity coordinator sat in the lounge with residents.

> *The activity coordinator sits beside Peggy and May, the three women sit together chatting like old friends. There is a sense of acceptance and belonging within this interaction and May and Peggy appear happy and relaxed as they talk. (Field notes, 28th September)*

Most of the activities in the home had an element of inclusion for participants and in some of the examples above they expressed pleasure in this. The experience of belonging in a group was clearly a contributory factor to wellbeing amongst residents be it in a large or intimate setting and there was an obvious element of comfort and relaxed contentment derived from these settings. During one-to-one chats the activities assistant sat beside Peggy and the two women drank tea in one another's company:

> *[Peggy] sips her tea. She says 'that's a lovely cup of tea' and sighs again. She appears happy and relaxed and enjoying the company. It feels like the two are old friends as they sit quietly side by side. (Field notes, 10th November)*

On another occasion the activity coordinator applied Audrey's make up. Audrey, who had been distressed earlier that day, became deeply relaxed during the interaction and her wellbeing improved as a result:

> *Audrey appears deeply relaxed and calm. She holds her head up with her eyes closed and breaths slowly and deeply. […] She is tranquil and her wellbeing has improved. During the interaction there appears to be a deep connectedness between the women. (Field notes, 29th August)*

Feeling a deep sense of inclusion and belonging in large group activities or one to one interactions was a valuable element of participation and supported wellbeing amongst residents.

ACTIVITIES FOR ENJOYMENT AND PLEASURE

Although simple, provoking enjoyment and pleasure was sufficient to give meaning to an activity. While enjoyment and pleasure often overlapped a second meaning (for example a sense of personal achievement) it could also occur independently. On one occasion for example a care worker noticed that Peggy had become withdrawn and asked her if she would like to go for a walk and Peggy agreed:

> [*The care worker] takes her by the arm and supports her to walk up and down the corridor. The carer and Peggy pick things up along the way; a hat which Peggy puts on the carers head and a feather that the carer places in Peggy's hair. The two women laugh and talk together. They go out of sight for a time frame but when they return the carer says that they have been playing 'Cowboys and Indians'. Peggy looks flushed and delighted, she had three feathers in her hair and a feather boa around her shoulders and a pompom, she is linking arms with the carer and smiling. (Field notes, 29th September)*

While there appeared to be no deep psychological meaning to this interaction it was not without positivity and meaning since it was evident that engaging in the activity caused Peggy to experience enjoyment and pleasure. In another example, a nurse kicked a ball with Stanley as they walked through the corridor:

> *Stanley has been standing in silence by the wall. The nurse attracts his attention and kicks a football towards him. His face instantly brightens as he kicks it back to her. They kick the ball back and forth between them down the corridor. Both Stanley and the nurse laughing with pleasure at this simple interaction. (Field notes, 19th November)*

Again the primary meaning within this activity for Stanley was that it led to him experiencing a level of enjoyment and pleasure. Both instances are not dissimilar to Kitwood's (1997a) definition of 'play' as an episode that is spontaneous, expressive and that has no goal beyond the activity itself and activities that are grounded in impulse and self-expression.

KEEPING BUSY

Although there is less empirical evidence, the importance of using activity as a means of keeping busy or active cannot be understated. To residents, keeping busy appeared to be preferable to a state of disengagement and this view was often articulated during the focus group. May, for example explained how she had always been busy at home:

> *May: 'Well you see there were always things to do at home and we were always busy. Being a woman you know there was always something to do. But I liked it like that, yes I*

> *liked it. It's better than sitting around all day twiddling [she holds up her thumbs] isn't it?' (Focus group)*

In addition, Stanley expressed a desire to keep busy:

> *'I think it's important to keep busy. Well it's what it's all about isn't it.' (Stanley: Focus group)*

It was also noted that on occasion during periods of prolonged inactivity, residents who were able would walk around and look for activity. Edith, Dorothy, Norma, Stanley and Audrey were all observed attempting to seek out activity and occasionally became distressed when a care worker asked them to sit down. On one occasion Dorothy, who had been sitting alone and in silence for over an hour, stood up and appeared to be looking for something to do. A care worker led her back to her chair and asked her to sit down. Dorothy was not content with this inactivity however:

> *Dorothy rises again and still appears to be looking for something to do. Again a care worker asked her to sit. Dorothy screams 'I don't want to sit. I don't want to sit there anymore'. (Field notes 10th November)*

The encounter appears to demonstrate Dorothy's need for *something* to do. The evidence from the DCM showed that in almost all instances, residents experienced higher levels of mood during engagement in an activity than when they were in a state of passivity or disengagement. This appeared to be the case regardless of the *type* of activity participants were engaged in even if that activity did not appear to correspond to their self-reported preferences. This was the case so long as the activity did not cause distress.

The Importance of Person-Centred Activity

Since the *type* of activity appeared to make little difference to wellbeing of residents there seems little evidence to support the fact that activities need to directly correspond to individuals' self-reported preferences. It is important however that activities do not cause actual distress and that they are tailored to suit the unique needs and abilities of the individual; they should not be too simple as to be patronising nor too complex as to provoke frustration or anxiety.

TAILORING ACTIVITIES TO AN INDIVIDUAL'S ABILITY

One clear element that emerged during conversations with residents and from observations was the importance of tailoring activities to suit an individual's intellectual and physical abilities. Residents themselves reported physical problems such as arthritis and mobility difficulties as barriers to participation and during the focus group spoke of the importance of tailoring activity to suit their individual abilities. They were able to suggest simplified versions of favourite activities such as making a pompom instead of knitting a jumper or making small lavender bags rather than endeavouring to make a dress from scratch. In so doing, they identified the need for specific activities to be tailored to their current physical and cognitive limitations if they were to be successful. The importance of tailoring activity to individual ability cannot be overstated. If an activity is not appropriately adapted it can lead to poorer outcomes for a person living with dementia. If an activity was too simplistic, it could lead the individual to feel patronised or become bored and disengaged. Activities that were too complex also caused disengagement or worse, frustration, anxiety and consequently ill-being. It was rare that activities were oversimplified enough to cause ill-being, however there were instances where an activity was so difficult as to cause an individual to become disengaged. For example:

> *The activities assistant gives May and Peggy a 1,000 piece jigsaw to do, she pours the pieces out on the table in front of them and walks away. May picks up a piece and looks at it, it is clearly too complex and she looks away becoming instantly disengaged. Neither woman engages, it is far too complex. (Field notes, 18th June)*

In this situation, the activities assistant would have been more successful had she assessed Peggy and May's unique abilities and tailored the activity appropriately.

Ill-being as frustration was observed during activities that were too physically or cognitively challenging. One of the clearest examples of this was during a game of hangman when Freda became confused and frustrated as she felt unable to participate. The activities assistant asked people to call out letters during the game and Freda appeared unable to make sense of the request:

> *Freda appears to try hard to engage but finds it too difficult and becomes increasingly frustrated. She seems to be unable to process what the activities assistant is asking her*

> *to do. Her ME scores is -1 due to her apparent frustration and confusion at the game. (Field notes, 18th November)*

On another occasion Freda became frustrated as she struggled to process information quickly enough to participate in the keep fit session.

> *Freda has been trying hard to copy the keep fit instructor but appears to be finding it difficult to follow her instructions. [...] Eventually she gives up and becomes disengaged. Her ME score drops to -1. (Field notes, 24th August)*

In this instance the keep fit instructor seemed skilful at accommodating physical limitations to enable each resident to participate in their own way depending on their unique ability by adapting each exercise. For example during one exercise she was encouraging residents to lift their knees as high as they could:

> *She notices one or two residents struggling with this and so she encourages people to tap their toes if they are finding the move difficult and they immediately join in. (Field notes, 24th August)*

However, as the field notes above suggest, she appeared less able to tailor the activity to support individuals with cognitive limitations.

Difficulties in participating did not always cause ill-being amongst participants. Most of the participants engaged in the game of hangman for example appeared to find the concept too difficult:

> *The assistant gives them a clue about the word but again most residents find it too hard. 'This is something you wear on your feet', Eleanor gave the answer 'moon' and then 'fingers'. (Field notes, 18th November)*

Although in most cases it did not have a negative impact upon their wellbeing and unlike Freda, they showed no signs of ill-being as a result of their difficulties. However, these examples illustrate the importance of closely observing the residents to ensure that they are not experiencing ill-being and taking steps to support them should negative mood occur.

There were other examples of staff planning simplified activities to make them easier for people living with dementia. One method was to offer simplified versions of traditional activities such as painting wooden bird boxes rather than attempting fine art. During the baking group for example, the activities assistant had concluded (probably correctly) that weighing out the different ingredients and following a recipe was beyond the abilities of the group she was working with and so simplified the activity by using pre-prepared powdered cake mixture. This only required participants to add a quantity of water and mix before dividing into cases and baking enabling a deeper level of participation than would have otherwise been possible had they watched her making the cake:

> *[The activities assistant] has judged the abilities of her participants well and has pitched this activity perfectly. All three have been profoundly engaged in making the cakes in a way that they may not have been had the task been too complex. (Field notes, 25th August)*

Although it is acknowledged that pitching activities at the right physical and intellectual level, particularly in group situations when each participant will have different skills and abilities, this is an important consideration in activity planning as it directly impacts an individual's ability to engage with an activity in a positive way and ultimately influence their wellbeing during that activity.

PERSON-CENTRED ACTIVITIES IN A GROUP LIVING ENVIRONMENT

A theme that links closely with the importance of tailoring activity to individuals' ability is the principle of delivering activities in a person-centred way and the challenges of doing so within a group living environment. One of the most salient examples of this challenge emerged during an incident with the care home's resident cat; Bubble the cat was brought onto the second floor for Mollie (who loves animals) to engage with:

> *Mollie immediately begins to try and engage with Bubble, she appears to love animals. She strokes it saying 'oh you're a lovely pussy cat aren't you', 'come here to me, oooh you are a lovely thing'. Another resident (not my participant) looks at the cat and makes a hissing sound as though to try and shoo it away saying 'go away filthy cat, go away filthy cat'. She is clearly distressed by the cat's presence. (Field notes, 16th June)*

Although brief, this episode throws into sharp relief the challenges of delivering person-centred interventions in a group environment where every individual has unique preferences and dislikes. In-depth knowledge of the resident helped to minimise distress as far as was possible. For example Margaret's care plan specifically requested staff not to engage her in reminiscence as she did not like to talk about the past. Similarly, staff knew to cover a collection of dolls on the first floor whenever Dorothy went there to attend a group as the sight of dolls upset her greatly (although for some residents dolls were a therapeutic activity). These examples not only underline the challenges but also demonstrate the value of staff who know their residents well as they can take steps to mitigate factors that may cause ill-being or distress.

Summary

The findings laid out in Chapter Five (above) demonstrate that participants spent a relatively small amount of time engaged in positive and meaningful activities compared to time spent in behaviours associated with passivity and disengagement. This appears incongruous with their desire for activity. The evidence from observational and interactional data shows that residents living with dementia appeared keen to participate in a variety of different activities. They reported a desire to participate in a number of tangible activities in six overlapping categories: physically active or out of doors activities, activities involving an element of creativity and self-expression, activities relating to physical intellectual and sensory games, normalising and activities with a predominantly social element.

While residents communicated clear examples of the things they would like to do during focused conversations, spontaneous interactions and in the focus group, it became clear during observations that it was not the *type* of activity that was important (for individuals happily engaged in activities not related to the self-reported preferences), but the *meaning* behind the activity. Meaning was found in activity when it supported a sense of purpose or enabled an individual to ‘feel useful’ or to utilise their skills for personal achievement, when it supported a continuation of self and identity through action or memory, when it fostered a feeling of connectedness and inclusion or when it brought enjoyment. Residents also expressed a wish to engage in activity as a means to keep active, to have something to do. As discussed, there were inconsistencies between participants’ levels of engagement and their desire to engage. The following chapter, therefore, considers the specific factors that may have prevented (or facilitated) engagement at Forest View and explores how it may be possible to better support residents living with dementia in care homes to engage in activities.

Chapter Seven - Factors Affecting Engagement and a Strategy for Promoting Activity in Care Homes

The evidence gathered using the Dementia Care Mapping (DCM) and concurrent ethnographic field notes suggests that despite the findings that people living with dementia valued the opportunity to participate in activities, the majority of their day was spent in a state of passivity. The care home appeared ill equipped to support appropriate levels of engagement even with an extensive programme of activities and a care philosophy that emphasised the importance of positive engagement and resident wellbeing. The reasons for suboptimal levels are complex and multifactorial. However, through analysis of the data, a number of barriers to activity provision were identified. These included the declining cognitive and physical abilities of residents, the limited quality of resources available for activities, limitations within the formal programme of activities, care workers' perception of their roles, care workers' values, experience and skills, the culture of care (including the leadership within the home) and time constraints.

While residents were offered the opportunity to participate in activities during the formal programme of activities, this programme could in reality only support engagement for a short amount of time (if an individual was engaged at all). This in itself would have been less problematic had individuals had the opportunity to engage in activities beyond those facilitated by the fixed programme. However, there appeared to be little support to engage in any activities within the wider context of care. Furthermore, declining cognitive abilities often limited an individual's ability to independently initiate or sustain their own activities as much as they expressed a willingness for engagement. These findings make the case for a more fluid and organic approach to activity provision in care homes; an approach whereby care workers (as well as activities staff) are responsible for supporting individuals to engage in activities.

Activities Workshops and the Person-Centred Care Assessment Tool

During this research, care workers were invited to attend activities workshops where they were asked to discuss current levels of engagement in the home and strategies to better support residents to participate in activities. These workshops were designed to seek the views of care staff about how to make activities a reality in everyday care practices. Data gathered using Dementia Care Mapping, ethnographic observations, conversations and the focus group with residents was used to inform staff workshops. The purpose of this was to give them a better understanding of the activities residents would like to engage in, the meaning of activities for residents and the importance of supporting engagement. The ultimate goal of these workshops was to attempt to affect a positive shift in the culture of care towards a collective consciousness that better valued activities and offered more opportunities for engagement. They were designed to do this by offering care workers a safe space to reflect upon their practice. A second purpose of the staff workshops was to use care workers' experiences to gain a better insight into the factors that they felt had an impact on their ability to engage the residents.

ACTIVITIES WORKSHOPS

Three activities workshops were planned for the beginning of the second, third and fourth data collection phases with a view to engaging approximately 18 members of care staff on three occasions (Table Twelve, p. 155). However, organising these workshops within a real care setting was not without significant difficulties as there was a lack of support for the workshops from the care home management. Workshops were cancelled as other training was booked at the same time and those that went ahead were ill attended. Of the nine planned workshops only five took place. These involved a total of 20 members of staff, three of whom attended twice. Each participating care worker has been given a letter as a means of identification (A - T). The workshops were designed and facilitated in partnership between the researcher and the training and development manager at Forest View and each kept to the same basic structure (Appendix xiv - *Plan for Activities Workshops with Staff*).

Table Twelve - Planned Activities Workshops

Phase	Workshop	Attendees	Duration	Content of Workshop
Two	1	4 (A, B, C, D)	90 mins	Completed P-Cat tool anonymously, discussed DCM data from phase one and participants' reported activity preferences. Discussed barriers to activity provision and how care workers might be supported to engage residents in activity during everyday care.
	2	4 (E, F, G, H)	90 mins	
	3	4 (I, J, K, L)	90 mins	
Three	4	n/a	n/a	Cancelled (by care home)
	5	n/a	n/a	Cancelled (by care home)
	6	n/a	n/a	Cancelled (by care home)
Four	7	5 (A, C, M, N, O)	75 mins	Completed P-Cat tool anonymously, discussed DCM data Phases One to Four. Discussed barriers to activity provision (unresolved/unchanged since previous workshop) and how care workers might be supported to engage residents in activity
	8	6 (B, P, Q, R, S, T)	75 mins	
	9	n/a	n/a	Cancelled (by care home)

The training and development manager made the decision about which members of staff were invited to attend the workshops and chose those that showed a particular aptitude in working in a person-centred way and who she considered might be most receptive to the idea of better supporting resident engagement. For example, one new member of staff (referred to in the Table above as 'N') showed particular skills in delivering care in a person-centred way and supporting engagement amongst residents. For example, when Peggy was looking withdrawn one afternoon, N supported her to go for a walk along the corridor and engaged her in a fun and innovative way (see p. 147). As a result of her style of care, N was invited to attend a workshop during phase four. By selecting participants in this way, workshops were attended by staff who displayed the most positive practices and who appeared to be most passionate about resident wellbeing. This is of note since it may have had an impact upon the answers given in the P-CAT and upon the data gathered during these workshops.

At the beginning of each workshop, attendees were asked to anonymously complete a Person-centred Care Assessment Tool (P-CAT). The DCM Coding frameworks were briefly introduced before the analysed data was presented by the researcher. Within this context, the qualitative presentation of the DCM data proved to be highly effective. Certainly, presenting the data about engagement in one clear figure, painted a far stronger picture of levels of resident engagement than qualitative data alone would have been able to do. This data was used to initiate a discussion amongst the care staff about how they felt about engagement levels within the home. The researcher then presented data about the activities the residents wanted to do using data from the interviews, spontaneous conversations and observations before asking care workers for ideas about how they might engage their residents more. What was clear from the workshops is that staff genuinely appeared to be committed to offering their residents the best possible experience in the home but that there was a limited understanding about the principles of person-centred care.

Within the workshops care workers were asked about their own views regarding the barriers to their encouraging and supporting participation in activities and asked how overall engagement may be improved. Due to the action research element of this project it was particularly important that care workers felt encouraged and empowered to be part of the reflective process and to take control of suggesting changes to practice. Attendees of the workshops independently identified three main barriers to initiating activities amongst their residents, these were; time limitations: ‘we don’t have the time’ (p. 177), limited practical tools for activity provision: ‘we don’t have the resources’ (p. 179) and limited management and peer support: ‘people will think we are shirking our work’ (p. 172). Additional factors were identified during observations of practice.

CARE WORKER PERCEPTIONS OF PRACTICE: RESULTS FROM THE P-CAT

To measure the extent to which care staff rated the home and their own practices as person-centred, attendees of the activities workshops (prior to phases two and four) were asked to complete a Person-Centred Care Assessment Tool (P-CAT) at the beginning of the session (Appendix vi - *Person-Centred Care Assessment Tool*). This tool used a five point self-reported assessment scale to record care workers’ own perceptions of the care culture in the home. The statements within the P-CAT are split into three facets of person-centred care, the first being *personalising care,* which represents care workers’ own care practices and includes statements 1-7. The second is *organisational support,* which refers to the leadership of the care home and incorporates statements 8-11 and the third relates to the *environmental accessibility* referring to the physical environment; statements 12 and 13. Care workers were asked to complete the tool with reference to their everyday practices and were not specifically asked to think about this in the context of resident engagement in positive and meaningful activities.

An analysis of the completed P-CATs showed that care staff felt that their care practices, the care home environment and the organisational support from the leadership team were considerably person-centred. The three highest scoring statements recorded during the workshops were:

- *Residents are offered the opportunity to be involved in individualised everyday activities*
- *The quality of interaction between staff and residents is more important than getting the task done*
- *I simply do not have time to provide person-centred care (reverse rated which meant that staff felt that they did have time to provide this type of care)*

Care workers' own care practices (personalising care) was scored as the most person-centred aspect of the home at 3.96/5, followed by organisational support; 3.66/5 and finally environmental accessibility; 3.24/5 (Table Thirteen).

Table Thirteen – Person-Centred Care Assessment Tool (P-CAT) Results

Statement	**Statement score**	**Statement rank**
1. We often discuss how to give person-centred care	3.91	6
2. We have formal team meetings to discuss residents' care	3.78	7 =
3. The life history of the resident is formally used in the care plans we use	3.96	5
4. The quality of interaction is more important than getting the task done	4.13	2 =
5. We are free to alter work routines based on residents' preferences	4.09	4
6. Residents are offered the opportunity to be involved in individualised everyday activities	4.17	1
7. Assessment of residents' needs is undertaken on a daily basis	3.65	9
8. I simply do not have time to provide person-centred care (reverse rated)	4.13	2 =
9. The environment feels chaotic (reverse rated)	3.39	10
10. We have to get work done before we can worry about a home like environment (reverse rated)	3.35	11=
11. The organisation prevents me from providing person-centred care (reverse rated)	3.78	7=
12. It is hard for residents to find their way around (reverse rated)	3.35	11=
13. Residents are able to access outside space if they wish	3.13	13
Total mean score	3.76	

The results of this tool appear to paint a different picture to the data collected using DCM data and unstructured observations. This may indicate that despite the fact that there was a strong person-centred discourse within the home, that person-centred practices were formalised through discussion in team meetings and that staff received training about person-centred care, it was less evident in everyday care practices. Indeed, while the results of the P-CAT show a strong person-centred rhetoric, discussions with staff during the workshops suggested that care workers did not feel that they had the necessary tools to engage residents better in interaction and activity. However, these results also reveal a potential lack of understanding of the need and desire that people living with dementia have to participate in activities.

The P-CAT indicated that care workers felt residents had an opportunity to engage in everyday activities and that their interactions with residents were more important than care tasks. This suggests that they were unaware of the prolonged periods of passivity experienced by residents in the home and observed by DCM. There appeared to be little or no insight amongst care workers that residents were unengaged for the majority of their day; the tacit assumption was that there was an activity programme in the care home, therefore residents were appropriately engaged. Indeed, members of staff appeared to be genuinely surprised by the findings from the DCM, which led to questions from some about the accuracy of the findings as they felt that their residents were more engaged in activity than was the case. For example, when they were shown an analysis of the BCC data from the first phase showing participants passively engaged or unengaged (categories B, C, N, U and Y) for 50% of their time one response was:

> *'I don't think that can be right at all. Our residents, they don't spend that much time like that.' (Care worker J, Workshop 3)*

There did, however, appear to be a desire for change and a willingness to support residents in the best way possible amongst some attendees of the activities workshops. Some members of staff for example, reacted in a more pragmatic and reflective way to the DCM data presented to them:

> *That's not what I expected actually. It's not good for us […] it shows we have to do more stuff with them to engage them (Care worker A, Workshop 1)*

And expressed a desire to take action to improve their own care practices:

> *'I would definitely like to see the residents more engaged. I think this is an important thing you know. It is an important quality of life thing and we need to do it. To help them more I mean.' (Care worker R, Workshop 8)*

Others expressed regret at the lack of activity amongst their residents despite the fact that they worked hard to meet residents' needs, for example:

> *'That is tough for us to see because we work really hard and to see they are all sitting around all day is sad.' (Care worker K, Workshop 3)*

Care workers who reacted in this way appeared to be eager to develop their practices and were instrumental in identifying potential barriers to their engaging residents in a more positive way and helped to formulate a plan to increase levels of engagement and wellbeing within the context of everyday care in the home.

Factors Affecting Engagement and Wellbeing

Thematic analysis of the findings revealed seven key themes relating to factors influencing engagement in care homes (Table Fourteen*,* p. 160). These were individual abilities and unique personalities, environmental factors, the structured programme of activities, care worker perception of their role, individual care workers, the culture of care and staff time pressures. 'Individual abilities and unique personalities' refer to the cognitive and physical abilities of residents with dementia and their propensity to engage in activities and social interaction. 'Environmental factors' refer to the architectural and interior design of the space and resources for engagement. 'The structured programme of activities' is about the programme led by the activities staff. 'Care workers' perception of their role' relates to how care workers viewed their own role as physical care providers and how this is seen as separate to psychosocial care. 'Individual care workers' considers how past experiences, training and a care worker's unique personality influences their tendency to support residents to engage in activity. 'The culture of care' refers to the wider philosophy of care in the home and finally 'time constraints' relates to the very real time limitations that care workers experienced.

Table Fourteen - Factors Affecting Engagement amongst Residents Living with Dementia

Theme	Factors	Page
The structured programme of activities	• Organisation and facilitation of activity programme • The activity programme as a small proportion of time • Wellbeing following participation in the activity programme • Leads to the notion of separate sphere of roles (activities staff to provide activities and care staff to provide physical care)	98-101 160-162 164-165 173-175
Individual abilities and unique personality	• Resident physical abilities • Resident cognitive abilities • Resident unique personality and sociality (including motivation for activity and extent of self-directed activity)	149-151, 165-166 149-151, 165-166 123-125
The culture of care	• Interactions in care • The culture of doing *for* rather than doing *with* • The use of the TV • Leadership and management • Prioritisation of needs (physical over psychological)	166-169 169-170 170-171 171-173 163-164
Staff time pressures	• Staff to resident ratio • Periods of increased need (e.g. illness amongst residents) • The use of agency staff • 'We don't have the time'	95 177 96, 168, 177 177-179
Environmental factors	• Architectural design of the space • Interior design including fixtures and fittings • Resources for activities: 'we don't have the resources'	92-95 92-95 179
Care workers' perceptions of their roles	• 'It's not my job'; care workers do not perceive supporting activity as their job • Care worker perception of people with dementia and understanding of their desire for engagement	173 175-176
Individual care workers	• Care worker value base • Emotional investment in residents • Past work experience • Relevant training	176-177 96, 168, 177 176-177 176-177

ACTIVITIES AS A SMALL PROPORTION OF TIME

The activity programme offered residents at Forest View positive opportunities to engage in a variety of different activities at set times during the day. However, data gathered using DCM provides compelling evidence to suggest that there were significant limitations to this programme as the levels of engagement amongst participants appears to have been suboptimal. Although self-evident, it is important to consider that activities delivered within the formal weekly programme accounted for a relatively small proportion of a resident's waking day (if they were engaged at all). On one occasion for example, a group of six scouts visited the care home for approximately 60 minutes and engaged positively with some of the residents in a way that had a significant impact upon their wellbeing. On the ground floor one talked to Eleanor about her life as a nurse while another played a game with Freda and Stanley[3]. As the group had to visit each of the home's four floors, they could only spend 15 minutes with the residents on the ground floor and although their interactions were decidedly positive, they were short-lived; their visit accounted for just 3% of the eight hour observation that day and 2% of the residents' waking day (assuming they were awake for 12 hours). This short amount of time was inadequate to lead to any significant increase in individuals' overall wellbeing throughout the day (as set out by their WIB scores and ME values within the DCM coding framework). Freda, for example, spent the three time frames experiencing a Mood and Engagement Value of +5 and yet her overall WIB score during the day was + 0.9 signifying a state of overall neutral mood and limited levels of engagement. This was a common occurrence within the activities delivered by the activities programme with some activities lasting no more than a few moments for each resident.

There was a clear trade-off for the activities staff between engaging a large number of people in one-to-one activities for a short space of time or engaging just a few in an activity for a longer duration and in a more therapeutic way. Activity sessions were finite and limited to two ninety minute sessions during the day. Within these limitations it was impossible for activities staff to engage many residents on a personal level for a significant amount of time during the day. For example:

> *One-to-one chats are on the activities agenda this morning. The activities assistant is trying to see as many people as possible but in doing so only has a few minutes to spend with each person. It feels too short to be a meaningful or therapeutic interaction. (Field notes, 28th September)*

On this occasion the 'chat' lasted for less than 1% of some residents waking day and were too short to make any significant impact to engagement or wellbeing. Large scale group sessions were longer; the entertainment sessions for example lasted for between 45 and 90 minutes accounting for 6 - 12% of a 12 hour period. However, these did not occur every day and not every resident attended every group. Only three residents attended the baking group for example and this accounted for only 5% of the home's total population. In this respect the activities staff had a difficult task as it seemed impossible for them to engage

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[3] Stanley, a resident of the first floor had come onto the ground floor with the scouts.

each of the 60 residents for a prolonged period of time during the day without additional support. Due to the very real time constraints placed on the activities staff there were instances when residents were excluded from an activity altogether. For example, when the activity coordinator was making greetings cards on the ground floor she did not have sufficient time to engage all the residents on the floor in the activity. The activity itself was time and labour intensive and therefore in the 20 minute that she had, only three of the 17 residents had the opportunity to participate.

The fact that engagement in the activities programme in reality often only accounted for a small proportion of each resident’s day would have been less problematic if individuals had had the opportunity for engagement in activities beyond that programme. However, the evidence is that there was almost no support with engagement outside of the activities planned by the activities staff. This was noted on several occasions and even when the activities staff engaged some residents in positive activities, other residents remained disengaged or withdrawn. On one occasion for example the activities assistant spent time giving Peggy a manicure, an interaction that she enjoyed. While the field notes describe the positivity of this event, they note the passivity of the other residents:

> *The two women are chatting together as the [the activities assistant] paints her nails. Peggy appears deeply engaged in this activity and really enjoying it. Stanley and May are sitting in silence both staring into the middle distance, Bill has his eyes closed but is not asleep. The room is silent apart from the two women, everyone else here seems completely disengaged. (Field notes, 10th November)*

On a different occasion the researcher stayed in the lounge of the ground floor while the activities staff took a group of residents (including Eleanor) to the pub:

> *The residents on the floor are all sat in silence and there is nothing going on. Dorothy is asleep, Freda and Edith are sitting looking at the floor. As they haven’t gone to the pub there is simply nothing for them to do. (Field notes, 13th November)*

The notes explicitly state that there was little to engage those residents who were unable or chose not to participate in the activities run by the activities staff. This suggests that care staff did not support residents to engage in a positive way during their everyday interactions.

THE ACTIVITY PROGRAMME AS AN EXPENDABLE PART OF THE DAILY ROUTINE

A further limitation of the activities programme to make a significant difference to overall mood and engagement in the home was the fact that activities, even when planned, often failed to take place. Table Fifteen (below), shows the morning activities that were planned during this period and compares this to what actually took place in the home.

Table Fifteen – Planned Activities Compared to What Happened

Day	Planned activity (11.00-12.00)	Description of what occurred
Wednesday	Pamper and Sensory Session	The activity coordinator was asked to show relatives of a prospective resident around the home during the morning and therefore the session did not take place.
Thursday	Games Hour	This took place as planned for the allotted hour; approximately half the time on the ground floor and half on the first.
Friday	Giant Dominoes	The activities assistant was sent on an errand by the management. This was to pick up medication for some of the residents. She was absent from the home for most of the morning so the session did not take place.
Sunday	Gentlemen's Social Club	At 11am there was only one gentleman out of bed and dressed so the activity coordinator was unable to go ahead with the Gentlemen's Social as planned. However, other activity occurred in its place.
Monday	Crossword and Word Search	The activity coordinator was asked to cover the reception desk in the morning and therefore the activity session did not take place.
Tuesday	Mystery Objects Game	The activities assistant was away from the home collecting medication for the residents until 11.30 (the session was planned for between 11 and noon). As she had less time than she had planned, she was only able to engage residents on the first floor before lunch was served. No activities occurred on the other floors.
Wednesday	Puzzles	One resident was given one puzzle on the ground floor, no other resident was engaged in puzzles although the activity coordinator did sit and chat to one participant.
Thursday	Whiteboard Games	The activity coordinator was sent on an errand for the management and so the games did not occur.

This cannot be seen as a failure of the programme in itself but is indicative of the low value placed on activity provision by the management of Forest View as well as the wider care team. Within the daily care routine, activities and the activities staff appeared to be considered as the most expendable members of staff. In consequence, it was the activities staff who were routinely asked to cover for absences or to run essential errands with the result that they were unable to facilitate activities and spend time with the residents. The smaller scale morning activities appeared to be most affected by this since large sized afternoon activities were often facilitated by external professionals and therefore were less easy to cancel at short notice. Table Fifteen (above) shows that during one eight day period in November for example, the field notes record that of eight morning activities scheduled only one took place as planned. Of the others, one did occur but only for half the scheduled session and as a result the activities assistant could only run an activity on one of the floors. The remaining six did not take place. This problem appears to be indicative of a culture that did not value the maintenance of psychological and intellectual needs in the same way as physical and medical care. It also highlights managerial and logistical issues evident in the home. These findings highlight the importance of protecting the time of the activities staff and not regarding their role as superfluous to everyday care. It is also imperative that activities are regarded as an essential part of care.

WELLBEING FOLLOWING ENGAGEMENT IN THE FORMAL PROGRAMME OF ACTIVITIES

Increased levels of wellbeing appeared to be limited to the duration of the activity and that mood did not appear to stay elevated following participation and in some instances mood levels deteriorated significantly directly after an activity. Stanley's mood often declined following participation in activities and particularly after music based entertainment, which appeared to be his favourite. On one occasion he had been observed to be in a neutral mood for much of the day and then experienced considerable and sustained levels of high mood and engagement during a sing-along. Upon returning from that group however he appeared to become distressed:

> *As soon as Stanley is back on the floor he appears lost and unhappy, he sits himself down at the back of the room alone. He puts his head in his hands and begins talking to himself in a distressed manner and arguing with someone who is not there. After the music session where Stanley's wellbeing was almost consistently at +5 he is now in -1. The session seems to have had no long-term benefit on his wellbeing. (Field notes, 28th September)*

This pattern was observed frequently with both Edith's and Dorothy's mood often deteriorating following periods of positive participation. However, for the majority of participants the end of positive engagement often meant a return to neutrality and passivity:

> *Peggy, May and Bill have been back on the First Floor [following the entertainment session] for a few moments. They are already sitting in silence and appear disengaged. This is so different from just a few minutes ago when they were singing along with the entertainer and appeared very happy and deeply engrossed in the activity. (Field notes, 28th September)*

Although this is not a criticism of the activity programme itself, it points to the need for people living with dementia to continue to engage in activities beyond the programme within the wider context of care.

COGNITIVE AND PHYSICAL BARRIERS TO ENGAGEMENT

The participants themselves identified cognitive, physical and motivational limitations as barriers to their own engagement. Pain in hands and joints as well as decreased mobility and dexterity were often cited as a reason for difficulties participating in activities. During a focused conversation, Vera said that she was no longer able to paint due to her arthritic fingers, which made it almost impossible to hold a brush:

> '*Well you see I've got to be in the mood you see. And these hands* [she holds out her hands. They are swollen and stiff], *well I'm not being funny but it's too much with a brush* [she tries to make a gripping motion with her hands as if trying to hold a pen or a brush]. *I'm 91 you know.' (Focused Conversation with Vera)*

She also reported that her inability to create what she considered to be 'worthwhile art' reduced her motivation to engage in any art related activity. Dorothy and Edith too reported physical barriers to engagement in their preferred activities. Both said that they had enjoyed crafts such as needlework and knitting but said that they could no longer successfully perform such complex tasks due to the loss of dexterity in their fingers and their difficulties in following a complex pattern:

> *Edith: 'I couldn't do it now. No you see I couldn't follow [a knitting pattern] nowadays.'*
> *Dorothy: 'Lost.'*
> *Edith: 'Yes you get lost in it all you know with all the tangles of wool.' (Focus group)*

Although this was the only instance when residents acknowledged that their cognitive decline might have affected their participation in activities, dementia appeared to have been a significantly limiting factor upon levels of engagement. The fact that cognitive impairment might have necessitated a simplification of activities has already been discussed and was acknowledged by both residents and staff. However, it was clear that this impairment also prevented engagement itself. With the exception of Margaret (who did not have a formal diagnosis) and Bill, who both engaged in reading when they had suitable material close by, residents living with dementia appeared to engage in self-directed activities less than those who didn't have dementia. While within this study, data was not collected to look at this with accuracy, the difference in engagement between residents was noted in a reflective diary:

> *As the field research draws to a close it has been interesting to see that the individuals in the home who do not have dementia have appeared far more engaged than those who do. Although they have not been participants I have watched residents without dementia engage in their own activities often and independently of any external support. My participants (with the exception of Freda and Bill) have largely appeared unable to do this, although they have engaged in supported activities the same as everyone else. (Extract from reflective diary, November 2015)*

People living with dementia appeared to be less able to initiate and sustain their own activities without significant input or support. This is despite the fact that they have a strong desire for engagement. The evidence suggests therefore that these individuals need significant support from external agencies (for example care and nursing staff or activities staff) to participate in activity. The fact that overall, participants spent a significant percentage of their time in a state of passivity or disengagement points to the fact that such support was not always forthcoming.

EVERYDAY CARE INTERACTIONS

Everyday care interactions between staff and the residents had the potential to engage individuals in something positive and meaningful and to improve levels of wellbeing. During the course of the data collection, hundreds of interactions between participants and staff were observed and recorded. These fell broadly into three categories: positive interactions, negative interactions and minimal interactions. Positive interactions, recorded within DCM as Personal Enhancers, were defined as episodes that were positive, person-centred and upheld the personhood of an individual living with dementia by meeting their psychosocial needs. Negative interactions were recorded as Personal Detractions and were episodes of malignant psychology which undermined an individual's personhood and therefore their wellbeing (Appendix v - *Dementia Care Mapping: Personal enhancers and personal* *detractions*). In total, 151 Enhancing interactions and 89 Detracting interactions were observed during the field research. Minimal interactions were the most common type of interaction. These were short interactions, usually necessary to complete a care task or a brief nod to a resident as a care worker passed by. Such interactions often had neither a positive nor a negative effect upon personhood and wellbeing. A fourth theme emerged when studying interactions between residents and care workers and this concerned periods of no interaction. No interaction referred to episodes when staff had no contact with their residents for prolonged periods of time.

Positive interactions were those that upheld an individual's personhood by fulfilling one of five key psychosocial needs: those of Comfort, Identity, Attachment, Occupation and Inclusion (Kitwood 1997). There were examples of care workers using positive person work to promote wellbeing amongst residents. For example:

> *A carer comes over to Mollie, she says 'you're flashing your sexy legs again Mollie' (Mollie's skirt has risen up past her knees). Mollie giggles and the carer kneels down to help her to rearrange her skirt. She says 'there that's better' and both women smile warmly at one another. The carer embraces Mollie warmly and with genuine affection, the women give each other a kiss on the cheek. Mollie is smiling all the while; the carer says 'you are so lovely Mollie' and hugs her again. (Field notes, 16th June)*

In this example, the care worker engaged with Mollie in a way that showed warmth and affection and Mollie's wellbeing improved significantly as a result of this. On another occasion, a care worker noticed that May and Peggy had been sitting in silence for much of the day and engaged them in conversation for several minutes:

> *The carer sits with Peggy and May and spends some time chatting to them. She talks to them about the view in the fields below and points out some rabbits, both May and Peggy seem delighted at this. […] the women sit together looking at the magazines, drinking tea and chatting. They appear relaxed and happy. (Field notes, 29th September)*

Again this positive interaction improved their levels of mood and engagement within the DCM framework.

Negative interactions or periods of malignant social psychology were the least frequent of the four types of interaction. Staff were usually unconscious of negative interactions, which often appeared to be the result of time constraints. Indeed, episodes of malignant social psychology occurred more often when a floor was short staffed or when there was a high proportion of agency staff on the floor. The majority of negative interactions related to ignoring residents' requests for engagement, interaction and support. For example:

> *Audrey walks back into the lounge, she is ready for bed. She is crying and evidently distressed. She walks up to the Assistant Manager of the home who has come onto the floor, she holds out her hands to him looking for comfort and support. He goes into the dining room shutting the door on her face and ignoring her completely. She continues to cry. She is looking at the closed door in front of her. (Field notes, 16th June)*

Agency care workers were more likely to act in a way that undermined individual personhood. It is probable that these temporary staff did not know the residents well and therefore failed to recognise their personhood. They also did not have the same level of emotional investment in their wellbeing as permanent care workers. For example:

> *Audrey is sitting with the agency carer who is watching the TV. She tries to engage him in conversation but he replies in monosyllables and appeared annoyed with her and scowls at her. He continues to look at the TV. (Field notes 29thAugust)*

The majority of interactions witnessed between staff and participants were **minimal interactions**. These were interactions that lasted no more than a few seconds and held no opportunity to support an individual's personhood or to sustain wellbeing. For example:

> *A carer walks past Dorothy. She says 'alright Dorothy' and is gone again before Dorothy has a chance to acknowledge her. (Field notes 8th July)*

Minimal interactions also occurred while care workers were performing care tasks. For example:

> *Edith is given tea and cake, the interaction is over and the carer has walked away before Edith has fully realised what is going on, Edith tries to thank the carer but she has already gone. (Field notes, 23rd August)*

On this occasion, the minimal interaction might also have been personally detracting since the care worker was evidently outpacing Edith. These minimal interactions were indicative of a task orientated approach to care that valued completing tasks in as short a time as possible over offering each resident a quality experience and opportunities for engagement. They are also suggestive of a culture of care that does not value the fulfilment of residents' psychosocial needs in the same way that it values physical needs.

Periods of **no interaction** between care workers and residents were recorded often. There were several occasions, for example, when the field notes document prolonged periods of time during which residents living with dementia had no opportunity for positive engagement or interaction. For example:

> *There is absolutely nothing to report, nothing has happened for 40 minutes Stanley, May and Peggy are still sitting in silence, occasionally one or the other has glanced up but mostly they look into the middle distance. […] Stanley has fallen asleep. Neither May nor Peggy have spoken for an hour. Now the lights in the lounge, which are operated by motion sensors, switch off due to the lack of activity and the residents sit in the semi darkness. (Field notes 18th June)*

On another occasion:

> *There is nothing happening in the home, the atmosphere feels monotonous. […] No care worker has come into the lounge for over half an hour and nobody has spoken. (Field notes, 28th August)*

These findings correspond to those from the DCM coding framework, which showed that participants spent a high proportion of their time in Behaviour Category Codes associated with no interaction, for example passivity and disengagement (50.1%).

DOING *FOR* THE PERSON RATHER THAN DOING *WITH* THE PERSON

There was a trend towards doing things *for* residents rather than supporting them to do things for themselves. This appeared to come from some care workers' desire to look after their residents. For example when discussing the importance of supporting residents to engage in household tasks one care worker said:

> *'These people, they have worked hard all their life you know. I can't say to them do this chore or do that chore. They should be able to relax.' (Care worker N, Workshop 7)*

While the attitude appears to be borne out of positive regard for the residents and a desire to enable them to rest, denying residents the opportunity to engage in simple homemaking tasks prevented potentially positive engagement. For example after one meal:

> *Edith rises and picks up her empty plate. She begins walking over to the sink with it apparently to wash it up. A care worker stops her. She says 'I'll take that Edith, you go*

> *and sit yourself down'. She has prevented Edith from engaging in an activity which would have been natural to her in her own home. (Field notes 11th November)*

Edith appeared keen to help out but was prevented from doing so and as a result she became passive and then withdrawn. In this instance the carer has stemmed Edith's self-directed activity and denied her an opportunity for her to feel a sense of purpose by helping out around the home. The care worker's intervention was well meant if ill-informed. She had mentioned in an earlier workshop that she did not feel residents should be made to engage in work-like activity. While it is true that individuals should be able to relax if they choose, they should also be given the opportunity to engage. By preventing residents to engage in work-like activities, the care workers were framing them as dependent and passive in a way that was not conducive to successfully supporting a more holistic approach to engagement.

The use of the Television

The television appears to have been used to excess as a tool for engagement within the wider context of care with little regard given to whether or not it was successful in appropriately engaging residents. It was almost always switched on. Instances of inappropriate programme content and residents' disengagement with the television are prevalent amongst the field notes. In addition, far from engaging residents, the television acted as a barrier to positive activity. For example:

> *May and Peggy have been talking intermittently. As soon as the TV went on their conversation stopped and both women have become withdrawn. They are both staring at the floor. The TV has ceased all engagement. (Field notes 18th June)*

On a separate occasion the volume of the television made verbal interaction challenging:

> *The motor racing on the TV dominated the soundscape. No one is watching this and all conversation is impossible. (Field notes 23rd August)*

On occasion the television appeared to be on for benefit of the care workers:

> *None of the residents are watching the TV, it is a programme about knife crime. But an agency worker sitting in the lounge appears engrossed in it. (Field notes, 29th August)*

However there were some instances when media was used to positive effect such as when the care workers played appropriate music during one meal time.

> *A carer turns off the TV and puts Vera Lynn on the CD player in the lounge. Stanley has had his head in his hands and has been withdrawn but now the music starts he looks up and smiles. The carer encourages Stanley and Bill to dance with her briefly before leaving, when she has gone Stanley appears visibly relaxed; his whole posture has changed. He and Peggy are tapping their feet and the whole atmosphere of the home has changed. (Field notes, 17th November)*

This appears to have had a positive impact upon levels of engagement and wellbeing since participants began to engage in expressive activities by tapping their feet to the music or singing along.

There were only two occasions when residents were observed to be engaged with the TV, Dorothy was engaged while watching the tennis and the residents on the first floor appeared to enjoy watching Morecambe and Wise and Miranda on one day (this had been carefully selected for them by the nurse). Therefore, while media can be a tool for engagement for people living with dementia in care homes, there often appeared to be little thought as to how it was used. Inappropriate content on the TV often resulted in disengagement amongst participants.

LEADERSHIP AND MANAGEMENT

Leadership was a factor affecting the culture of care and it was interesting to observe how members of the management team interacted with residents. It is probable that the management team could have had a constructive influence on care practices in the home by setting a positive example to care staff and interacting with residents in a way that upheld personhood and improved wellbeing. This however was not observed. During the 27 days of observations in Forest View, the home's manager was only observed on a floor on one very brief occasion. In this instance she did not attempt to interact with any resident. On the contrary, her presence halted a positive interaction that was happening between a care worker and one of the residents:

> *One care worker is sitting beside May and talks to her. May starts to eat and the two women chat happily together sitting side by side. […] The home's manager arrives on the floor and goes over to the nurses' station. The care worker immediately jumps up and*

> *pretends to look busy by the food trolley apparently worried that she will be questioned for sitting with a resident. May is now sitting alone and in silence. The manager does not engage with any of the residents in any way and leaves again immediately. (Field notes, 17th November)*

That the manager attempted no interaction with the residents does not set the best example for care staff. In addition, the presence of the management led to a care worker ceasing a quality interaction with one of the residents since she believed she would be reprimanded for doing so. The fact that on no occasion was the care home manager observed interacting with any resident cannot be overstated.

In the extract above, the care worker felt that she did not have permission to sit with May and engage her in a quality interaction[4]. This is evident from the way she immediately suspended the interaction when the manager came onto the floor. During the workshops, care workers agreed that they felt that they did not have permission from the management or from their colleagues to engage the residents in positive activities. They unanimously reported that spending time engaging with residents in a positive way rather than delivering personal care, would be perceived by others to be 'skiving'. During the workshops, the training and development manager informed care workers that the management team would like to see them engaging more with the residents and that this was part of their role as a care worker. One response however was:

> *'Well you say that but it really isn't true. I was sitting with [a resident] one day and [the manager] came past and said "if you really have nothing to do I suggest you go and ask so-and-so what needs doing".' (Care worker E, Workshop 2)*

Again this shows the disparity between management rhetoric and how they behaved during real care and demonstrates a lack of support for staff to positively engage residents. Similarly, care workers felt they would be perceived to be skiving by other members of their own team. As one member of staff explained:

> *'We are just always so busy and if someone is sitting down with the residents then they aren't doing their job and everyone else has to work harder to cover them. We just can't do that to each other.' (Care worker F, Workshop 2)*

During a separate workshop another care worker said:

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[4] The care worker in question reported this to the researcher at the end of the day's observations.

> *'I feel like people would think I was skiving if I [sat and engaged residents] and I wouldn't want that.' (Care worker A, Workshop 7)*

These points link to care workers' own view that their caring role did not include engaging residents in activity and also relates to the very real time pressures that care workers felt they were under to perform physical care tasks in a timely manner.

CARE WORKERS' PERCEPTION OF THEIR ROLE

There appeared to be a tacit assumption that because there were regular activities in the home, residents were engaged in positive and meaningful activities. When one care worker was shown the finding from the DCM she disagreed saying:

> '*No. We have two activity coordinators who do activities with [the participants], I always see them involved with that, singing and things. They are not sitting around like this. No way. Anyway surely this is [the Activities staffs'] job.' (Care worker A, Workshop 1)*

It is easy to see how this perception may arise. For example when the PAT dog visited the home a casual observer may have seen her in the lounge for a few minutes approaching several residents. However, findings from the observations showed that none of the five participants in the lounge had the opportunity to interact with the dog. Similarly, when the Scout group visited the home, the ground floor lounge seemed alive and exciting; without using DCM it would have been easy to overlook the fact that both Dorothy and Edith remained sitting in silence and were not asked if they would like to join in with the children. What the care worker's statement (above) makes clear is that care staff tended to see activity provision as the preserve of the activities staff and activities themselves as an addition to their own care practices rather than as an integral part of care. This is of particular importance as, if care staff believe that activities are not part their job they are unlikely to endeavour to engage residents in positive and meaningful activities throughout the day.

The ideas that providing activities was the preserve of the activities staff was evident in care practices too. The data presented thus far in this chapter and in Chapter Five demonstrates that care staff rarely engaged their residents in a way that supported positive engagement in activities. While there were a number of reasons for this (for example care staff were too busy performing care tasks or they did not feel they had adequate management support) the failure to see activity provision as part of their own caring role surely has a part to play. Possibly the most important finding of this research is that both the opportunities to engage in activities and resident wellbeing considerably improved on the day that the activities staff were away and consequentially there were no formal activities planned. On this day, participants experienced greater levels of engagement and wellbeing than on any other day observed (Appendix xv - *Group Care Summary: 29th September 2015*). Although at first it may seem incongruous, when activities staff were absent, care workers suddenly felt it was *their* duty to engage residents. During the day, the nurse on duty, who also acted as the unit manager reminded her staff to offer activities to their residents and explained her motivations to the researcher:

> *'I am trying to get [care workers] to engage the residents today because [the activity coordinator] is away so the residents wouldn't have anything to do otherwise.' (Field notes 29th September)*

In addition, as one care worker engaged Peggy in a game, she said to the researcher:

> *'We have to do activities with the residents today because [the activity coordinator] isn't here so today it's our job for today.' (Field notes 29th September)*

On this day, residents were engaged for 37% of their day (this compares favourably to the overall average of 16.6%) and experienced an average Mood and Engagement Value of +2.0 (compared to the average of +1.0, see Chapter Five). Care workers worked well as a team to successfully deliver activities but although effective the activities were not difficult to set up or time consuming. To take one example, the nurse took control of the TV and put on a slapstick comedy, which participants engaged with and enjoyed (participants did not usually engage with the TV):

> *The participants are watching the TV and laughing, they appear engaged and happy. They do not usually engage with the TV as the programmes often appear to be inappropriate. (Field notes, 29th September)*

On another occasion, a care worker asked Stanley to help her to wheel the laundry trolley down the corridor as she collected dirty laundry from residents' rooms, which he enjoyed, particularly as this fed into his wishes to feel helpful around the home:

> *Stanley has been wheeling the trolley with the care worker for 20 minutes. He has been deeply engaged in his task and has appeared happy. When the care worker thanks him for all his hard work he beams and appears delighted. (Field notes, 29th September)*

During the observation there was an experienced unit manager (nurse) and a full care team made up of permanent members of staff on duty, which is likely to have added to the quality of care provision. In addition, none of the residents were ill or required extra attention and these factors must also be taken into account when considering why staff felt able to deliver activities. However, these things were present on some other days, which were not so successful. The unique element in this instance appears to be the absence of activities staff and the change that this had on staff perceptions of their own roles as activity providers. It points clearly to the fact that there was a perceived divide between the responsibility to provide physical care (the role of the care worker and nurse) and the responsibility to provide psychosocial care (the activities staff). On a day when this divide was blurred (owing to the absence of activities staff), care workers integrated activities into their care practices. This had a positive impact on engagement and wellbeing in the home.

PERCEPTIONS OF RESIDENTS LIVING WITH DEMENTIA

A further theme became clear during the course of presenting the DCM findings during staff workshops. This was the perception that residents living with dementia did not want to engage in activities. When asked what they felt about the fact that their residents spent so much time unengaged and withdrawn one member of staff replied:

> *'Well these are people with dementia and people with dementia don't want to do activities anymore. I know these people and they would prefer to sit down.' (Care worker C, Workshop 7)*

This view contrasts starkly with the evidence collected during observations, focus group and conversations that suggests people living with dementia are keen to be involved in activities. What appears to have contributed to this perception is that residents living with dementia rarely initiated their own activities which was taken by some staff to mean that they were not interested in being involved in anything:

> *'There is lots of stuff to do around the home but they choose to sit and don't do anything.' (Care worker N, Workshop 7)*

It is more likely that individuals' cognitive impairment prevented them from self-directed activities. That said, it was evident that cognitive impairment did not prevent individuals from enjoying participation in an activity if they were offered the opportunity to do so. One care worker felt that residents often declined to engage in activities:

> *'We do ask and they say no so what can you do. If they don't want to do it then they don't want to do it. You can't force them.' (Care worker A, Workshop 7)*

And while this was to some extent true, the field notes show that participants often declined to participate in activities if they were not asked in an appropriate manner. For example, on one occasion, the member of staff quoted above asked Vera if she would like to go down to the ground floor to watch the entertainment:

> *She approaches Vera, stands over her and says "do you wanna go down" without explaining where down is what is going on. She stands over Vera's wheelchair. Vera does not respond and the care worker shrugs and walks away. (Field notes, 18th June)*

In this case Vera's non response was taken as a refusal to take part when in fact the care worker did not offer Vera any information about what was going on or give her time to respond with the result that Vera missed out on participating in an activity. The tacit assumption that people living with dementia do not wish to participate in activities on the basis that they do not initiate activity or do not always want to do the activity on offer is one that needs to be challenged in order to encourage care staff to promote participation during everyday care of residents.

INDIVIDUAL CARE WORKERS' VALUE BASE, EXPERIENCE AND TRAINING

The backgrounds, experiences and unique personalities of individual members of staff had a role to play in the way they interacted with their residents or attempted to engage them in activity. Some appeared more willing and able to offer good quality interactions and opportunities for engagement than others. It is unfortunate that temporary members of staff appeared to engage in negative, minimal or task focused interactions, particularly due to the high numbers of temporary staff employed at Forest View. The reasons behind the fact that temporary staff delivered a poorer quality of care remains unclear. However, it is likely to be partly due to the fact that they did not know the residents well and consequently had less of an emotional investment in them.

Interactions between permanent members of staff and residents appeared to be more positive. Nevertheless, there were significant differences in the ways that different members of staff cared for their residents. While some were clearly attached to their residents and would try to interact with them as much as possible, for example:

> *[A care worker] is still engaging May and Peggy in lively conversation. Whenever this girl is working the home seems more full of life and she always tries to make time to engage the residents in fun and positive ways even if she can only spare a few moments (Field notes, 17th November).*

Others would never attempt to do this and focused only on physical care tasks, for example:

> *One of the care workers is sitting with G [a resident who requires one-to one-care]. Her job is to sit and support G during her shift. She does not interact with or even look at G or any of the other residents sitting around her and instead looks at her nails, at the TV or out of the window. It is just my impression but it looks as though she really does not want to be here. (Field notes, 28th August)*

It is a weakness of this study that it did not seek to capture exactly why this might have been the case although the field notes suggest that it has to do with a combination of factors including previous work experience, education and training and an individual's unique value base. Further research may elucidate these complexities. It was clear however, that some members of staff viewed care work as simply a job that was easy to obtain without previous experience or formal qualifications. The young care worker from the extract above summed her position up well when she said to the researcher 'well it was either this or bar work'. Her disinterest in the job was plain and it was evident in every one of her interactions with the residents. Conversely, there were individuals who enjoyed their work and who had a strong emotional investment in their residents. These care staff were more conscious of the nature of their interactions and more willing to treat residents as unique individuals and to support their personhood.

TIME CONSTRAINTS: 'WE DON'T HAVE THE TIME'

One of the greatest barriers appeared to be time constraints despite reasonable resident to staff ratios. Time constraints were the result of a multitude of reasons including the organisation of tasks, staff turnover, staff shortages, the use of agency staff and occasions when one or a number of residents required additional support due to illness. The fact that care workers appeared too busy with physical care tasks to engage residents was often noted during observations:

> *Dorothy and Freda continue to sit in silence. They have had no interaction today. But with staff shortages the care workers appear too busy to give them any time. (Field notes, 23rd August)*

This did not mean that care workers did not want to engage with their residents. Some care workers were observed engaging positively with residents after their shift since they did not have the time to do so during the day. For example, at the end of a particularly busy shift after the day staff had handed over to the night staff:

> *20:15 – Now that her shift is over [a care worker] has made tea for herself, Peggy and May. Now she sits beside the two women and engages them in conversation […] [The care worker] has been chatting to Peggy and May for 15 minutes but now she says she needs to get home (it is now 35 mins since the end of her shift). As she leaves she stops and says to me 'They're lovely. And it's nice to spend some time with them. We don't get a chance to in the day you see' (Field notes, 18th June)*

In this example the care worker spent her off-duty (and therefore unpaid) time engaging residents. This point illustrates a desire that some members of staff had to interact with and engage residents, but points to time pressures being a significant barrier.

During the activities workshops, care workers themselves identified time constraints as a barrier to engaging residents in activities or quality interactions. Every one of the 20 attendees agreed that they did not have time to support activities and that this was the predominant factor contributing to disengagement amongst residents. For example:

> *'I don't know when we can do activities. We are so busy making sure people are up and dressed and fed, there is a real emphasis on these things. At the end of the day we really don't have the time.' (Care worker D, Workshop 1)*

Furthermore, some suggested that an increase in the number of staff would be expedient:

> *'If they want us to do more stuff [with residents] then they need to employ more staff. We can't do it with what we've got, it's not possible.' (Care worker L, Workshop 3)*

Interestingly, this contrasts with what care workers stated using the P-CAT. Within this tool they all 'disagreed' or 'strongly disagreed' with the statement: *I simply do not have time to* *provide person-centred care.* This point may suggest that care workers did not see providing activities as part of person-centred care.

ENVIRONMENTAL FACTORS: 'WE DON'T HAVE THE RESOURCES'

Forest View was designed and built in line with dementia design guidelines and to promote maximum engagement amongst residents. The home appeared to have a number of resources dedicated to promoting activities amongst the residents such as books, games and arts and craft materials. Despite this, when asked about the factors that acted as a barrier to engagement amongst residents, care workers cited a lack of physical tools or resources. The reason for this appears to be that, despite the fact that the home had invested in a variety of resources, these appeared to be inaccessible to care workers:

> *'All of the activities stuff is stored on the ground floor. So if I want to do something with Audrey, for example, I have to go all the way down there which takes time, and when I get back she will probably have forgotten.' (Care worker B, Workshop 1)*

Others reported that while they had access to resources, they were often in disrepair to the extent that they were unusable. For example:

> *'Stanley wants to play the piano right, but I can't get the keyboard to work. It has no batteries and there is no electrical lead so it doesn't work. So really, what's the point? And he was so excited about that too.' (Care worker L, Workshop 3)*

And:

> *'We wanted to do a pompom with Edith and I got the stuff out and the wool and everything was so tangled. It would have taken ages to sort out so in the end I didn't bother. It's a shame really because we have all of this stuff, it just doesn't work.' (Care worker J, Workshop 3)*

Other care workers also gave examples of how the resources which were available to them did not work in practice. This highlights the very simple but apparently overlooked fact that for activity resources to have any real benefit, they need to be both available and in a useable condition although who would ultimately be responsible for this given the time pressures for existing members of staff is unclear. When looking to improve levels of engagement and wellbeing, care workers asked for appropriate resources to enable them to do the job.

Improving Wellbeing amongst Residents Living with Dementia in Care Homes

The way to better support people living with dementia in care homes to engage in activities is to integrate the provision of activities within everyday care delivery. *How* this might be achieved in practice appeared to be more problematic. The findings of this thesis coupled with relevant academic literature demonstrate that there is no quick fix to the issue of high inactivity and disengagement amongst people living with dementia in care homes or to the possible physical and psychological challenges resulting from prolonged passivity. While the simple answer is to support residents living with dementia to engage in more activities, there are significant complexities in how this might be achieved in real life care within the limited budgetary and staffing constraints experienced by care homes.

When asked, care workers appeared to have a clear idea of the factors limiting their abilities to engagement with their residents within their care practices. They articulated that these were: a lack of time (time constraints), a lack of resources (environmental factors) and a lack of permission (culture of care). While one cannot dispute these conclusions, observational data revealed that care workers' perception of their roles and more specifically the separation between the spheres of physical care and activity were probably more significant factors contributing to the dearth of activities available to residents. The perception appeared to be that supporting engagement was not the role of care and nursing staff and that activity provision was solely the preserve of activities staff. This perception was a significantly limiting factor to resident engagement. This is not to argue that the formal activity programme did not have its place in the care home, but makes the case that careful consideration needs to be given to engaging people living with dementia beyond that programme and for a conscious effort not to separate 'activities' and 'physical care'.

Given the fact that with cognitive impairment, an individual's ability to independently initiate or sustain activity becomes limited, care workers need to support the individuals under their care to engage in activity. This is a difficult task considering the complexity of factors affecting activity provision. This thesis argues that a reconceptualisation of care workers' roles is vital in achieving greater participation and that the current polarisation of physical care and support with engagement is not only unhelpful but potentially damaging.

Correspondingly, psychological care needs to be reframed as equal to physical care and embedded into care practices. In the context of this research (and it is assumed within the majority of care homes) there was little financial resource to support higher staff ratios, which might help to mitigate time constraints which may have acted as a barrier to activity provision. Therefore a way of supporting activity within their everyday practice needs to be sought.

AN INTEGRATED APPROACH TO ACTIVITY

During the activities workshops care and nursing staff were asked to come up with ways in which they might successfully integrate activities into their own care routines. Working collaboratively in this way and co-creating an action plan gave care workers a sense of ownership over the agreed plan. More importantly, however, was that care workers used their knowledge and expertise of working in the care home every day to formulate a plan that might work in practice. As a group, care workers identified two principal ways in which they might better support residents to engage in activities:

1. By supporting residents to engage in simple activities that were quick to initiate and required minimal support for a resident to be able to sustain engagement;
2. By supporting residents to engage in activities within the care workers' everyday routine.

Table Sixteen (p. 182) and Table Seventeen (p. 183) present a synthesis of care workers' ideas about how they might better support residents to engage in activities throughout the day. Table Sixteen, refers to facilitating quick activities. As time constraints were the factor that they felt was the most problematic to their engaging individuals in activities, they felt that any activities they did deliver needed to be quick to initiate or part of their everyday care routine. While the former appeared simple enough to undertake, given a certain amount of knowledge about the residents (regarding their individual preferences and abilities), care workers identified resources as problematic. Such resources as there were, were not in good working order and therefore care workers were not able to quickly utilise these. These were often simple things (for example knitting wool being too tangled to use, pens that did not work and the fact that most of the resources were stored on the ground floor so not easily accessible to the first and second floors), yet care workers reported them to be debilitating when attempting to engage residents quickly.

'But this stuff needs to be working. If the brushes are dried up and the paint is dried up with the best will in the world we won't do [activities with the residents].' (Care worker C, workshop 7)

Care workers requested person-centred grab boxes on each floor filled with resources that would be easily accessible, in a good working order and would quickly promote engagement. Suggestions for person-centred resources included flower arranging equipment, pompom making equipment, paint and brushes, colouring pens and adult colouring books. With appropriate resources, care workers agreed that they could make the strategy in Table Sixteen work in practice.

Table Sixteen - Quick Activities

Plan	Example
It is possible for care workers to set up quick and easy activities for individuals such as arts and craft or intellectual activities. With practice it might take no more than a few moments to facilitate. 1. Lay out the resources from the grab box on a table in the lounge 2. When individuals are brought into the lounge, ask them if they would like to sit at the activity table or ask them for help with the different activities. For example, ask them if they could help to make a floral decoration for the tables at lunch time 3. Help them to start the activity. For example show them how to put flowers into an oasis to create a display 4. Continue with your care tasks but when you pass the activities table congratulate the residents on their achievements and encourage them to continue in their pursuits	A care worker sets out drawing or flower arranging equipment on a table. When she brings a resident into the lounge she asks them if they would like to sit at that table. She spends two minutes starting them off on the activity. Whenever any care worker passes the lounge during their everyday tasks they offer encouragement in an attempt to sustain the activity. A care worker gives a resident a simple word puzzle and sits with them for a few moments to get them started (this is very different from leaving puzzles lying around). Every time a care worker passes they offer short encouragement.

Table Seventeen describes how activities may be delivered as part of the care workers' everyday care routine. Care workers agreed that they could engage people more within their routine by asking them to support with certain simple tasks around the care home. Residents could for example help to clear up after dinner, polish tables or help to fold laundry. This might give them the opportunity to engage in normalising activities and activities which offer them a sense of purpose or an opportunity to feel useful. Such activities required no additional resources but care workers did feel that this might take up their already limited time.

Table Seventeen - Activities as Part of an Everyday Routine

Plan	Example
Activities might be supported within care workers' everyday tasks so that they do not take up a significant amount of time. These activities would include asking residents to help out around the care home. 1. Identify simple everyday tasks that might be appropriate for residents to support you with. For example, collecting dirty laundry from individuals' bedrooms, handing round cake during afternoon tea, drawing the curtains etc. 2. Ask the resident for their help (links to a sense of purpose, discussed above) 3. Support that resident to help you with that task Ensure that every care interaction is used as a positive interaction.	The care worker has to wheel the linen trolley to each room to collect dirty towels and replace them with clean. She asks a resident to support her in her task. The resident spends the next 30 minutes supporting the care worker to push the trolley up the corridor, stopping outside every room. A care worker asks a resident to help her clear the tables after lunch or to wash or dry up tea cups after tea.

The activities proposed in the tables (above) were designed to be delivered to complement the programme of activities provided by the formal programme of activities. The intention was that creating a more holistic approach to activity provision would maximise participation amongst individuals throughout the day rather than limiting opportunities for engagement to prescribed times and in prescribed ways. It is acknowledged that activities may need to be carefully considered to ensure that they are appropriate for each individual and that this in itself is no easy task. During the activities workshops care workers agreed that the two plans might be possible in practice given the appropriate resources and providing they knew the resident well.

Implementing the Activity Strategies

These brief plans were developed with consideration of the research findings from the observational, interactional and workshop data that illustrated: (i) residents living with dementia wanted more opportunity to engage in activities and that there were current limitations in the way activity was supported, (ii) the self-reported activity preferences of residents living with dementia and (iii) staff reported barriers to supporting engagement which were related to time, resources, management and peer support. Within this plan, care workers came up with specific activities that might be attempted with each participant in line with their unique abilities and preferences. However, following the development of this plan there were few occasions when it was observed to be working in practice. The DCM data showed that overall wellbeing from person to person and within groups did not improve over time but remained static with group Well and Ill-Being Scores (WIB scores) unchanged at around +1 (Appendix xiii - *Mood and Engagement Values: A breakdown by phases one to four*). This is substantiated by the field notes that showed no increase in activity provision during the course of the research. There were some examples of good practice as a direct result of the plans; during one observation for example a care worker who had attended the workshop asked Stanley to support her to wheel the laundry trolley to each room to collect dirty washing. During a separate observation, Edith and Dorothy were given pompoms to make by care workers. Yet these were isolated examples and did not provide significant overall improvements to levels of mood and engagement nor were they sufficient in increasing the amount of time that residents spent in positive and meaningful activities compared to passivity and disengagement or tasks for care (Appendix xii - *Behaviour Category Codes: A breakdown by phases one to four*).

Throughout the research, care workers continued to highlight time constraints 'we don't have the time' and management support 'people will think we're shirking our work' as significant barriers to engaging residents. If these barriers endured then supporting engagement was likely to remain difficult. During the fourth phase of the research therefore, care workers also requested more supervised time to support the development of reflective practice and more management support:

> *Care worker T: 'Yeah the strategy is OK and stuff but, well it would be good if we could talk to someone about what we were trying to do and to get their advice and stuff.'*
> *Care worker Q: 'For guidance.'*
> *Care worker T: 'For guidance yeah, And maybe talk to each other about what worked with which resident and stuff.'*
> *Care worker Q: 'Yeah but there isn't time to do that is there.'*
> *Care worker T: 'Well if they seriously want us to do this they could make time. I mean we do a handover every day.' (Care workers T and Q, Workshop 8)*

They felt it would help them to discuss engagement with team leaders and also to talk to each other about what worked in practice with each resident so that activities may be better embedded within the culture of care. These discussions and the activities plans laid the foundations for change by equipping members of staff with the knowledge of the issues and providing them with some tools to bring about positive change.

CHANGES MADE BY THE CARE HOME

Upon an initial report of these findings, composed during the fourth phase of the data collection (November 2015) and delivered in December 2015, two changes were made at Forest View. First, the time of the activities staff was preserved and they were no longer called upon to run errands or to cover staff shortages. It is likely that as a result of this, residents were given more opportunities to engage in the formal plan of activities. Secondly, the training and development manager introduced a section about the importance of activity in the induction session for new staff. In this section all new staff were told about the importance of supporting residents to engage in activities and care workers specifically were informed that this was part of their role. The activity coordinator attended this part of the inductions to give staff examples of how this might be done in practice. While this is a positive start, it is unlikely to solve the problem of extensive passivity amongst residents with dementia. Informing new staff of their responsibility to support with activities is unlikely to have a significant effect if their core personal values do not support this approach (i.e. if they see their new role simply as a job and are disinterested in supporting their residents' wellbeing) or if following the induction they are thrown into a culture of care that does not appreciate the value of activities. However, as these changes happened after the research, no data was collected to judge their effectiveness.

Summary

The findings presented in the chapters above (Chapters Five, Six and Seven) detail the factors that might affect the opportunities for a person living with dementia to engage in activities in the long term. These factors appear complex and multifaceted. Yet it is only by gaining a clear understanding of what these factors are that we can attempt to formulate a solution as to how better to engage individuals. By using a 'tool kit approach' (Innes and Kelly 2007) to data collection including structured and unstructured observations, conversations and a focus group with residents, and workshops with care staff, it has been possible to develop a picture of the main elements that might affect engagement in care homes. Seven factors were identified. These were an individual's cognitive and physical ability and their unique personality, environmental factors including resources for activities, the formal activity programme, care workers' perception of their roles and of people living with dementia, individual care workers' knowledge, experience and values, the culture of care including the influence of the management and time constraints. Care workers themselves identified time constraints, resources and organisational support as barriers to activities amongst residents. Yet it seems probable that care worker perception of their roles has a bigger part to play in influencing activity provision. There appeared to be a clear perception that activity provision was the preserve of the activities staff and that the role of the care worker was to provide physical care. Separating the spheres of physical and psychosocial care in this way is not helpful.

During the workshops, care workers were asked to come up with ideas about how they might better support people living with dementia to engage in activities within everyday care. Recognising care workers as knowledgeable about what might work in practice (and what definitely would not work), they were asked to co-create strategies that might better support engagement and wellbeing amongst their residents. They agreed that it might be possible to engage residents in simple activities that were quick to set up, providing that these activities were appropriately resourced. They also agreed that it may be possible for them to engage residents more in household chores within their daily care routine. However, despite the strategies detailed above and the apparent willingness of care workers to better support their residents, the evidence from the DCM suggests that greater levels of engagement did not happen in a way that was robust enough to improve overall mood and engagement of individuals (Appendix xii - *Behaviour Category Codes: A breakdown by phases one to four* and Appendix xiii - *Mood and Engagement Values: A breakdown by phases one to four*).

Chapter Eight – Discussion: Promoting Wellbeing through Engagement in Activities among Individuals Living with Dementia in Care Homes

This was an ethnographic, action research doctoral study with theoretical foundations in the principles of social constructivism, person-centred care and the value of participation in activities to people living with dementia as a means to improving their wellbeing. The research took place over a period of 21 months in a care home that specialised in dementia and nursing care and that had aspirations to provide the highest level of care and support to its residents. The focus of this thesis was to observe how residents living with dementia spent their everyday lives, to identify their activity preferences and the *meaning* underlying participation in activities. Additionally, this study sought to examine the factors that had an impact on engagement and develop a strategy to better support people living with dementia in care homes to engage in activities throughout their day.

Eleven individuals with a diagnosis of dementia and two who were assessed as likely to have dementia (by a lead mental health nurse at the home) took part in this study. The 13 participants were observed using Dementia Care Mapping (DCM) and concurrent in-depth ethnographic observations. They also spoke about their activity preferences in ad hoc or spontaneous conversations with the researcher and three individuals were successfully engaged in sustained and focused conversations. Eight of the participants took part in a focus group to discuss activity preferences and activity provision in the home. In addition, 20 care workers took part in five activities workshops facilitated by the researcher and Forest View's in house training and development manager. The purpose of these workshops was to discuss the observational data, their own care practices and how activity provision may be improved with particular reference to promoting participation in activities beyond those offered by the activities staff in the formal programme of activities. In these workshops, care workers also discussed the barriers to positive engagement amongst residents. Findings from the observational and interactional data presented in Chapter Five and Chapter Six suggested a clear link between the opportunity for participation in activities and residents' wellbeing. However, the data also reveals that positive engagement amongst residents remained relatively low and that participants spent a significant amount of time in a passive or disengaged state (Chapter Five). These findings indicated that in itself, the activities programme was not sufficient to fulfil residents' expressed need for regular activity. In addition, within the wider context of care, opportunities for residents to participate in any form of activity beyond those necessary for physical care were rare and interactions between residents and staff were often brief, task orientated and had relatively little positive impact upon resident engagement and wellbeing.

The findings that residents were often disengaged despite the activity programme lends weight to the case for a more fluid approach to activity provision than is possible within a structured programme alone. Care workers were clear in reporting their own perceived barriers to activity provision in the wider context of care including lack of time, shortage of resources and insufficient peer and management support. However, dialogue during the workshop combined with thick ethnographic data revealed deep-seated obstacles concerning care workers' own perceptions of their roles. These entrenched perceptions were reflected in their practices. This is a critical element to the findings of this research since it may go some way to explain the apparent lack of quality interactions between staff and residents. It is also important that these perceptions are appropriately addressed in order to create a culture of care that better supports residents to engage in activities throughout the day as this is likely to have a positive effect on their wellbeing.

The overarching question that this thesis has sought to answer was:

> *Can wellbeing for people living with dementia in care homes be improved by increasing their opportunities for engagement in positive and meaningful activities?*

A likely answer to this question would be that while it is probable that increased opportunities for engagement in positive and meaningful activities will increase wellbeing for individuals living with dementia, *how* this might be achieved within the context of long-term care is a highly complex issue.

The Findings: A Brief Overview

This thesis is based upon the assumptions that people living with dementia should be cared for in a person-centred way that supports their psychological and social needs, as well as their physical needs. Within this philosophical approach people living with dementia in care homes should be afforded every opportunity to participate in activities that are meaningful to them. The first aim of this thesis was to consider engagement in activities amongst people living with dementia in a care home. Underlying this aim were the following objectives:

1. To ascertain current levels of engagement and wellbeing amongst individuals living with dementia in care homes.
2. To examine how activities are currently delivered within a care home environment.
3. To determine the types of activities that individuals living with dementia value and would like to engage in.
4. To examine the relationship between types of engagement and wellbeing.

Using evidence gathered during this research it was possible to begin to respond to these objectives by making a number of key assertions based on the findings of the study (see *Mood and Engagement in Care Homes* p. 192). These assertions have been developed by examining the central threads or themes in the findings within a social constructivist perspective (Chapters Four to Seven) and are that:

- People living with dementia in care homes continue to spend the majority of their time engaged in behaviours relating to passivity or disengagement
- When individuals living with dementia do engage in activity it is often as part of a prescribed programme of activities rather than during every day care interactions or through independent self-directed activity.
- Formal activity programmes are not sufficient to ensure optimal levels of engagement and wellbeing amongst people living with dementia (they offer individuals limited opportunity to engage in activities *throughout* the day).

- People living with dementia retain a desire and ability to participate in a variety of different activities following admission to a care home.
- Residents with dementia remain able to clearly articulate their activity preferences given appropriate means to do so.
- Wellbeing during engagement in activities occurs when an individual feels a sense of purpose or a sense of personal achievement, the activity supports a sense of identity or self, the activity creates a feeling of inclusion and belonging, an individual derived enjoyment and pleasure from engagement or the activity offers them a means to keep busy.
- People living with dementia in care homes usually experience higher levels of wellbeing during participation in positive and meaningful activities.

A second aim of this thesis was to explore ways in which opportunities for engagement amongst people living with dementia in care homes might be improved in a sustainable way (i.e. within current budgetary and staffing limitations). Supporting this aim were the following two objectives:

1. To explore the factors that impact upon levels of engagement amongst people living with dementia in care homes.
2. To work collaboratively with staff to identify how we might use this knowledge to develop a strategy to improve levels of engagement (within current budgetary and staffing constraints).

There were seven main factors that impact upon individuals' opportunities to engage in positive activities (Figure Ten, p. 211). These were (i) the individuals' abilities (both cognitive and physical) and unique personality, (ii) environmental factors (including architectural design, interior design and resources for activities), (iii) the structured programme of activities facilitated by dedicated activity staff, (iv) care workers' perception of their role and responsibilities and of people living with dementia, (v) care worker value base, knowledge and skill, (vi) the culture of care (including the prioritisation of resident needs and leadership of the home) and (vii) staff time constraints (see *Factors affecting engagement* p. 200). By identifying factors that impact engagement it may be possible to work towards a strategy to address the problem of excessive passivity and disengagement amongst individuals living with dementia in care (see *A strategy for promoting wellbeing in care homes* p. 212).

The findings relating to factors affecting engagement in everyday care were to an extent informed by care workers' perspectives. Furthermore, the idea to look for solutions within current staffing and budgetary limitations (rather than increasing the number of activities staff or employing more external professionals) was a result of explicit direction from the care home's management who were unable to increase resources for activities. It was also a consequence of the research aim to ensure this research was sustainable and that it may be translated into other care home settings without the need for additional costly resources and staff.

ENSURING RIGOUR AND VALIDITY IN THE FINDINGS

During this research, validity and rigour within the findings was ensured by using Noble and Smith's (2015) framework, which highlights the importance of acknowledging bias in sampling as well as the researcher's core beliefs. Keeping detailed records, demonstrating a clear process, representing all aspects of the data and including rich verbatim data is also important. This framework also notes the value of engaging with other researchers and participants as a means to validate findings.

Within this thesis, it has been acknowledged that the sample is far from diverse (p. 103). However, in terms of age and gender it appears representative of the majority of European care homes where the vast majority of residents are female and over 80 years of age (Killich-Heart 2017). In addition, despite the lack of diversity amongst the participants, the findings might be considered generalisable, particularly because they are repeated in other studies. As social research does not occur in a vacuum and is influenced by the researcher, the researcher's core beliefs have been clearly laid down (p. 52). In addition, a clear transparent decision making trail regarding the interpretation of the data is essential for transparency in the analysis (Braun and Clarke 2006) and this is included in the appendices of this document (Appendix xvi - *Thematic Analysis: Coding framework* and Appendix xvii - *Thematic Analysis: Map of coding framework*). Furthermore, rich verbatim field notes and extracts from conversations have been presented to support the findings (Chapters Four to Seven) and subsequent analysis.

During the process of completing this thesis, the researcher had the opportunity to engage with other academics who were experts in the field of dementia care and in the methods used within this research. However, one limitation of this study lies in the researcher's presentation of the findings to participants. While this was intended, it was ultimately not a possibility; by the time the raw data had been processed and analysed, the majority of the original participants no longer resided at Forest View. Nevertheless, the majority of the framework was adhered to and the data was collected in a systematic way using reliable methods. As a result this thesis can claim validity and rigour.

Mood and Engagement in Care Homes

The opportunities for engagement in activities is increasingly identified as synonymous with good quality of care delivery both in the UK (Wenborn et al. 2013; UK Government 2014; National Institute for Health and Care Excellence (NICE) 2018) and internationally (Edvardsson et al. 2014; Tak et al. 2015; Milte et al. 2016). Furthermore, participation in activities is recognised as an indicator of quality of life and linked to individual wellbeing (Moyle and O'Dwyer 2012; Edvardsson et al, 2010b), it has also been identified as a human right (Convention on the Rights of Persons with Disabilities (CRPD) 2017). For these reasons, *The Care Act* of 2014 advocates care and support that promotes wellbeing by providing opportunities for engagement in work or work like activities, recreational activities and social interaction (UK Government 2014). Similarly, the National Institute for Health and Care Excellence states that individuals, particularly those living with dementia, 'need a range of activities to choose from and support to maintain existing interests' (NICE 2018).

While acknowledging that organic changes in the brain may cause increased passivity amongst people living with dementia (Holthe et al. 2007), there is consensus amongst academic literature that activity levels amongst these individuals remains unacceptably low in care homes (Harper Ice 2002; Hancock et al. 2006; Wenborn et al. 2013). Indeed, care provision typically focuses on meeting the basic physical needs of an individual. Satisfying psychological and social needs are often afforded low priority (Green and Cooper 2000; Buettner and Fitzsimmons 2003; NICE 2018). Nursing homes are required to provide activities for residents and attempt to do so within the context of a formal activity programme, yet in reality these programmes have a limited capacity to engage individuals for any significant length of time (Cohen-Mansfield et al. 2010). The lack of appropriate support to participate in positive activity is often cited as the reason behind prolonged periods of passivity and disengagement amongst people living with dementia in care homes (Kuhn et al. 2002; Chung 2004; Kuhn et al. 2004). However, while it is also true that these individuals (like all individuals) require periods of self-directed passivity (Beerens et al. 2016; Kaufmann et al. 2016) and rest (Holthe et al. 2007) during the day, the findings of this thesis suggest that levels of engagement at Forest View were suboptimal. This conclusion was informed by participants themselves, who often expressed a wish to be engaged in activities (particularly normalising activities) around the home and who often became withdrawn and even distressed as a result of prolonged passivity.

LEVELS OF ENGAGEMENT IN DEMENTIA CARE

Providing meaningful activities has been identified as an essential component of person-centred care by people living with dementia, their family members and care workers (Edvardsson et al. 2010b). However, a recent study concluded that ‘most nursing home residents spend their day inactive (sleeping, watching TV or doing nothing)’ (den Ouden et al. 2015, p.967). Dementia Care Mapping results showed that despite the rich and varied activity programme offered at Forest View, residents living with dementia spent a significant amount of their time (50.1% on average) in behaviour categories associated with passivity or disengagement including instances of distress. This is the equivalent of six hours out of a 12 hour period. Accompanying ethnographic field notes suggest that much of this time was spent sitting in front of the television but not engaged with its content. One third of residents’ time (33.3%) was spent engaged in tasks relating to physical maintenance such as receiving personal care, eating or drinking and walking from one place to another, an equivalent of four hours in a 12 hour period. On average, residents spent 16.6% of their time engaged in activities which have been defined within this thesis as positive and meaningful, this is an equivalent of two hours in a 12 hour period. Yet in some instances, individual residents spent up to 82% of their day experiencing passivity and disengagement and the remaining 18% in behaviours associated with physical maintenance and no evidence of positive engagement throughout the day. Residents were most likely to experience passive and disengaged behaviour during unstructured time. That is to say, when they were not engaged in the activity programme or engaged in activities such as eating or receiving personal care. These findings are consistent with those from other related research describing limited opportunities for engagement amongst people living with dementia in care homes and report significant periods of passivity and disengagement amongst these individuals (Harper Ice 2002; Hancock et al. 2006; Edvardsson et al. 2014; den Ouden et al. 2015).

Studies using Dementia Care Mapping to assess levels of engagement amongst individuals living with dementia in care homes have found them to be relatively low with active behaviour categories accounting for between two and 19% of residents' time (Innes and Surr 2001; Kuhn et al. 2002; Chung 2004). Alternative methods have produced similar conclusions. These include research using structured observational tools (Nolan et al. 1995; Norberg et al, 2001; Harper Ice 2002; Cohen-Mansfield et al.2010; den Ouden et al. 2015), unstructured observations and interviews with people living with dementia (Holthe et al. 2007), as well as staff questionnaires (Smit et al. 2016; Edvardsson et al. 2014). However, there continues to be a question mark over the accuracy in assessing activity levels by using proxy staff ratings, which may be less reliable than observational tools (Edvardsson et al. 2014; Smit et al. 2016). The data gathered during this research has demonstrated that there are often discrepancies in staff recorded participation, as the latter was often highly optimistic. For example, residents were recorded not only as having participated in an activity but also as having enjoyed it despite the fact that although they were in the room there was no evidence of engagement. The finding is not unique to this thesis; other studies have discovered inconsistencies between staff recording and researcher observations in the examination of the lived experience of people with dementia and found engagement to be over recorded by staff (Buettner and Fitzsimmons 2003; Bowling et al. 2015; Smit et al. 2017).

ACTIVITY PROVISION FOR PEOPLE LIVING WITH DEMENTIA IN CARE HOMES

Levels of engagement amongst residents living with dementia at Forest View were considered to be suboptimal. This was despite an extensive programme of activities on offer in the care home. While residents often showed higher levels of mood and engagement when participating in this programme it was often used as the sole method of engagement and in itself was not sufficient to bring about optimal levels of engagement in activity. In most care homes the word 'activity' often denotes activities delivered by dedicated activity staff or occupational therapists as a formal programme (Green and Cooper 2000; Kuhn et al. 2004). Yet in reality, these activity programmes can only engage individuals for relatively short periods of time (Edvardsson et al. 2014; Cohen-Mansfield et al. 2009a) and therefore the evidence suggests that the overall effects of most activity programmes is slight (Vernooij-Dassen 2007). Often, little thought is given to the importance of engaging individuals beyond activity programmes and to offering opportunities for engagement *throughout* the day rather than at prescribed times and in prescribed ways (Harmer and Orrell 2008; Edvardsson et al. 2014; Tak et al. 2015). Within this doctoral research, residents living with dementia were found to have limited opportunities for engagement beyond the formal programme. The findings in this thesis demonstrate the limitations on relying on a formal activity programme as the sole vehicle for engagement. They also fail to provide a sufficient variety of activity. Other authors have found that while structured activity programmes seem to facilitate participation in leisure activities they fail to facilitate important engagement in self-care and work like occupations (Green and Cooper 2000; Harmer and Orrell 2008), which are equally as valuable (Chung 2004; Edvardsson et al. 2014). This makes a clear case for a more holistic approach to engagement by ensuring that activities are integrated into everyday care interactions, a point echoed in previous research (Brooker and Woolley 2007; Hamer and Orrel 2008; Wenborn et al. 2013).

A critical element to the findings of this thesis and one rarely articulated elsewhere (with the exception of Kuhn et al. 2004; Smit et al. 2014; Smit et al. 2017) is that formal activity programmes may be a *preventative* element to resident engagement. This is because having an activity programme facilitated by dedicated activities staff separates the spheres of physical care (which may also be defined as task orientated care or normal care) and psychosocial care. Such a separation removes the responsibility of facilitating activities from care workers. Physical care becomes the responsibility of care and nursing staff and activities the preserve of activities staff. What is essential, however, is that there is an integration of the two spheres of care. The findings from this research reveal that on an occasion when the dedicated activities staff were absent from the home, the level of engagement and consequently the mood of the residents significantly improved. This was because care workers acknowledged the fact that without planned activities it was their job to encourage engagement amongst residents and this they endeavoured to do throughout the day and as part of their care (see *Factors affecting engagement* pp. 200-212).

In the wider context of care, the television often appears to have been used to excess as the only tool to engage residents. The finding is not unique to this thesis (Milte et al. 2016). While watching the television has been found to be a positive activity amongst older people living in care homes (Östlund, 2010), it may be less positive for individuals living with dementia (de Medeiros et al. 2009; Gústafsdóttir 2015) for it is limited in its ability to fulfil their fundamental psychological needs (Atwal et al. 2003). The televisions in Forest View were switched on for the majority of observations and although individuals were sat near it, there was little evidence of any resident engaging with the content. Indeed, often no thought was given to programme content which was regularly considered by the researcher to be inappropriate and therefore of limited value to the audience (as evidenced by their lack of engagement with it). This corresponds to the findings of other research (de Medeiros et al. 2009), suggesting that people living with dementia rarely engaged with the television and therefore its value as a tool for engagement in care homes is questionable. Research specifically about television viewing by people living with dementia in care homes found that the use of the TV appeared so widespread because it functioned as 'an easy-to-implement diversionary activity when caregivers must reconcile competing demands' (de Medeiros et al. 2009 p. 346). The findings of this thesis are consistent with that analysis.

WHAT IS MEANINGFUL ACTIVITY FOR PEOPLE LIVING WITH DEMENTIA?

While there is a growing body of literature dedicated to examining what might constitute meaningful activity for people living with dementia in the community and in care homes (Phinney et al. 2007; Roland and Chappell 2015; Milte et al. 2016), there is no single definition of the term in research (Harmer and Orrell 2008; Mansbach et al. 2017). Within this study, meaningful activity was considered to be social, vocational and leisure activities. These activities were distinct from disengagement, passivity and tasks necessary for physical care. Increased wellbeing, as indicated by positive mood and engagement and the fulfilment of psychological needs (defined by Kitwood 1997a, p 82-83), was used as a measure of meaning as were self-reported activity preferences.

Through conversations and observations, activities were shown to have a positive impact on wellbeing when they fulfilled one of six core elements: a sense of purpose, personal achievement, a sense of self and identity, a feeling of inclusion, enjoyment and pleasure and an opportunity to keep busy. Some of these themes fit into Kitwood and Bredins (1992) conceptualisation of wellbeing for they suggest the importance of a sense of self-esteem and personal worth, which was evident in an individual's wish for personal achievement and making a contribution to the home. In addition, Kitwood (1997) defined wellbeing in terms of the fulfilment of the five key psychological needs: those of comfort, attachment, identity, inclusion and occupation. Within this thesis, individuals living with dementia appeared to find meaning in engagement when that engagement contributed to the fulfilment of the needs of inclusion (a sense of inclusion and belonging), identity (a sense of self and identity) and occupation (keeping busy).

Enabling an individual to utilise their skills and abilities for personal achievement or to make a valuable contribution to life in the home created a sense of pride and purpose, as did personal achievement. A sense of identity and with it the multiple socially constructed elements of the self was supported by connecting an individual with their past self and past identity whether by engaging in a familiar activity or through reminiscence. This helped to create continuity between the past and present. Fostering a sense of inclusion and belonging occurred when individuals were made to feel like a valuable part of the social environment and there was evidence that positive effect or enjoyment in itself was enough to make an activity 'meaningful' to an individual. In addition, participants valued activity as a means of 'keeping busy' and reported that remaining active was preferable to a state of inactivity. Therefore engagement in itself was identified as being as important as or more important than the *type* of activity being engaged in. Observational data also showed this to be true for when invited, participants engaged in a range of activities (not only those corresponding to their expressed preferences) and appeared to enjoy doing so providing that activity was tailored to their unique abilities and delivered in a way that was person-centred (Kuhn et al. 2004; Kolanowski et al. 2006; Cohen-Mansfield et al. 2010; Tak et al. 2015). These factors appeared to be more important than the activity itself and this is supported by further research concluding that activity type is of lesser importance to mood than the process of being engaged (Beerens et al. 2016).

In other relevant studies the importance of fostering a sense of purpose through feeling useful and personal achievement have emerged as strong themes concerning the meaning of engagement (Gerritsen et al. 2007; Moyle and O'Dwyer 2012; Milte et al. 2016; Cohen-Mansfield 2017; Mansbach et al. 2017); indeed people living with dementia have reported the importance of 'goal pursuit and purpose in life' to their own wellbeing (Mak 2011, p. 180). In addition, creating a feeling of belonging or connectedness (Roland and Chappell 2015; Han et al. 2016; Mansbach et al. 2017;), supporting or sustaining a sense of self and identity (Phinney et al. 2007; Harmer and Orrell 2008; Cohen-Mansfield et al. 2010; Mansbach et al. 2017; Han et al. 2016) and engaging simply for enjoyment (Harmer and Orrell 2008; Smit et al. 2016) can have a positive effect on wellbeing. In line with the findings of this research, there is also an argument for the importance of activity simply for the purpose of keeping busy and active. In previous research, 'having things to do' was reported to be of great importance to people living with dementia (O’Sullivan and Hocking 2013, p. 171, Phinney et al. 2007; Roach and Drummond 2014; Milte et al. 2016). Interestingly however, while this emerges as a theme in studies explicitly seeking the views of these individuals (Phinney et al. 2007; Williamson 2010; O’Sullivan and Hocking 2013) it is rarely included in studies that have gathered information about activity preferences by proxy means (Green and Cooper 2000; Roland and Chappell 2015; Mansbach et al. 2017; Cohen-Mansfield 2017). This points to discrepancies in collecting data using proxy measures compared to seeking information directly from individuals (Kolanowski et al. 2006; Harmer and Orrell 2008).

Within this thesis the importance of hearing the voice of the individuals living with dementia as a means of generating more accurate data is acknowledged. Therefore, when focused conversations proved to be insufficient to gather the required data, a process of spontaneous, ad hoc conversations was employed. This meant that during daily observations, when an individual appeared to feel ready to engage in conversation about activity, the researcher encouraged and supported them to do so. During this ‘spontaneous conversation’ Mapping was temporarily suspended while the researcher engaged with the participant. The content of the conversation was immediately logged within the ethnographic field notes. This method proved to be more successful than traditional focused conversations since the spontaneous conversations occurred only when the individual felt ready to talk.

This thesis contributes valuable evidence to the discussion about meaningful activities in care homes and has explicitly sought the views of people living with dementia themselves to investigate activity preferences and the meaning of engagement to these individuals. As the inconsistencies between first hand and proxy accounts of activity preferences have been evidenced (Harmer and Orrell 2008), the views from family members and care workers were purposefully not sought as part of this thesis. This is despite the argument that family members and care workers might be able to provide valuable insight into resident activity preferences (Port et al. 2011). It was considered important to hear the voice of the person living with dementia as it often remains overlooked in similar research (Mansbach et al. 2017).

THE RELATIONSHIP BETWEEN MOOD AND PARTICIPATION IN ACTIVITIES

The relationship between engagement in positive and meaningful activities and wellbeing was a core assumption of the research question. In the context of this thesis, the definition of 'meaningful activity' considered the enjoyment derived from that activity as an important factor. The research findings outlined in the chapters above (Chapters Four to Seven) are consistent with established academic literature which argues that engagement in activities is an innate human need (Wilcock 2003), which contributes to the fulfilment of psychological and social needs (Kitwood 1997a). They also support those of other research, which demonstrate a connection between the opportunity to participate in a variety of positive activities and wellbeing for people living with dementia in care homes (Chung 2004; Schreiner et al. 2005; Moyle and O'Dwyer 2012; Beerens et al. 2016; Mansbach et al. 2017) assuming those activities are tailored to their unique abilities (Smit et al. 2016).

Dementia Care Mapping was a useful tool with which to study engagement and wellbeing. It is a well-established and rigorously tested research tool based directly on Kitwood's work about person-centred care (Kitwood and Bredin 1992a; Kitwood 1997a). Due to simultaneous coding frameworks relating to activity and mood the tool enables a direct comparison between the two entities within a compact five-minute period. This enables a coherent picture of the relationship between different types of engagement (or disengagement) on mood. Using Dementia Care Mapping has shown that engaging in a range of recreational, leisure, vocational, and social activities improves wellbeing amongst people living with dementia in care homes. Combining this with unstructured observations and conversations with individuals has illustrated *why* activities might help to promote a sense of wellbeing amongst residents living with dementia.

This thesis concludes that the type of activity an individual was engaged in was of less importance than the fact that they were engaged in activity. It directly supports the supposition that 'although certain types of activity are known to particularly influence wellbeing, it seems that frequent activity involvement is more important than involvement in specific activities sporadically' (Smit et al.2017 p. 14). Indeed, the evidence suggests that so long as an activity was pitched at an appropriate cognitive and physical level (Kolanowski et al. 2006) and that engagement in the activity did not cause personal distress, the act of 'doing' in itself has meaning (Phinney et al. 2007). Equally, the evidence suggests that a lack of opportunity for quality engagement caused residents living with dementia to become withdrawn and, on occasion, frustrated and distressed. Within the DCM data there appeared to be an association between low levels of participation in activity and a neutral mood state or ill-being. There is a clear case therefore for better levels of engagement in activity (beyond the short periods of activity that an activities programme is able to offer) as a means to increase the mood and wellbeing of people living with dementia in care homes throughout the day. Supporting an individual living with dementia to engage in activities is an important part of caring for them (Beerens et al. 2016). Yet the real challenge is ensuring that regular engagement in activity becomes an integrated part of care practices (Brooker and Woolley 2007; Vernooij-Dassen 2007).

Factors Affecting Engagement

As discussed, the wish reported by residents living with dementia to participate in activities appears incongruous with the high levels of disengagement and passivity evident in care homes. There is an evident need therefore to better support these individuals to participate in activities within the sphere of person-centred care. Yet delivering person-centred care is not without significant challenges. This thesis acknowledges that the factors that might facilitate or impede levels of engagement amongst people living with dementia in care homes are complex and multifaceted (Brooker and Woolley, 2007; Wenborn et al. 2013). Before any strategy can be put in place to improve activity provision, it is important to explore the factors that influence levels of activity amongst people living with dementia in care homes.

Using a range of appropriate methods of data collection, this thesis identified a number of factors that were influential upon levels of engagement among residents and synthesised these into seven key elements:

- **Individual abilities and unique personality** considers the individual's cognitive and physical abilities as well as their unique personal characteristics and motivation for activity.
- **Environmental Factors** takes into account the physical environment of the care home and the ability of this environment to support participation in activity. It includes both the architectural and interior design of the space as well as resources to support and sustain activity.

- **The structured programme of activities** relates to the planned activities facilitated by dedicated activity staff.
- **Care workers' perceptions of their roles and of people living with dementia** reflects upon individual care workers' understanding of their job and responsibilities with specific focus on engaging residents. This also considers their perception of residents living with dementia.
- **Individual care workers** includes care worker knowledge, abilities, previous life and work experience, their personality, value base and skills in supporting appropriate activities.
- **The culture of care** acknowledges the way that an organisation works and how it promotes certain approaches to caring for residents. This includes the leadership of the organisation and prioritisation of tasks.
- **Staff time pressures** relates to the very real pressures members of staff were under and considers staff shortage, periods of increased resident need and the use of agency staff.

AN INDIVIDUALS' UNIQUE PERSONALITY AND SOCIALITY

The individuals who took part in this study were unanimous in their wish to participate in recreational, social and vocational activities. The evidence suggests that those residents who were better able to initiate and sustain activity independently and who had a natural tendency to be sociable experienced better levels of wellbeing. In addition, care workers appeared more likely to engage sociable or more socially skilled residents in quality interaction than those who had a more introverted disposition; these individuals were more likely to experience brief interactions from care workers (Nolan et al. 1995). Therefore levels of engagement were to an extent related to an individual's sociability and personality (Harmer and Orrell 2008; Cohen-Mansfield 2017). Margaret, who occupied herself by reading a newspaper or engaging in intellectually stimulating puzzles had the highest levels of mood and engagement of all the residents, as indicated by her WIB score of +1.4. May, Peggy and Eleanor also engaged in spontaneous interactions between one another or with the family members of other residents. As a result of their tendency to sociability their levels of wellbeing were above the cohort average; +1.3, +1.2 and +1.2 respectively. This corresponds with findings that an individual's ability to participate is related to their unique personality and tendency to seek social contact (Harmer and Orrell 2008). On the other hand, severe physical illness or a tendency to experience high levels of restlessness and distress resulted in lower overall levels of positive mood and engagement (for example Norma; -0.4 and Audrey +0.6).

COGNITIVE AND PHYSICAL LIMITATIONS

Cognitive impairment and physical limitations often appeared to be preventative factors to their initiating and sustaining positive engagement of their own accord. This finding has been made by other studies of people living with dementia in care homes (Green and Cooper 2000; Holthe et al. 2007; Cohen-Mansfield et al. 2009b; Cohen-Mansfield et al. 2017). With cognitive decline, participation in activity appears to have presented more challenges to the individual (Phinney at al. 2007; Cohen-Mansfield 2017). Indeed, on one occasion, two residents were observed discussing how their declining cognitive abilities made it difficult to follow knitting patterns. However, this was the only instance during the field research when participants identified cognition as a potential barrier to participation. The association between cognitive impairment and a reduced participation in both self-directed and staff led activities is embedded in a number of research papers, which note that levels of engagement decrease with declining cognitive abilities (Kuhn et al. 2004; Zimmerman et al. 2005; Hancock et al. 2006; Cohen-Mansfield et al. 2010) resulting from declining skills (Mansbach et al. 2017) and a lack of motivation (Green and Cooper 2000; Harmer and Orrell 2008). Increased fatigue also plays a part in reduced levels of self-initiated activity (den Ouden et al. 2015). In addition, residents themselves noted physical impairment as a barrier to engagement. In these circumstances skilled support from others becomes necessary to support engagement (Chung 2004; Wenborn et al. 2013).

While both cognitive and physical limitations might act as obstacles to engagement (Port et al. 2011), the need and desire to participate in positive activities does not disappear with dementia (Kitwood 1997a). Therefore cognitive and physical limitations should not act as barriers to positive activity; 'excess disability' in this area may be countered with appropriate support (Chung 2004 p.29). Skilful facilitation can increase the opportunity for engagement in positive and meaningful activities amongst people living with dementia in care homes (Green and Cooper 2000; Chung 2004; Cohen-Mansfield et al. 2010; Smit et al. 2016).

ENVIRONMENTAL FACTORS

Individuals living with dementia may become more dependent on their physical environment to compensate for declining physical, cognitive and sensory abilities (Brawley 2001). This environment therefore, has the capacity to maximise their skills and capabilities (Calkins 2009; Davis et al. 2009) and should be designed to support engagement (Cohen-Mansfield et al. 2010; Tak et al. 2015). There is evidence of an association between the design of the physical environment and the wellbeing of individuals living with dementia (Calkins 2009; Bradshaw et al. 2012). While this thesis does not argue with this theoretical standpoint, the design of Forest View and availability of resources for activities does not appear to have led to optimal levels of engagement amongst residents. The home appears to have been created with dementia design principles in mind and with a view to supporting engagement within the environment. This was done by organising care in relatively small units of no more than 17 people, creating a home like living space including a working kitchen on every floor and ensuring the provision of resources for daily activities such as a daily newspaper (Calkins 2009). Despite this, levels of engagement remained low, particularly levels of self-directed and spontaneous engagement. In addition, although there was a dementia friendly garden designed to promote engagement, residents were rarely observed in this garden. Due to the locked nature of the units, the outdoor space (including the balcony on the ground floor) was mostly inaccessible. These findings correspond to those of other research suggesting that engagement and socialisation is influenced by a complex interplay of factors of which the environment is only one (Smit et al. 2017). Even the best designed environment will not automatically lead to increased levels of activity amongst individuals living with dementia (Smit et al. 2017; Wenborn 2017). Indeed, with the progression of dementia, the physical environment becomes of less importance to engagement than appropriate support from a third party (Perrin et al. 2008; Cohen-Mansfield et al. 2010). Therefore we may conclude that ability of members of staff (activities staff, care and nursing staff) to facilitate engagement is of significantly greater importance to engagement than a good quality physical environment (Smit et al. 2017).

As well as an appropriate physical setting, resources are essential to support engagement (Tak et al. 2015). In this research care workers cited a lack of physical resources as preventative to resident engagement. While it is true that resources were often not immediately to hand and that many were not kept in a suitable condition, the evidence suggests that even when resources were readily available (for example the daily newspaper or the accessible kitchen) these were not utilised by care workers. This finding is echoed in other research concluding that low levels of engagement amongst residents is not as a result of limited resources but due to a lack of knowledge of about individuals' activity preferences and a lack of understanding of how to facilitate appropriate activity (Port et al. 2011; Smit et al. 2017). The physical environment, though important, may not be as influential upon levels of engagement as other factors such as care worker ability and the culture of care.

THE STRUCTURED PROGRAMME OF ACTIVITIES

Despite an emphasis on providing activity programmes in care homes, engagement and wellbeing within these settings does not appear to have improved significantly (Nolan et al. 1995; Harper Ice 2002). Indeed, this thesis argues that not only do activity programmes provide insufficient opportunity for engagement but that they can be a preventative factor in engagement amongst people living with dementia in care homes. The activity programme at Forest View was considered to be ineffective in providing appropriate opportunities for engagement, particularly in everyday activities and social interaction which has been identified as crucial to wellbeing in care (Edvardsson et al. 2014; National Institute for Health and Care Excellence (NICE) 2018). Other authors have also reported on the suboptimal outcomes of formal activity programmes owing to their inability to facilitate appropriate levels of engagement or appropriate quality activities (Chung 2004; Brooker and Woolley 2007; Cohen-Mansfield et al. 2010; Edvardsson et al. 2014). Fixed activity programmes do not have the necessary flexibility to accommodate the engagement needs of individuals (Buettner and Fitzsimmons 2003; Tak et al. 2015) as they offer little in the way of choice and control over the type or timing of engagement (Port et al. 2011; Tak et al. 2015). The evidence suggests that these programmes also fail to engage people for an appropriate length of time during the day (Harper Ice 2002; Cohen-Mansfield et al. 2010; Tak et al. 2015). Studies also show that activity programmes do not focus on supporting people living with dementia to do what they consider to be important to their own quality of life for example 'being useful' (Gerritsen et al. 2007). In addition, they neglect to support individuals to participate in normal everyday activities such as work like activities or household tasks (focusing instead on leisure based activities), which have been identified as important to quality of life and wellbeing (Green and Cooper 2000; Chung 2004; Edvardsson et al. 2014). There is also evidence to suggest that delivering activities as part of a set plan may add to the institutionalisation and dependence of residents living with dementia rather than seeking to optimise their independence and self-determination in encouraging self-directed engagement (Harmer and Orrell 2008).

A clear and significant finding in this research was that the formal activity programme could be preventative to resident engagement because, as a result of this programme, there was an assumption amongst care workers that supporting activities was not part of their job. ‘Activities’ were viewed as organised activities and became a very separate entity from everyday care. Therefore, supporting residents to engage in activities was perceived by care workers as an addition to ‘normal’ task focused care rather than an integral and important part of it. This was evident when care workers reported that the responsibility of supporting engagement lay with the activities staff and not with them and reported that the activity programme alone was sufficient to engage residents for an appropriate amount of time. Furthermore, the assumption was that if residents were engaged in an activity run by the activity staff for a few moments then there was no need to support them in any other activity for the rest of the day. This point is noted in other observational research exploring daily lived experience of people living with dementia in nursing homes (Nolan et al. 1995; Harper Ice 2002). In reality however, engagement in the activity programme only accounted for a small proportion of an individual’s day, if any at all (Cohen-Mansfield et al. 2010).

To enable optimal engagement in care homes, a more fluid and spontaneous approach is required (Harper Ice 2002; Edvardsson et al. 2014; Tak et al. 2015) with individually tailored rather than group activity plans (Brooker and Woolley 2007; Brooker et al. 2007; Smit et al. 2016). In addition, far from separating the realms of physical (task focused) and psychological (supporting positive engagement) care they should be interwoven. The message to care and nursing staff needs to be that facilitating opportunities for engagement in positive and meaningful activities is the responsibility of every member of staff and should not lie solely on the shoulders of one or two individuals dedicated to activities (Nolan et al. 1995; Smith et al. 2009; Edvardsson et al. 2014; Tak et al. 2015). This places the emphasis on a need to change care worker perceptions of their roles and responsibilities as well as the wider culture of care (Tak et al. 2015; Smit et al. 2017).

CARE WORKER PERCEPTION OF THE CARE ROLE AND OF PEOPLE LIVING WITH DEMENTIA

As discussed, changing care and nursing staff perceptions of their roles is essential to begin to offer people living with dementia in care homes a more holistic opportunity for engagement. Having an activity programme was preventative to activity provision as it caused a division between the physical and psychosocial elements of care; care workers appeared to view the physical maintenance of their residents as their role and responsibility while supporting with activities was viewed solely as the responsibility of the activities staff. This was illustrated by one care worker during an activities workshop when they were asked to consider the evidence gathered during DCM observations that showed high levels of passivity and disengagement amongst residents. The care worker responded to this information saying: 'No way. Anyway surely this is [the Activities staffs'] job' (Care worker B, Workshop 1, also see Pulsford 1997). The lack of opportunity for residents to engage in activities, beyond the activity programme, suggests a limited basic understanding of person-centred care amongst care and nursing staff. This limited understanding was also highlighted using the P-CAT tool; care workers rated their practices as highly person-centred while the observational evidence suggests that this was not always the case.

Staff perceptions of people living with dementia also impacted upon their level of support for activities. To appropriately support activities, care workers need to recognise and value the personhood of the individual (Kitwood 1997a) as well as their selfhood (Sabat 2001). Yet these facets of care are often neglected by those who work with individuals experiencing cognitive decline (Kitwood 1997a). Amongst some care workers at Forest View people living with dementia were viewed as inevitably dependent and there appeared to be tacit negative assumptions about their capabilities and ability to attain a state of wellbeing. This is not a new finding. Other authors have commented about the negative assumptions made about people living with dementia and the impact this has upon the care and support they receive (Kitwood 1997a; Moyle and O'Dwyer 2012). Engagement amongst residents in care homes might improve with a recapitulation of the roles and responsibilities of care workers to include the importance of supporting activity and a better understanding of people living with dementia. This would require additional staff training and support, not only to change perceptions but to equip care and nursing staff with the skills to support participation amongst people living with dementia.

INDIVIDUAL CARE WORKERS' VALUE BASE, KNOWLEDGE AND SKILL

There appeared to be an overall lack of understanding about what might engage an individual living with dementia or about how traditional activities might be modified to better engage individuals living with. There was also little evidence of care and nursing staff using every day interactions as a tool for engagement yet this is an important element of person-centred care. The findings correspond to relevant academic research suggesting that a lack of knowledge and understanding amongst care workers about how to deliver appropriate activities acts as a significant barrier to engagement (Holthe et al. 2007; Smith et al. 2009; Port et al. 2011; Smit et al. 2016) and that care workers have insufficient skills to use everyday encounters to support activity (Kitwood 1997a; Kuhn et al. 2004). This supports the idea that this lack of knowledge and understanding is the principal reason for the overuse of the television as a tool for engagement (de Medeiros et al. 2009). Poor quality training is a barrier to resident engagement for failing to equip care and nursing staff with sufficient knowledge of resident needs (Milte et al. 2016). Therefore, providing care and nursing staff with the necessary skills and expertise to support those living with the condition is essential and can help to develop a positive culture (Kirkley et al. 2011; Klich-Heartt 2017). Yet training alone is not sufficient to ensure quality care delivery (Nolan et al. 2008).

During this research it became clear that past work experience and care workers' own unique personalities and value base also predicted their ability to deliver care in a person-centred way and successfully support engagement. Although this thesis did not gather data about care worker experience, education and values it was evident that the number of years of practical and care related education (such as NVQs) were of less importance to person-centred practice than an individual's value base and the quality of their relationship with residents. While some care and nursing staff viewed their occupation simply as a job, others were more emotionally invested in their work and genuinely wanted to support the residents in the best possible way. There was a clear difference in the quality of care delivered by these two groups of care workers. Recruiting staff with a person-centred value base therefore, might be as important or more important as delivering the right training (Innes and Surr 2001; Kirkley et al. 2011). Raising the status of care workers should also be considered (Innes and Surr 2001, Nolan et al. 2008). For some of those working at Forest View, care appeared to be a career of last resort with one commenting 'it was either this or bar work'. This attitude was evident in her approach to her work. Indeed, care workers lie at the bottom of an organisational hierarchy with limited opportunity for career development (Capstick 2003). They are also poorly paid for their work (Innes and Surr 2001). It may therefore be unrealistic to ask care workers to treat their residents with absolute positive regard if they are not treated in this way (Capstick 2003).

It is probable that positive attitudes, a propensity for person-centred care and a reflective approach to practice care is innate within an individual worker and therefore not always significantly influenced by training. The low status afforded to care workers and the relatively small recompense they receive is likely to be an important factor in the *way* that these individuals work. It is of great importance that this low positioning of care workers is addressed to ensure a better quality and more motivated workforce. That said, training does play a part in the delivery of quality care. Therefore, a deeper exploration of these issues appears necessary.

THE CULTURE OF CARE AND PRIORITISATION OF NEEDS

The culture of care is a 'pattern of shared basic assumptions developed by a group and founded to work as it adapts to problems, and taught to new members as the correct way to perceive, think and feel' (Killett at al. 2016, p 161). As such, the culture of care is in itself a social construction as well as being a critical factor influencing the quality of care delivery (Kitwood 1997a; Brooker and Woolley 2007; Killett et al. 2016). A number of authors cite organisational issues as the main reason for prolonged disengagement amongst residents living with dementia (Hancock et al. 2006; Harmer and Orrell 2008; Smith et al. 2009). While there is currently a movement to improve the culture of long-term settings (Killett et al. 2016), care often continues to be delivered in a way that is physical and task orientated and within a fixed routine; person-centred care and psychosocial care are often a secondary consideration and therefore often remain a neglected facet of care (Grealish et al. 2018). Care homes seem better prepared to meet the physical needs of their residents, while social needs often remain unfulfilled (Hancock et al. 2006). Furthermore there appears to be a deeply embedded approach within care of doing things *for* a person living with dementia rather than doing things *with* them, which in itself can lead to disengagement and dependency (Holthe et al. 2007; NICE 2018).

At Forest View it was clear that despite the management's rhetoric emphasising the importance of adopting a person-centred approach to care encouraging residents to remain as active as possible, the reality was somewhat different. While a clear care philosophy can offer a good guide to care workers (Smit et al. 2017), these philosophical statements are often not reflected in the observed culture of care (Green and Cooper 2000; Harmer and Orrell 2008; Kirkley et al. 2011). One key reason for this observed in this research, is the prioritisation of physical care demands over psychological or social needs and the polarisation of the two. Despite the fact that the majority of care workers participating in this study reported that the quality of their interaction with residents was more important than performing physical care (results from the P-CAT, p. 156), the observational evidence suggested that this was not the case. Residents' physical needs were regularly met to a high standard, yet this came at the expense of their psychosocial needs. This mirrors findings from related research which shows the low priority afforded to psychosocial needs amongst people living with dementia (Harmer and Orrell 2008; Innes 2009; Kirkley et al. 2011; Edvardsson et al. 2014; NICE 2018).

The management of the care home also has a significant role to play in shaping the culture of any organisation (Brooker et al.2007; Kirkley et al. 2011, Killett et al. 2016) and can act as an agent for positive change (McGreevy 2016). A manager's ability to limit the external pressures on their care and nursing staff, empower them to take responsibility for the wellbeing of residents and to remain open to change for the benefit of residents have been identified as key elements of a positive culture of care (Killett et al. 2016). At Forest View however, visionary leadership prioritising a person-centred approach to care appeared to be lacking. Care workers reported that the organisational structure of the care home did not prevent a person-centred approach to care (as reported using the P-CAT, p. 156). Yet they also said that the management and senior staff would regard them to be shirking their work if they were seen to be sitting engaging residents rather than busy with physical care tasks. This appears to suggest a management led culture that did not value quality interactions. Good quality and enlightened management might act as an agent for positive change providing there is a good relationship and effective communication between the leadership and care team (McGreevy 2016) and might have proved a way to counter the poverty of quality interaction and activity at Forest View.

TIME CONSTRAINTS

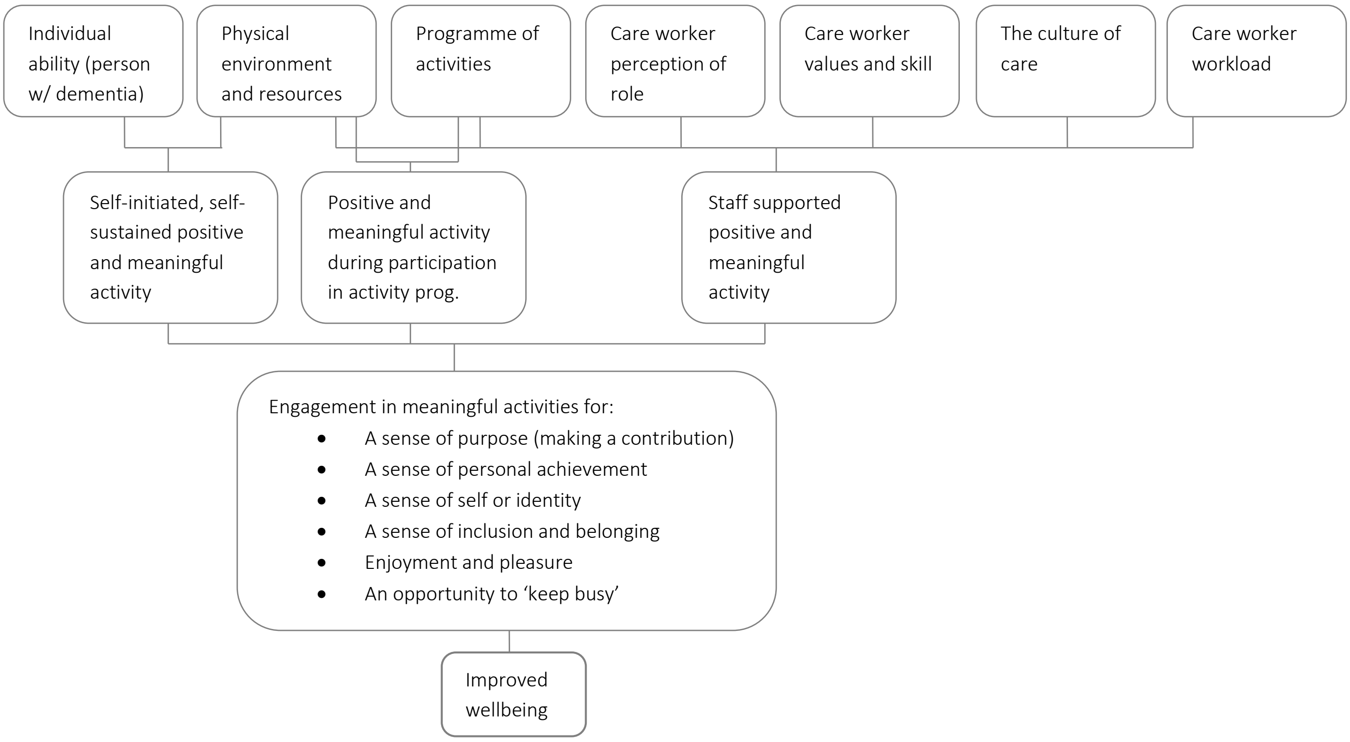
As budgets for social care remain tight, it is tempting to try and find a solution to the problem of prolonged passivity in care homes by suggesting new ways of working rather than by investing in increased staffing levels. However, even with appropriate training, a reconceptualisation of roles and an evolution in the culture of care it is likely that time constraints would continue to present a barrier to supporting residents to participate in activities. In the main, care and nursing staff were observed to be working hard to fulfil the needs of residents but faced significant time constraints. This was particularly true when the care home was short staffed, when there was a reliance on agency staff or during periods of increased physical needs amongst residents necessitating increased staff time. On the first floor where physical needs were greatest for example, staff were unable to support every resident to get out of bed before lunch was served at noon. This is not consistent with a person-centred approach to care since residents were given no choice as to when they could get up. Nevertheless, on the days when there was a full quota of permanent staff and no sickness amongst residents, participants appeared to have had a better experience in terms of increased engagement and mood levels. Although it is important to note that residents did remain passive or withdrawn for a significant proportion of their time during these days as staff continued to be busy. In the main, care workers were observed to be working hard but, due to their numerous responsibilities, the majority of their time was spent fulfilling residents' basic physical needs.

Other authors have identified multiple staff responsibilities (Harper Ice 2002; Kuhn 2002; Edvardsson et al. 2014) and insufficient staffing levels (Volicer et al. 2006; Harmer and Orrell 2008; Killett et al. 2016; Smit et al. 2017) as a barrier to activity provision (Royal College of Occupational Therapists (RCOT) 2013; Edvardsson et al. 2014; Smit et al. 2017) and as a predictive factor of poorer outcomes such as increased dependency amongst residents (Harper Ice 2002). That said, some studies suggest that increasing staff time only leads to increased physical care rather than the fulfilment of individuals' psychosocial needs (Nolan et al. 1995). While low staffing levels associated with an increase in instances of malignant social psychology, predominantly in the form of ignoring residents (Innes and Surr 2001), limited staff time and time constraints can only go some way to explaining the lack of opportunity for residents to engage in activity (Volicer et al. 2006). Taken alone, staff time constraints cannot adequately account for low levels of engagement amongst people living with dementia in care homes.

A Model of Factors Influencing engagement in Care Homes

The findings from this thesis demonstrated the complexity of factors affecting opportunities for engagement amongst residents living with dementia in care homes (Figure Ten, below). Cognitive impairment presents a very real challenge to self-directed occupation. Yet it is possible for people living with dementia to engage in activities given appropriate encouragement and support and providing that the activities offered are tailored to their unique abilities, that is to say neither too simple to be boring nor too difficult to cause frustration. For this to be possible however, the physical environment, formal activity programme, the construction of care worker roles and responsibilities, staff training, the culture of care and care worker workload need to be conducive to activity provision.

Figure Ten - A Model of Factors Influencing Engagement in Care Homes



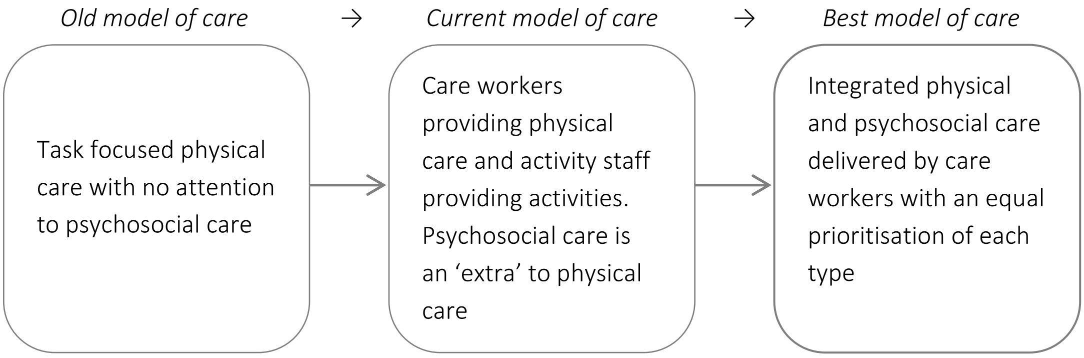
In Figure Ten the factors that promote or limit activities are presented in a simple model. This model recognises the complexity of factors influencing levels of engagement amongst individuals living with dementia. However, this thesis also acknowledges that participation in meaningful activities is just one of a number of ways that individuals can be better supported to live well in care homes (Bradshaw et al. 2012).

A Strategy for Promoting Wellbeing in Care Homes

With the advent of the psychosocial understanding of dementia, the corresponding psychosocial theories of personhood and the self and the concept of person-centred care, the care for people living with dementia has changed for the better. Care has evolved to consider not only the physical needs of people living with dementia and how to manage the disease but also how it might be possible to attend to individuals' psychological and sociological needs (Kitwood, 1997a; Brooker and Latham, 2016). Such a model of care has been shown to have a positive impact on the wellbeing and quality of life of people living with dementia. Increasing engagement in meaningful activities presents a great opportunity to improve dementia care (Vernooij-Dassen 2007) and significantly improve wellbeing (Port et al. 2011). Opportunities to engage in activity is essential to human beings (Wenbourn et al. 2008) and is an integral part of quality person-centred care (Kitwood 1997a). Opportunity to participate in 'cultural life, recreation, leisure and sport' has also been identified as an element of an individual's human rights (CRPD 2017, p. 22).

However, it appears that within care homes today, the physical needs of an individual and their psychosocial needs are split into two separate spheres. The one (physical) is the responsibility of care and nursing staff and the other (engagement, representing a psychosocial element of care) is the responsibility of dedicated activities staff within a formal programme of activities. The fact that one body of staff is significantly larger than the other is an indication of the priority put on physical care over psychosocial care. Supporting engagement, therefore, does not appear to be as valued as supporting an individual's physical care needs. This model is not ideal. Care needs to evolve so that activities become an integral part of care delivery rather than a mere addition to it. There is still a place for the formal activity programme, but it cannot be the sole vehicle for engagement amongst residents. Care workers and nursing staff need to be part of the movement to support engagement within their role and beyond any formal activity programme. In this way activities may become an integral part of care rather than simply a pleasant 'bolt-on' (Figure Eleven, p. 213). It is acknowledged however that this is no easy task.

Figure Eleven - An Evolution of Care Practices to Improve Opportunities for Engagement in Activities



This thesis has demonstrated that developing a strategy and training some care staff in the value of activities is in itself not enough to increase positive and meaningful engagement amongst residents without a wider cultural shift and a reconceptualisation of the care worker role. A more multifactorial approach is needed to address the high levels of inactivity amongst people living with dementia in care homes. This approach includes developing individualised activity plans for each resident that take into account their unique preferences and abilities and that are specific or directive enough to enable staff to follow simple steps (Brooker and Wooley 2007; Smith et al. 2009; Pool 2012).

IMPROVING OPPORTUNITIES FOR ENGAGEMENT

In recognition of the very real time pressures experienced by care workers, the activities suggested need to be quick to set up and sustain (such as setting up a simple flower arranging activity and then occasionally offering encouragement) or embedded within care practices (such as asking for help to clear up or move a trolley). The latter strategy enables a move away from the dominant model of care where residents often represent passive 'guests' while care workers play the part of more active 'hosts' (Holthe et al. 2007) and opens the door to a more collaborative way of working whereby residents do things *with* care workers rather than have things done *to* them. However, for this to be successful seven further elements need to be in place. These are:

- A physical environment and appropriate resources to support engagement.
- A reconstruction of the role of a care worker and a job description that includes activity provision as a core responsibility.
- The recruitment of care home staff who value the wellbeing of their residents and who are committed to supporting their wellbeing.
- Appropriate staff training about the value of activities to people living with dementia.
- A culture of care that values activities and that is underpinned by strong and visionary leadership and management with a clear philosophy.
- A reduced resident to staff ratio to mitigate care worker time constraints.
- An activity programme of structured activities to facilitate group activities. This needs to be carefully managed so as to dispel the notion that 'activity' merely refers to an activity organised within this programme.

In so doing, the conclusions drawn in this thesis are not dissimilar to those made by Brooker and Woolley (2007), Pool (2012) and by Smit and her colleagues (2017). They suggests a multifactorial approach to the problem of prolonged disengagement amongst people living with dementia in care homes that takes into account the unique preferences and abilities of these individuals.

DEVELOPING REFLECTIVE PRACTICE IN CARE HOMES

A positive part of the field research was that it afforded care workers a safe space to discuss and reflect upon their own caring practices and role in the home. Reflectivity is a key aspect of other care based roles such as social work and nursing as it enables individuals to improve their skills and therefore facilitates continued professional development. This is considered to be important in developing effective practitioners (Knott 2016). Care workers at Forest View however were not offered the space or the time to think about their practices in a reflective way. Yet they appear capable of and willing to engage in reflectivity given appropriate encouragement. This became clear during the course of the field research; the workshops conducted as part of the project appeared to be the only time that care workers were asked to think about the care they provided and the implications of their practice upon the lived experience of residents. One example of this was when care workers were shown a snapshot of how resident participants spent their time in the home using results from DCM.

This showed that during phase one, these individuals spent almost 52% of their time in behaviours associated with passivity, social withdrawal or distress. The response to these results from care workers appeared to suggest that they had never really considered how residents spent their time. There was also a tacit and widely held assumption that simply because there was a dedicated activity programme facilitated by two members of staff, all of the residents were consequently appropriately engaged in meaningful activities for a sufficient period of time. For some, these workshops appeared to be the first and only time that they were encouraged to think differently and to observe the way in which residents in the home actually spent their days. This realisation facilitated a real understanding of the importance of supporting residents to engage in activities and also generated a discussion about how this might be achieved.

Providing this safe space for care workers to reflect upon their practice enabled these individuals to learn by engaging with others and to collectively challenge their traditional approach to practice. It also offered them a secure environment to discuss and make sense of their experiences and from there, to initiate positive change within the institution. The field notes recorded during the latter part of the field research document instances of care workers starting to notice passivity or social withdrawal amongst residents and on occasion, their attempts to engage individuals in a positive and meaningful way. Learning through engagement with peers in this way is a key element of action research (Coghlan and Brannick 2014) and may be one way to achieve best practice in care homes with particular reference to increasing opportunities for engagement in meaningful activities.

Key Messages and a Contribution to Knowledge

This thesis contributes to the body of knowledge concerned with improving opportunities for people living with dementia in care homes to engage in activities. Key findings have emerged which support a better understanding of the factors affecting engagement and wellbeing in care homes. Through these findings, clear messages for care home managers and relevant policy makers have emerged. Nevertheless, this thesis does not claim to complete the picture and therefore raises questions for further research relating to activity provision in care homes. This is essential to create a better understanding of this issue.

KEY MESSAGES FOR CARE HOME MANAGERS

This thesis offers several key messages for care home managers:

1. An in-depth knowledge of each resident is important to providing good quality person-centred care, thus the importance of ensuring continuity of care workers by reducing staff turnover as well as the reliance on agency staff cannot be overstated. Evidence presented in this thesis indicates that staff shortages and a high proportion of temporary staff leads to increased disengagement amongst residents.
2. If there is an activities programme and dedicated activities staff it is important to preserve their time. They cannot engage residents in activities if they are assigned other tasks.
3. It is important to recruit individuals who fundamentally wish to support the personhood of the people they care for and with a personal value base which supports good quality person-centred care.
4. There is a need to reconceptualise the role of care workers to include quality interaction and support with activities alongside physical care tasks and also to blur the sharp distinction between physical care and psychological care.
5. Care workers are supported to develop a more reflective style of practice and to consider their role in providing activity focused interventions. This can be achieved in reflective sessions similar to the workshops delivered within this research.
6. It is important that physical care is not prioritised at the expense of psychosocial support. This may be achieved by having a clear vision and being able to effectively communicate this vision to care workers via dedicated training and appropriate supervision.
7. Care home managers need to acknowledge that good quality care is costly and that it may be expedient to employ additional staff if residents appear unengaged for much of their day. While reconstructing the meaning of the care role, providing good quality training and supervision and employing the right people will result in better outcomes for residents. If care workers are ultimately too busy supporting physical needs then levels of engagement are likely to suffer.
8. It is important to lead by example; to engage with residents in a way that is appropriate and that upholds their personhood as well as maximises their opportunity for engagement. Managers can act as agents for positive cultural

change, but to do so they need to demonstrate that positive culture in their own practices.

KEY MESSAGES FOR POLICY MAKERS

Current policy recognises the importance of wellbeing and of 'living well with dementia' (DoH 2014; DoH 2016) and continued engagement has been identified as a key component of living well in care homes (RCOT, 2013). Despite this, there is little included in statutory requirements for care homes to support residents to engage in activities for an appropriate amount of time throughout their day (Care Quality Commission 2017). This in itself may be one of the driving forces behind the higher priority given to physical care within long-term care culture at the expense of psychological care. A key message to policy makers would be to recognise the importance of providing appropriate levels of engagement and to embed this in legislation. Commissioners of services are also requested to recognise the value of engagement in activities and to appreciate that good quality care might cost more than simply providing physical care in a cheaper 'warehouse' style model.

SUGGESTIONS FOR FURTHER RESEARCH

This thesis highlights the need for some further research to gain a greater understanding of supporting engagement in dementia care.

1. The need for activity varies between each individual and every person needs periods of self-directed passivity (Beerens et al. 2016; Kaufmann et al. 2016) and rest during the day (Holthe et al. 2007). Further research needs to be done to establish what might be an appropriate level of engagement for people living with dementia in care homes. While individuals should not expect to be engaged in stimulating activity throughout the day, current levels of passivity and withdrawal are unacceptable and it would be valuable to ascertain where the balance lies.
2. During this doctoral research it became clear that care workers' own unique value base and personality predicted their ability to successfully engage residents in activity. However, limited data was collected regarding this issue (although it was mentioned in the field notes and in a reflective diary). A further exploration of these elements seems imperative.

3. Future research should be considered, which seeks to implement a more integrated and holistic approach to engagement in care homes and then studies the mood and engagement of residents as a result of this. Following the findings from this thesis, it is likely that such an approach would improve levels of positive engagement and wellbeing amongst individuals living with dementia.
4. More research needs to be conducted that looks specifically at *how* to imbed increased opportunities for residents to engage in activities into everyday care.

A CONTRIBUTION TO KNOWLEDGE

This thesis has contributed to the academic discussion about activity provision for people living with dementia in care homes. The research has looked at the levels of engagement amongst residents living with dementia in care homes and found them to be lacking even with a formal programme of rich and varied activities. It has sought to hear the voices of the person living with dementia when considering activity preferences and what makes activities *meaningful* to them. This is an important aspect of the research as the voice of those living with dementia is so often lost in favour of proxy accounts (Harmer and Orrell 2008). This is particularly the case when individuals are experiencing more advanced dementia and methods such as interviews become increasingly difficult. This thesis has provided valuable insight into what people living with dementia in care homes might find meaningful within the context of engaging in activities by using ad hoc or spontaneous conversations embedded in ethnographic observations and a focus group to identify underlying meaning in engagement. While interviews proved difficult in eliciting relevant information, spontaneous conversations occurred when the participant (rather than the researcher) was ready to talk. In so doing, the research has been responsive to the needs of participants' abilities by seeking original ways to gather data. This approach enabled the collection of valuable first-hand accounts.

This thesis has also added to the body of literature considering the different factors that might facilitate or prevent engagement amongst people living with dementia in care homes. This is currently an under researched field of study. Nevertheless, it is of great importance since it is only by gaining a better understanding of these factors that we might improve opportunities for engagement and in doing so improve the wellbeing of residents living with dementia. The thesis has also reinforced the findings of a recent study citing resident abilities, the physical environment, organised activities, the culture of care, staff education and training and time constraints as influential to activity provision (Smit e al, 2017). It has also identified that care workers' perceptions of their own roles and responsibilities is a barrier to engagement. This highlighted an urgent need to reconceptualise the role of the care worker to include supporting activity as well as performing physical care. These findings were reached by drawing on the research frameworks of ethnography and action research and using a 'tool kit approach' (Innes and Kelly 2007) to data collection. This facilitated a more holistic understanding of the subject demonstrating the value of such an approach.

Conclusions

Occupation is an innate human need (Wolcock 2003; Wenborn et al. 2008). Amongst older people, remaining physically, socially and cognitively active is associated with 'successful ageing' and an enhanced quality of life (Havighurst 1961; Foster and Walker 2015). Furthermore, engaging in meaningful activities has been identified by people living with dementia as a key element of person-centred care and essential to their wellbeing (Phinney et al. 2007; Williamson 2010; Edvardsson et al. 2014; Tak et al. 2015; Kaufmann and Engel 2016). It is also a basic human right (CRPD 2017). Yet, people living with dementia in care homes do not always get sufficient opportunities to engage in activities throughout their day and as a result spend much of their time in a state of passivity or disengaged with their surroundings (Harper Ice 2002; den Ouden et al. 2015; Smit et al. 2016). This is an issue that this thesis has sought to address.

Within this study, the research frameworks of ethnography and action research were drawn upon to examine the lived experience of people living with dementia in care homes, with particular reference to their levels of engagement in positive and meaningful activities. Participants reported their wish for more opportunity to engage in a variety of different types of activity. These included physical and outdoor activities, creative activities, fun and games, normalising activities and social activities (see also, Tak et al. 2015). In addition, using observational and interactional data, several factors were identified that gave *meaning* to engagement in activities. These were that the activity supported an individual to feel as though they were contributing to their environment (feeling useful), that an activity created opportunities for personal achievement, that an activity supported an individual's sense of self or identity and that it facilitated a feeling of inclusion and belonging. Activities also held meaning for an individual if engagement created an opportunity for enjoyment and pleasure and if it enabled an individual simply to keep busy; keeping busy was perceived by residents to be a preferable state to passivity.

However, findings from the observations show that residents living with dementia spent the majority of their time in a state of passivity or disengagement or in behaviours that were essential for their physical care and maintenance such as eating or drinking (83.4%). Residents spent 16.6% of their time in activities that, within the context of this study, were regarded as positive and meaningful. The findings illustrate that the formal programme of activities, facilitated by dedicated activities staff (often the norm in care home settings) was in itself insufficient to support appropriate levels of engagement amongst residents. Despite this rich and varied programme, residents continued to spend the majority of their time in a passive or withdrawn state. This appeared to be because the activity programme could only engage individuals for a relatively short period of time during the day, if indeed they were engaged at all. In addition, there were few opportunities for residents to participate in activities beyond this formal programme. Both engagement in self-directed activities and activities supported by members of the care and nursing staff appeared somewhat rare.

The evidence suggests that to improve opportunities for engagement in activities, activities need to become an integral part of everyday care. Therefore, responsibility to offer opportunities for this engagement cannot lie with the activities staff alone but need to be supported by every member of staff. Care workers identified a lack of resources for activities, the culture of care and time constraints as the most limiting factors to improving resident engagement. While this is true, it is likely that care workers' perception of their roles had a significant part to play in the high level of passivity amongst people living with dementia. Indeed, care workers appeared to view a distinct separation in the spheres of physical care and psychosocial care. A number of care workers, for example, viewed physical care as an essential part of their role but reported that supporting engagement was not part of their job. A key finding of this thesis, therefore, is that it is essential to integrate activity provision into the everyday care of individuals living with dementia. If physical and psychosocial care remain in separate spheres, physical care as the domain of care workers and activities as the domain of dedicated activity staff, then optimal levels of engagement cannot possibly be attained. Reconstructing the perception of care roles to include the responsibility for supporting engagement is therefore of vital importance.

Using an action research approach, the researcher worked in partnership with care workers to facilitate the co-creation of a strategy to improve opportunities for resident engagement within the context of everyday care. Within this strategy, care workers agreed that they might be able to increase support for activity if those activities were quick to set up or could be woven into their everyday care routine. Yet despite the development of a strategy, there was little evidence of improvement to resident engagement and wellbeing during the field research. That is not to say that the strategy created by care workers might not work. However, for it to be successful there are additional elements that need to be put into place. These are: (i) a physical environment and appropriate resources to support engagement, (ii) a reconstruction of the role of a care worker and a job description that includes activity provision as a core responsibility, (iii) the recruitment of care home staff who are committed to supporting resident wellbeing, (iv) appropriate staff training about the value of activities, (v) a culture of care that values activities and that is underpinned by strong and visionary leadership and management with a clear philosophy, (vi) a reduced resident to staff ratio to mitigate care worker time constraints and (vii) an activity programme of structured activities to facilitate group activities (however this latter element needs to be carefully managed so as to dispel the notion that 'activity' merely refers to an activity organised within this programme). As part of this strategy it is also important that care workers are offered the opportunity to develop a more reflective practice to consider their own role in improving the lived experience of residents. By adopting this approach, residents living with dementia in care homes may have an increased opportunity to engage in positive and meaningful activities in line with their expressed wishes. It is likely that this will contribute to improvements to individuals' wellbeing.

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Accompanying Material

Appendix i - Literature Review: Key search terms

The following subject terms were employed in various combinations to build up a collection of academic journal articles relevant to the thesis topic

Subject Term:
dementia OR Alzheimer*
care home OR residential care OR nursing home OR residential home OR long-term care OR long-term
wellbeing OR well-being OR well being
engagement OR activit* OR occupation* OR activities of daily living OR leisure OR hobb*
personhood OR person-hood OR person-centred care OR person-centred care
experience of dement* OR experience of Alzheimer*

An initial literature search was conducted during 2013 / 2014. A further search was conducted in May 2018 to identify additional relevant material. The cut-off date for identifying new literature was May 2018.

Example of 2018 literature search

Search Terms: (dementia OR Alzheimer*) AND (care home OR residential care OR nursing home OR residential home OR long-term care OR long-term care) AND (wellbeing OR well-being OR well being) AND (engagement OR activit* OR occupation* OR activities of daily living OR leisure OR hobb*)

Selected date range: 2014 – 2018

Limit to articles written in English and from peer review journals

Articles identified: 14

Number of articles with duplicates removed – 9

Articles included following review of titles and abstracts – 6

Articles excluded as (i) related to wellbeing in terms of pain management, (ii) focus of paper was visual impairment rather the people living with dementia, (iii) focus of paper was preventing neglect.

Appendix ii - Dementia Care Mapping: Operational rules for recording Behaviour Category Codes

(Adapted from Bradford Dementia Group 2005, pp 65-67)

These operational rules help mappers to make decisions about what to code when two or more behaviours occur within one time frame. There are four main rules that help a mapper to choose a BCC to record in any given time frame. They should be applied one at a time, always beginning with rule 1 and working through rules 2, 3 and 4 until a decision can be made.

Of two or more behaviours occur within one time frame.

Rule 1 – Order of precedence

Higher potential for positive mood and engagement categories take precedence over lower potential for positive Mood and Engagement categories.
High Potential Categories: A,D,E,F,G,I,J,K,L,O,P,R,S,T,V,X,Y

Categories that offer the potential for a higher level of positive Mood and Engagement always take coding priority over moderate and low potential categories.
Moderate potential categories: B

Only Code B is no higher potential categories are observed during the time frame. Always code B if only B and low potential categories are observed in the time frame. Codes with limited potential for positive mood and engagement (cannot exceed +1) are only coded if no high or moderate potential categories are observed during the time frame.
Low potential categories: C,U,W

Only code sleep (N) if no high, moderate or low potential categories are observed during the time frame.

If both categories are of the same potential

Rule 2 – Amount of time

Record the behaviour the participant was engaged in for the most amount of time.

If both behaviours are of the same potential and last for the same amount of time

Rule 3 – Most extreme ME value

Record the behaviour with the most extreme ME value, regardless of + or – sign.

If both behaviours are of the same potential, last for the same amount of time with the same extremity of ME value

Rule 4 – Latter part of time frame

Record the behaviour engaged in for the latter part of the time frame.

Appendix ii - Dementia Care Mapping: Operational rules for recording Behaviour Category Codes (continued).

Examples:

Rule 1: Order of Precedence

Mary is holding a doll with no signs of positive or negative mood (O+1) and then begins to withdraw and disengage (C-1): Code O+1.

Frances is considerably engaged in talking to Joseph (A+3), she then sits passively engaged in her environment (B+1): Code A+3.

Emma is sitting passively engaged (B+1), she then falls asleep (N): Code B+1.

Harry is walking across the room showing no signs of positive or negative mood (K+1), he then sits down and falls asleep: Code K+1.

Rule 2: Amount of time

Mary is holding a doll with no signs of positive or negative mood (O+1) for four minutes and the passes a brief remark to her relative (A+1): Code O+1.

Maria is staring at the floor for two minutes (C-1) and then sits rocking backwards and forwards with no signs of positive or negative mood for three minutes (W+1): Code W+1.

Rule 3: Most extreme ME value

Mary is holding a doll with no signs of positive or negative mood (O+1) for half the time frame and then begins a sustained positive conversation with a relative (A+3): Code A+3.

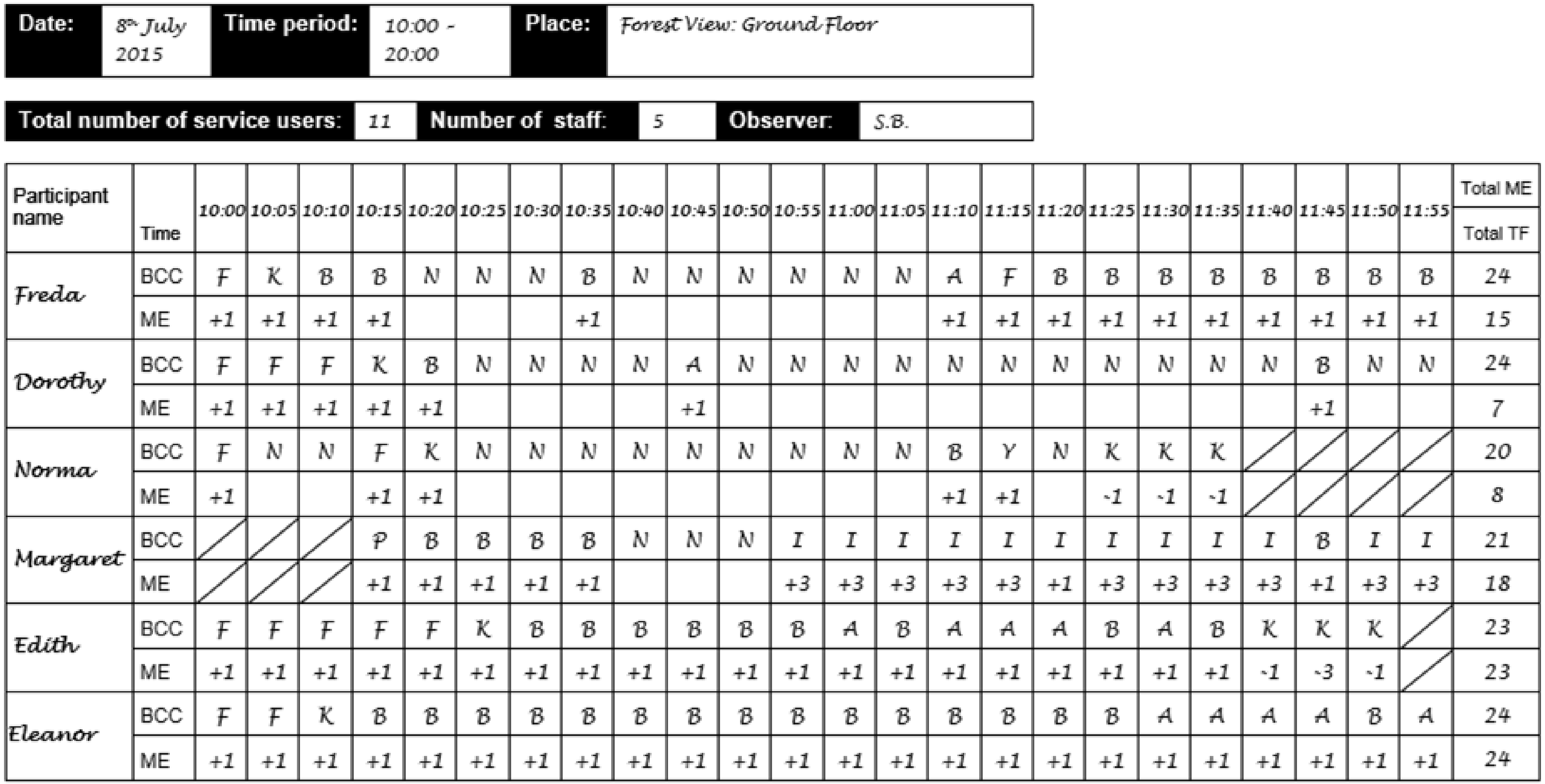
Tony is talking to himself in a highly animated way for half the time frame (Y+3) he then sits watching the television with no signs of positive or negative mood (L+1): Code Y+3.

Gertie is staring blankly at the floor for half the time (C-1), she then gets considerably distressed and begins to cry but receives no response (U-3). Code U-3.

Rule 4: Latter part of time frame

Mary is talking to herself with mild signs of negative mood for 2 ½ minutes (Y-1) and then holds a doll with no signs of positive or negative mood (O+1) for 2 ½ minutes: Code O+1.

Appendix iii - Dementia Care Mapping: Raw data sheet example



Date:	8th July 2015	**Time period:**	10:00 - 20:00	**Place:**	Forest View: Ground Floor
Total number of service users:	11	**Number of staff:**	5	**Observer:**	S.B.

Participant name	Time	10:00	10:05	10:10	10:15	10:20	10:25	10:30	10:35	10:40	10:45	10:50	10:55	11:00	11:05	11:10	11:15	11:20	11:25	11:30	11:35	11:40	11:45	11:50	11:55	Total ME Total TF
Freda	BCC	F	K	B	B	N	N	N	B	N	N	N	N	N	N	A	F	B	B	B	B	B	B	B	B	24
	ME	+1	+1	+1	+1				+1							+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	15
Dorothy	BCC	F	F	F	K	B	N	N	N	N	A	N	N	N	N	N	N	N	N	N	N	N	B	N	N	24
	ME	+1	+1	+1	+1	+1					+1												+1			7
Norma	BCC	F	N	N	F	K	N	N	N	N	N	N	N	N	N	B	Y	N	K	K	K	/	/	/	/	20
	ME	+1			+1	+1										+1	+1		-1	-1	-1	/	/	/	/	8
Margaret	BCC	/	/	/	P	B	B	B	B	N	N	N	I	I	I	I	I	I	I	I	I	I	B	I	I	21
	ME	/	/	/	+1	+1	+1	+1	+1				+3	+3	+3	+3	+3	+1	+3	+3	+3	+3	+1	+3	+3	18
Edith	BCC	F	F	F	F	F	K	B	B	B	B	B	B	A	B	A	A	A	B	A	B	K	K	K	/	23
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	-1	-3	-1	/	23
Eleanor	BCC	F	F	K	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	A	A	A	A	B	A	24
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	24

Blank Raw Data Sheets are available from: https://www.brad.ac.uk/health/dementia/dementia-care-mapping/dementia-care-mapping-data-sheets/ [Accessed 17th August 2018]
Also available from Bradford Dementia Group, 2005. *DCM 8 User's Manual*. Bradford: Bradford Dementia Group, p 129.

Appendix iv – Dementia Care Mapping: Calculating Well and Ill-Being (WIB) Score

(Adapted from Bradford Dementia Group 2005, pp 105-107)

Individual WIB Scores

The calculation for working out the individual WIB score is:

$$\frac{Sum\ of\ the\ relevant\ ME\ values}{The\ total\ number\ or\ relevant\ time\ frames}$$

1. To work out the sum of the relevant ME values, add up all the relevant ME values. An ME value is not relevant and cannot counted if the participant and mapper interacted during the time frame. So for Norma (in the example above: Appendix iv - Dementia Care Mapping: Raw data sheet example) the sum would be:

   +1 +1 +1 +1 +1 -1 -1 -1 = 3

   Always include the + or – sign. This is extremely important when assessing well or ill-being.
2. To find the number of relevant time frames add up the total number of time frames that have an ME value recorded. For Norma, this is 8.
3. Divide the figure from step one with that from step two. In the example above this would be:

   3 ÷ 8 = 0.375

4. Round this figure to the nearest decimal place.
5. Norma's WIB score would be +0.4.

The example used here is just to illustrate the method of calculation. Within the rules of Dementia Care Mapping, in order to calculate a WIB score, the mapper must have ME value data for at least four hours or 48 time frames for the individual.

Group WIB Scores

The group WIB score shows how a group of participants experiences well or ill-being over the course of an observation. This provides a single figure that summarised whether the group as a whole experiences well or ill-being. It is calculated using the following formula:

$$\frac{Sum\ of\ relevant\ ME\ values\ for\ all\ participants}{Total\ number\ of\ relevant\ time\ frames\ for\ all\ participents}$$

1. Add up all the relevant ME values for all participants.
2. Calculate the number of relevant time frames for all participants.
3. Divide the figure from step one with that from step two. This is the WIB score for the group.

Appendix v - Dementia Care Mapping: Personal enhancers and personal detractions

(Adapted from Bradford Dementia Group 2005, pp 72-77)

Personal Detractions

In DCM concrete examples of episodes of a malignant social psychology have been identified. They are called Personal Detractions. There are 17 types of Personal Detractions (PDs) that a mapper may record while observing. These 17 types can be subdivided into categories that undermine the core psychological needs being met.

Undermines conform needs

PD 1.	Intimidation - Making a participant frightened or fearful by using spoken threats or physical power.
PD 2.	Withholding - Refusing to give asked for attention, or to meet an evident need for contact.
PD 3.	Outpacing - Providing information at a rate too fast for a participant to understand

Undermines identity needs

PD 4.	Infantilisation- Treating a participant in a patronising way as if they were a small child.
PD 5.	Labelling – Using a label as the main way to describe or relate to a participant.
PD 6.	Disparagement – Telling a participant that they are incompetent, useless, worthless or incapable.

Undermines attachment needs

PD 7.	Accusation – Blaming a participant for things they have done or not been able to do.
PD 8.	Treachery- Using trickery or deception to distract or manipulate a participant in order to make them do or not do something.
PD 9.	Invalidation- Failing to acknowledge the reality of a participant.

Undermines occupation needs

PD 10.	Disempowerment – Not allowing a participant to use their abilities.
PD 11.	Imposition – Forcing a participant to do something, overriding their own desires or wishes, or denying them choice.
PD 12	Disruption- Intruding or interfering with something a participant is doing.
PD 13	Objectification – Treating the participant as if they were an object.

Undermines inclusion needs

PD 14.	Stigmatisation – Treating the participant as if they were a diseased object, an alien or an outcast.
PD 15	Ignoring- Carrying on (in conversation or action) as if the participant was not there.
PD 16.	Banishment – Sending the participant away or excluding them either physically or psychologically.
PD 17.	Mockery – Making fun of a participant; teasing, humiliating and making jokes at their expense.

Detractions are rated on a two point scale:

Detracting (D)	An episode that mildly or moderately detracts or 'puts down' the participant
Highly Detracting (hD)	An episode that severely or very severely detracts or 'puts down' the participant

Appendix v - Dementia Care Mapping: Personal enhancers and personal detractions (continued).

Personal Enhancers

Personal Enhancers provide a record of positive person work observed in a care setting. There are 17 types of Personal Enhancers (PDs) that a mapper may record while observing. These 17 types can be subdivided into categories that support the core psychological needs being met.

Supporting conform needs

PE 1. Warmth – Demonstrating genuine affection, care and concern for the participant.
PE 2. Holding – Providing safety, security and comfort to a participant.
PE 3. Relaxed Pace – Recognising the importance of helping to create a relaxed atmosphere.

Supporting identity needs

PE 4. Respect – Treating the participant as a valued member of society and recognising their experience and age.
PE 5. Acceptance – Entering into a relationship based on an attitude of acceptance or positive regard for the participant.
PE 6. Celebration – Recognising, supporting and taking delight in the skills and achievement of a participant.

Supporting attachment needs

PE 7. Acknowledgement – Recognising and attempting to support the participant as unique and valuing them as an individual.
PE 8. Genuineness – Being honest and open with the participant in a way that is sensitive to their needs and feelings.
PE 9. Validation – Recognising and supporting the reality of the participant. Sensitivity to feelings and emotions takes priority.

Supporting occupation needs

PE 10. Empowerment – Letting go of control and assisting the participant to employ their skills.
PE 11. Facilitation - Assessing the level of support required and providing it.
PE 12. Enabling – Recognising and encouraging a participant's engagement.
PE 13. Collaboration – Treating a participant as a full and equal partner in what is happening, consulting with them.

Supporting inclusion needs

PE 14. Recognition – Meeting the participant in his or her own uniqueness, bringing an open and unprejudiced attitude.
PE 15. Including – Enabling and encouraging the participant to feel included, physically and psychologically.
PE 16. Belonging – Providing a sense of acceptance in a particular setting regardless of disability.
PE 17. Fun – Accessing a free, creative way of being and using and responding to humour.

Enhancers are rated on a two point scale:

Enhancing (E)	An episode that is supportive of the personhood of the participant and shows use of interpersonal skills on behalf of the care worker.
Highly Enhancing (hE)	An episode that is highly supportive of the personhood of the participant and shows use of a high level of interpersonal skills on behalf of the care worker.

Appendix vi – Person-Centred Care Assessment Tool

As presented to care staff during activities workshops (page 1).

The Person-Centred Care Assessment Tool (P-CAT)

Instructions for use:

This questionnaire aims to measure the extent to which the care within this facility is experienced by staff as being person-centred. The questionnaire consists of 13 statements about the care. You are asked to decide to what extent you think the statements correspond to your own experiences working in Forest View. Please put a cross in the box for the alternative that you think best describes your experience. It is important that you answer all the statements, so if you feel uncertain, pick the alternative closest to your experience

Thank you for your time.

Appendix vi – Person-Centred Care Assessment Tool (P-CAT)
(As presented to care staff during activities workshops, continued, page 2).

The Person-Centred Care Assessment Tool

	Disagree completely 1	Disagree 2	Neither agree or disagree 3	Agree 4	Agree completely 5
1. We often discuss how to give person-centred care	☐	☐	☐	☐	☐
2. We have formal team meetings to discuss residents' care.	☐	☐	☐	☐	☐
3. The life history of the residents is formally used in the care plans we use	☐	☐	☐	☐	☐
4. The quality of the interaction between staff and residents is more important than getting the tasks done.	☐	☐	☐	☐	☐
5. We are free to alter work routines based on residents' preferences.	☐	☐	☐	☐	☐
6. Residents are offered the opportunity to be involved in individualized everyday activities.	☐	☐	☐	☐	☐
7. Assessment of residents' needs is undertaken on a daily basis.	☐	☐	☐	☐	☐
8. I simply do not have the time to provide person-centred care.	☐	☐	☐	☐	☐
9. The environment feels chaotic.	☐	☐	☐	☐	☐
10. We have to get the work done before we can worry about a homelike environment.	☐	☐	☐	☐	☐
11. This organization prevents me from providing person-centred care.	☐	☐	☐	☐	☐
12. It is hard for residents in this facility to find their way around.	☐	☐	☐	☐	☐
13. Residents are able to access outside space as they wish.	☐	☐	☐	☐	☐

Appendix vii – Person-Centred Care Assessment Tool: Scoring notes

The following scoring notes were received by email from Dr Deirdre Fetherstonhaugh (co-author of: 'Development and initial testing of the Person-centred Care Assessment Tool') on 14th August 2015.

NOTES ON SCORING OF THE PERSON-CENTRED CARE ASSESSMENT TOOL (P-CAT)

The 13-item P-CAT was constructed to evaluate to what extent staff in residential aged care perceive the care provided as being person-centred (Edvardsson et al., 2010). The P-CAT consists of three subscales covering the following dimensions of person-centredness: extent of personalizing care; amount of organizational support; and degree of environmental accessibility. Completion of the P-CAT involves asking members of staff to provide self-report ratings on items regarding aspects of person-centredness on a five-point Likert-scale ranging between '1=disagree completely' and '5=agree completely'. Those variables that were negatively worded were reverse coded to match other variables for the purpose of data analysis.

Normal distributions and means tests:

Items within each of the three subscales can be summed to generate subscale scores, as well as summing the total 13 items to generate a total score between 13 and 65, where higher scores indicate higher person-centredness. The P-CAT has satisfactory estimates of reliability (Cronbach's alpha 0.84) as well as tentative validity (Edvardsson et al., 2010).

A median split of P-CAT scores can be used to dichotomize respondents into high and low levels of person-centredness (pcc) for the t-test. Further relationships can be tested using the total summed score and the dichotomized variable with continuous and categorical variables.

Initial exploratory analysis would pick up whether providing a 'means' or 'median' would be an appropriate statistic to use.

Non normal distributions and crosstab analysis:

The scales can be collapsed into 3 points where *completely disagree/disagree*=total disagreement, *neither agree nor disagree*=neither, and *agree/completely agree*=total agreement. This helps with meeting assumptions for the chi square analysis by boosting cell numbers and enables responses to be categorised into the two variables of interest – disagree or agree for further analysis.

For the PCAT subscales of 'Extent of Personalizing Care' (PCAT 1-6, PCAT 11); 'Amount of Organisational Support' (PCAT 7-10 reverse scored) and 'Degree of Environmental Accessibility' (PCAT 12-13)), a score can be computed to enable groupings of levels of pcc. In comparison to the median split into high and low levels of person-centredness based on a total summed score, a more conservative approach can be used to split a summed subscale score into three groups of low, medium and high levels of pcc. For purposes of ease of understanding the levels of pcc are equated to the collapsed responses on the P-CAT scale of 'total disagreement', 'neither' and 'total agreement'. The maximum score that equates to 'low pcc' for the subscale of 'extent of personalizing care' (1 or 2 on the agreement scale) is 14 and the minimum score that equates to 'high pcc' on the same subscale (4 or 5 on the agreement scale) is 28. These scores are the critical points for 'low pcc' and 'high pcc'. The remaining scores between 14 and 26 are allocated 'medium pcc'.

Indications of a more person-centred approach by staff at one facility compared to another facility would be based on the differences in the percentage of responses in the 'high pcc' grouping for the factor 'Extent of Personalising Care'.

An example is given below:

For PCAT 1-6 and PCAT 11 these make up factor 1 – 'Extent of Personalising Care'. Sum these scores i.e. score 4 for 3 statements and 5 for 4 statements out of a total of 7 statements for this subscale and that equals 32 out of a total subscale score of 35 resulting in categorisation of 'high pcc' level as the cut-off score is 28. To get facility levels of pcc you would look at the proportion of scores that are 'low pcc', 'medium pcc' and 'high pcc'. You would then evaluate what is appropriate but consider that greater than 20% of respondents in the 'low pcc' category would be cause for intervention.

Please be aware that this scoring under *Non normal distributions and crosstab analysis* is not based on any benchmarks within the sector regarding person-centred care.

Reference:

Edvardsson, D., Fetherstonhaugh, D., Gibson, S. and Nay, R. (2010). Development and initial testing of the Person-centred Care Assessment Tool (P-CAT). *International Psychogeriatrics*, 22, 101-108.

Appendices viii – Information Sheets and Consent Forms

Appendix viii.i - Information Sheet for Residents Living with Dementia (page 1)

Promoting Wellbeing for People with Memory Problems Living in Care Homes

Photograph of the researcher

Thank you for taking the time to read this information sheet.

My name is Sophie Bushell. I am a PhD student at Bournemouth University and I am doing a research project about promoting wellbeing in care homes by introducing activities. To do this I need your help.

I would like to ask you about the activities you would like to do, either in Forest View or out in the community. With the help of staff in this home I would like to support you to do these activities and see if they improve your wellbeing. I would like to watch you doing the activities and ask you questions about how they make you feel.

From time to time I might ask if I can make an audio recording our conversations. This will help me to remember which activities you have done and what you have said. Any information I collect will be confidential and held securely at Bournemouth University. It will only be

Appendix viii.i continued (page 2).

I hope that you will choose to take part in this study however, you don’t have to if you don’t want to and if you do decide to participate you can withdraw at any time without having to give an explanation. If you don’t want to take part you will still receive the same care.

If you have any questions or concerns, please feel free to contact me by letter or telephone. Or you can ask me anything when I visit Forest View. My contact details are:

Sophie Bushell,
Room 101 Executive Business Centre,
89 Holdenhurst Road,
Bournemouth, BH8 8EB

Telephone: 01539 xxxxxx or 07xxxxxxxxx

If you have any concerns or complaints about this project you can take them to xxxxxx xxxxxx, Deputy Dean for Research and Professional Practice at Bournemouth University. Her contact details are:
Royal London House R118,
Christchurch Road,
Bournemouth, BH1 3LT.
Telephone 01202 xxxxxx
If you would like to take part in this study I will ask you to sign a consent form.

Appendix viii.ii – Consent Form for Residents Living with Dementia (page 1)

Consent Form

Promoting Wellbeing for People with Memory Problems Living in Care Homes

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Please tick or initial the box if you agree

I confirm that I have read and understood the information sheet for the above study and that I have been able to ask questions. ☐

I understand that my participation is voluntary and I am able to withdraw from the study at any time, without giving any reason. ☐

I understand that all information, including interview responses, will be kept confidential. ☐

I agree that audio recordings may be taken. ☐

I agree that the data can be used on condition that they are kept confidential and anonymised (this means that all identifying features about you will be removed). ☐

I understand that all data will be stored safely, and only seen by members of the research team. ☐

I agree to take part in the above study. ☐

Please turn over

Appendix viii.ii continued (page 2).

Please print, sign and date below:

Participant Name	Signature	Date
Researcher Name	Signature	Date

Thank you for your participation.

If you have any queries, please do not hesitate to contact:

Sophie Bushell on 07xxxxxxxxx or 01539 xxxxxx

Appendix viii.iii – Information Sheet for Relatives (page 1)

Promoting wellbeing for people with dementia living in care homes

Sophie Bushell, Student at Bournemouth University

✉ Room 101 Executive Business Centre, 89 Holdenhurst Road, Bournemouth, Dorset, BH8 8EB

☎ 01539 xxxxxx or 07xxxxxxxxx

@ sophie.bushell@bournemouth.ac.uk

Thank you for taking the time to read this information sheet.

My name is Sophie Bushell and I am a student at Bournemouth University. I am very interested in looking at ways to improve the wellbeing of people with dementia who live in long-term care. My PhD project looks at the benefits of supporting people with dementia to take part in activities that they have chosen themselves. Forest View is funding part of this study as they are also interested in improving wellbeing in this care home.

With your permission, I would like [insert name of resident] to take part in this research. Before you decide, it is important for you to understand why this research is being done and what it will involve. Please read the following information carefully and contact me if there is anything that is not clear or if you have any questions about this project, my details are at the top of this sheet.

What is the purpose of this study?

This study will explore whether engaging in activities will improve wellbeing for people with dementia living in care homes. This information can be used to improve care practices in Forest View as well as other care homes and to make life better for people with dementia.

Why has my relative been chosen?

Your relative has been chosen as they are living with dementia or memory problems and live in a care home.

What will happen if my relative does take part?

I would like to ask [insert name of resident] which activities they used to do before they came into the care home and which activities they would really like to do now. The carers at Forest View and I will

Appendix viii.iii continued (page 2).

then try and support [insert name of resident] to do this activity. We will make sure that we do not do any activities which may cause physical or psychological harm beyond what might be expected in everyday life.

While [insert name of resident] is participating in activities I would like to observe them to see if their participation improves their wellbeing. I would also like to ask them a few questions about what they thought of the activities and how the activities made them feel. I will audio record these conversations so that I have a record of what was said.

Does my relative have to take part?

No. It is up to you to decide whether or not you wish [insert name of resident] to take part. If you do decide that you are happy for him/her to take part I will ask you to sign a consent form. You are free to withdraw consent at any time, up until the point that data is anonymised, and without giving a reason. A decision to withdraw from this study, or a decision not to take part, will not affect the standard of care your relative receives.

What are the possible disadvantages and risks of taking part?

It is possible that [insert name of resident] might become distressed when taking part in activities, being observed or being asked questions by me. If this happens, I will stop observing / interviewing and try to comfort them immediately. Members of staff who know your relative well will also be around to help me.

What are the possible benefits of taking part?

Evidence suggests that activity participation is likely to have therapeutic benefits for people living in care and improve their wellbeing. In addition, the information we get from this study should help us in understanding the experiences of other people with dementia.

Will information be kept confidential?

All information which is collected about your relative during the study will be kept strictly confidential and anonymised. Any audio recordings of conversations will be destroyed as soon as they have been transcribed.

Appendix viii.iii continued (page 3).

What will happen to the results of the study?

The results of this study will be published as my Ph.D. thesis and as short reports to the care home to help them to provide better care. I will be giving a short presentation about the findings of this project in early 2016 or, if you would prefer, I could send you a short summary of my findings.

What other information might be collected?

I would like to ask your consent to include any quotes from your relative that might illustrate my findings. Any quotes I would use would be kept anonymous: no personal details about your relative would be included. If you are not happy for me to use quotes, don't worry; just leave the box on the consent form blank.

What if I have a complaint about this project?

If you have any concerns or complaints about this project you can contact xxxxxx xxxxxx, Deputy Dean for Research and Professional Practice at Bournemouth University using the details below:

Royal London House R118,
Christchurch Road, Bournemouth,
BH1 3LT
(01202) xxxxxxx
xxxxxxx@bournemouth.ac.uk

Please keep this sheet for future reference. If you are happy for [insert name of resident] to take part, please could you initial and sign one of the enclosed consent forms and post it to me in the stamped, addressed envelope (also enclosed) and keep the other copy for your reference. Please feel free to contact me if you have any questions or concerns.

Thank you

Sophie Bushell

Appendix viii.iv – Information Sheet for Staff Members (page 1)

Promoting wellbeing for people with dementia living in care homes

Sophie Bushell, PhD Student at Bournemouth University
Room 101 Executive Business Centre, 89 Holdenhurst Road, Bournemouth, Dorset, BH8 8EB
01539 xxxxxx or 07xxxxxxxxx

Thank you for taking the time to read this information sheet.

My name is Sophie Bushell and I am a student at Bournemouth University. I am interested in looking at ways to improving wellbeing for people with dementia who live in long-term care. My PhD project looks at the benefits of supporting people with dementia to take part in activities that they have chosen themselves. Forest View is funding part of this study as they are also interested in improving wellbeing in this care home. You might have met me during the past year as I have visited Forest View in order to get to know you and your residents better.

There are already some great activities going on at Forest View and I want to help to make this even better. I plan to ask residents which activities they used to do before they came to the care home and which activities they would like to do now. I would then like your help to support residents to do the activities that they have chosen. Alex and I will hold workshops with staff to plan how best we can do this.

If you agree to take part in this research project, I would like you to:

- Attend a workshop to plan and discuss how best we can support residents to take part in activities that they have chosen to do
- Support residents to take part in these activities
- Allow me to observe you supporting the residents doing activities
- Reflect upon your own care practices by filling in a simple questionnaire
- Sign a consent form saying you are happy to take part

Your participation will be voluntary and you can withdraw your consent at any time.

Appendix viii.iv continued (page 2).

If you have any concerns or complaints about this project you can contact xxxxxxx xxxxxx, Deputy Dean for Research and Professional Practice, HSS at Bournemouth University using the details below:

Address: Royal London House R118, Christchurch Road, Bournemouth, BH1 3LT

Telephone: 01202 xxxxxx Email: xxxxxx@bournemouth.ac.uk

I look forward to working with you over the coming weeks. If you have any questions do feel free to ask me when I next visit or contact me using the details above.

Appendix viii.v – Consent Form for Staff Members

Consent Form

Promoting wellbeing for people with dementia living in care homes

Please tick or initial
the box if you agree

I confirm that I have read and understood the information sheet for the above study and that I have been able to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason up until the point at which any data is anonymised.	☐
I understand that at the end of this research study a report will be written	☐
I understand that I will not be identified personally in any part of the research	☐
I give my consent for observations to be made of interactions between myself and people with dementia	☐
I agree to take part in the above study	☐

Please print, sign and date below:

Name	Signature	Date
Researcher Name	Signature	Date

Thank you for your participation.

If you have any queries, please do not hesitate to contact me:
Sophie Bushell on 07xxxxxxxxx or (01539) xxxxxx

Appendix ix - Extract from Raw Field Notes

8th July 2015
10:00 – 20:00 (10 hours)
Ground Floor: Freda, Dorothy, Norma, Margaret, Edith, Eleanor

10:00 – When I arrive on the floor there are five residents in the communal area on the lounge. They are engaging eating breakfast. It is a beautiful summer's morning and some of the windows are open to let that fresh air in, the whole feel of the home is light, airy and calm. It feels like a very pleasant place to be. Some of my residents chose to eat their breakfast in the dining room (Dorothy, Eleanor and Edith), while others are happily eating in the lounge (Norma and Freda). I have a sense of the carers being about attending to people in their own rooms.

10:06 – During the last timeframe residents have continued to eat their breakfast or sip tea intermittently, other than that they just sit quietly. They do not appear to be engaging with each other or with staff members who in any case I haven't seen. Norma has fallen asleep slumped in front of her breakfast, Freda stands up and looks around her before sitting back down.

10:10 – Nothing to report during this time frame. Some residents continue to eat showing no sign of positive or negative mood. Eleanor has walked into the lounge and sat in her favourite chair next to the TV.

10:14 – Not a lot has happened during the last 10 min, none of my residents have interacted with anyone. Dorothy has moved into the lounge. Norma is asleep. The others look bored. Margaret is wheeled into the lounge by a carer. She puts Margaret beside a table at the back of the room says 'here you go then' and walks away. There is no time for Margaret to respond. The interaction is minimal and Margaret shows no signs of positive or negative mood.

10:21 – Freda is now asleep too but the others are looking bored. Margaret, Dorothy and Eleanor both stare into the middle distance.

10: 23 – Norma wakes. She rises and stands by her chair. She stands there for a few moments as if contemplating where to go and then sits back down. She appears to fall asleep almost instantly.

10:25 – Three of my residents have now fallen asleep, the others are still awake but are passively just watching their surroundings with no other activity.

10:35 – Very little has happened my residents are all sitting alone either passively looking around them or fast asleep in their chairs. In the first 30 minutes I have not seen any of my residents speak to anyone.

10:40 – Very little has happened during the last 5 min. In fact very little has happened since I arrived on the floor 45 min ago. I have not seen any of my six residents engaged or interact with another person during the last 45 min. I have rarely seen a carer either, only as they passed through the lounge on their way from one wing of the home to the other. The residents are not seeking interaction however a quarter of an hour is a long time to sit in silence apparently not engaged in anything at all. Dorothy, Norma, Freda and Margaret are now asleep. Eleanor and Edith sit passively and occasionally glance up to indicate that they are passively engaged with their surroundings.

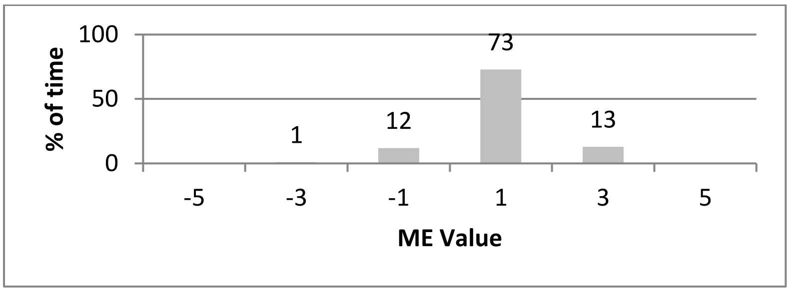
Appendix x - Individual Care Summary Example

Individual Care Summary - Dorothy
8th July 2015

1. Dorothy

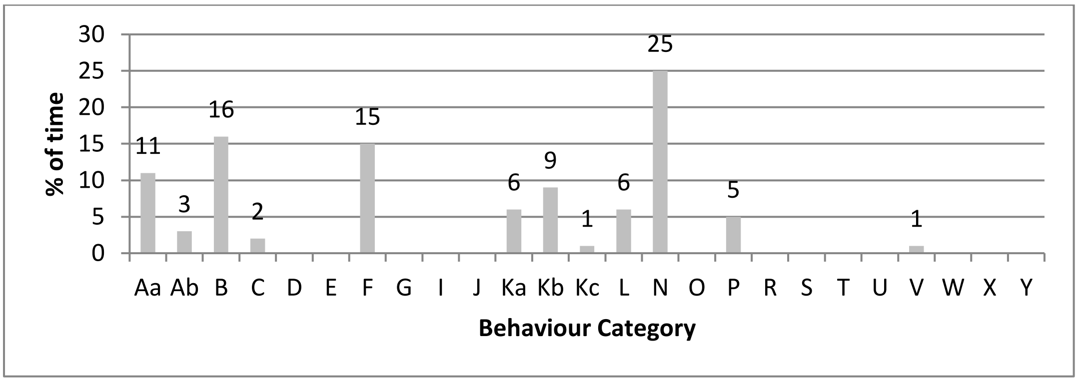
Dorothy is 78 and had a diagnosis of Alzheimer's disease. She has six children, many of whom lived close by and came to visit her reguarly. Dorothy keeps an album with photographs of her husband beside her bed and sometimes looks through it when she is missing him. On this afternoon, Dorothy became distressed as she appeared to be waiting for her children and husband to return from school and work.

2. Profile of wellbeing



Individual WIB score +1.0

3. Behaviour codes



Top 5 BCC: N - 25%, **B** – 16%, **F** – 15%, **Aa** – 11%, **Kb** – 9%

4. Psychological needs

16:31 – Dorothy: Pe 16 (inclusion, belonging, enhancing) carer involves Dorothy in conversation about her day

17:37 – Dorothy: Pe 2 (comfort, holding, enhancing) the carer attempts to sooth Dorothy when she feels upset, offering her comfort

Appendix x - Individual Care Summary Example (continued, page 2).

17:43 – Dorothy: Phe 2 (comfort, holding, highly enhancing) the carer skilfully offers Dorothy comfort and hugs her on the sofa as she fells upset

18:39 – Dorothy: Pd 9 (attachment, invalidation, detracting) the carer fails to acknowledge Dorothy's reality when she is trying to find her husband and family

19:35 – Dorothy: Phe 1 (comfort, warmth, highly enhancing) carer offers Dorothy warmth and affection and gives her a relaxing head massage

5. Comments about mood, engagement and wellbeing

- The behaviour that Dorothy engaged in most during this day was sleeping (N – 25% although this is probably much higher as she was not mapped between 14:20 and 15:35 during which the carers reported that she slept). Despite expressing a wish to join the trip to the pub, the carers and/or activity coordinator decided not to wake her when the time came and so she missed out engaging in this activity. Dorothy had not slept well during the previous night and did not sleep well during the night following this day. Is it possible that if she were engaged more during the day (and slept less) she would sleep better at night?
- Dorothy spent 16% of her time walking around the home. During this time she was expressing distress as she was worried that her family had not come home and was trying to look for them.
- Dorothy's mood elevated when she engaged in watching the tennis on the TV. Is it possible that if the TV is on it could show sports like this rather than usual day time TV that residents don't often engage with?
- Dorothy experiences the most PEs relating to 'comfort' as carers attempted to comfort her when she became distressed during the early evening. When a carer had some free time she spent 30 minutes giving Dorothy a head massage which Dorothy appeared to really enjoy.

Appendix xi - Group Care Summary Example

Group Care Summary
8th July 2015
10 hours (10:00-20:00)
Ground Floor: Dorothy, Norma, Margaret, Eleanor, Freda, Edith

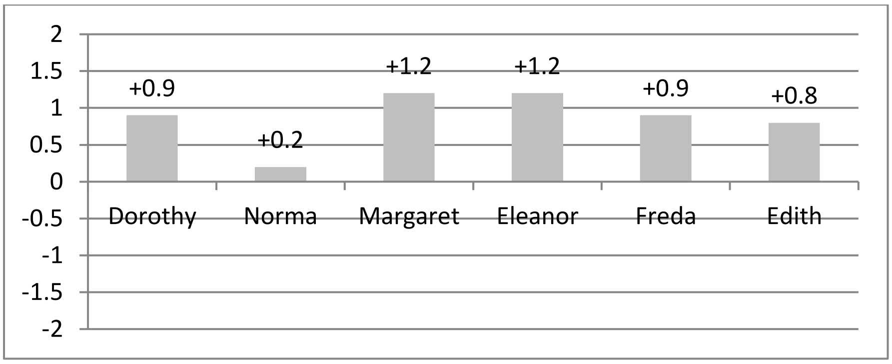
1. Overview

This Group Care Summary is drawn from Dementia Care Mapping observed on the ground floor of Forest View on 8th July 2015 between 10am and 8pm. In total six residents were observed on this day. There are a total of 17 residents on this floor, five members of care staff (although one care staff is one-to-one with a resident and sits with her all day) and one registered nurse: Ratio one carer to four residents plus one nurse for all 17. On this day the nurse came from an agency but all of the carers are permanent members of staff.

Both activity coordinators were working today. The planned activities were word searches in the morning and a trip to the pub in the afternoon.

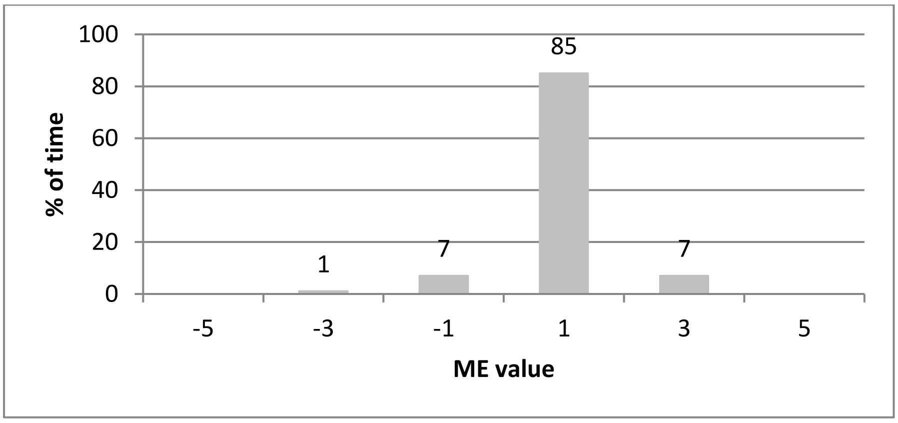
2. Well and ill-being scores

2.1 Individual WIB scores:



Mean WIB score +0.9

2.2 Group WIB profile:



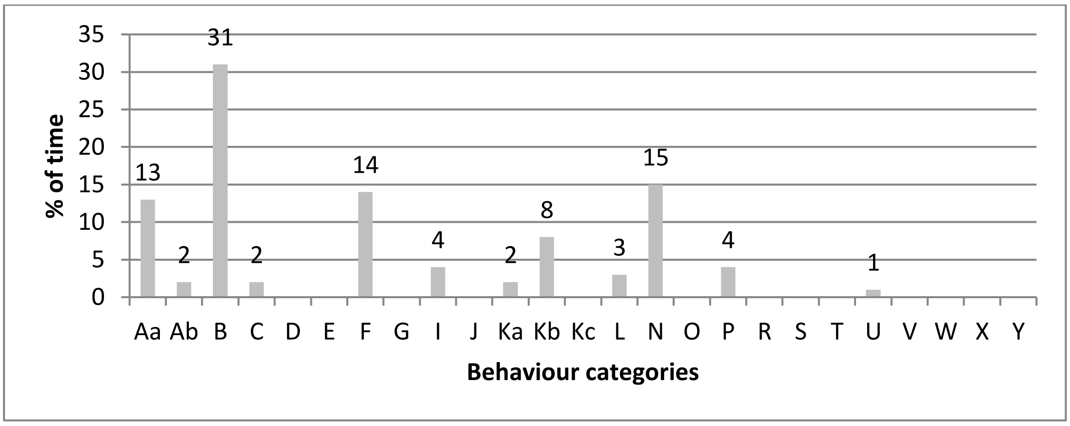
Appendix xi - Group Care Summary Example (continued, page 2).

2.3 WIB summary

- During the vast majority of the day 85% the group showed no signs of positive or negative mood
- 7% of the day was spent in considerable positive mood or engagement; the group did not spend any time showing exceptional levels of mood or engagement.
- 7% of the day was spent in slight negative mood or disengagement and 1% in considerable negative mood. None of the residents spent any time in exceptional negative mood.
- The group had a total WIB score of 0.9 which is a tenth of a percentage point below a neutral mood (+5 exceptional levels of mood and engagement, - 5 exceptional negative mood, +1 fairly neutral)

3. Behaviour codes

3.1 Behaviour Categories



Top 5 BCC: B - 31%, **N** - 15%, **F** – 14%, **Aa** – 13%, **Kb** – 8%

3.2 BCC Summary

- The behaviour engaged in for the largest part of the day by the group as a whole was B, occasionally showing casual interest in their surroundings without sustained engagement. What this meant in practice was that often residents would spend long periods of the five minute time frame looking at the floor or out in front of them and occasionally made a movement or looked around them showing a little interest in their surroundings. When they were in 'B' the residents showed no signs of positive or negative mood.
- As a group, the residents spent 15% of their time asleep in communal areas (N).
- 14% of the groups' day was spent eating or drinking, this was often done in silence.
- As a group, residents spent 13% of their time in Aa; brief verbal or non-verbal interaction with others. This often meant that a resident spent the majority of the timeframe unengaged and only a few moments in brief interaction communication; 'Aa' was coded however due to the priority of coding categories. Periods of communication were often very short and often did not last longer than 5 seconds.

Appendix xi - Group Care Summary Example (continued, page 3).

- The group spent 8% of the day walking around from place to place e.g. from the dining room to the lounge. This was usually done alone and in silence.
- In total the group spent 51% of their time in behaviours associated with passivity and disengagement, 39% in tasks for care and physical maintenance 9% in positive and meaningful activities.

4. Psychological needs

4.1 Enhancing and detracting interactions

Psychological Need	Highly detracting	Detracting	Enhancing	Highly enhancing
Comfort			2	2
Identity			1	3
Attachment		2		
Occupation		1	3	
Inclusion		1	3	1
Total		**4**	**9**	**6**

4.2 Personal enhancers and detractors observed

Comfort

16:25 – Edith: Pe 3 (relaxed pace, enhancing) the nurse lets Edith take her time when taking her medication and does not try to hurry her

17:37 – Dorothy: Pe 2 (holding, enhancing) the carer attempts to sooth Dorothy when she feels upset, offering her comfort

17:43 – Dorothy: Phe 2 (holding, highly enhancing) the carer skilfully offers Dorothy comfort and hugs her on the sofa as she fells upset

19:35 – Dorothy: Phe 1 (warmth, highly enhancing) carer offers Dorothy warmth and affection and gives her a relaxing head massage

Identity

Pub – Eleanor: Pe 6 (celebration, enhancing) the activity coordinator congratulates Eleanor when she gets the answers right during the pub quiz

16:35 – Margaret: Pe 6 (celebration, enhancing) Margaret shows the activity coordinator the word search she has done and the activity coordinator congratulates her

Appendix xi - Group Care Summary Example (continued, page 4).

16:47 – Edith: Pe 4 (respect, highly enhancing) the care worker asks Edith 'may I escort you to dinner madam' employing humour and respect that Edith positively responds to

16:50 – Eleanor: Pe 4 (respect, highly enhancing) as above

Attachment

17:16 – Edith: Pd 9 (invalidation, detracting) the carer fails to acknowledge that Edith feels unwell and does not offer her any comfort

18:39 – Dorothy: Pd 9 (invalidation, detracting) the carer fails to acknowledge Dorothy's reality when she is trying to find her husband and family

Occupation

11:11 – Margaret: Pe 12 (enabling, enhancing) Margret is given a word search to do

13:55 – Eleanor: Pe 11 (facilitation, enhancing) the carer gently and skilfully encourages Eleanor to participate in the afternoons activity and helps her to put on her shoes and coat

Pub – Eleanor: Pe 10 (empowerment, enhancing) Eleanor is assisted to employ her abilities and skills during the pub quiz

18:03 – Eleanor: Pd 11 (imposition, detracting) carer overrides Eleanor's wishes when she asks to go to bed the carer asks her to wait

Inclusion

11:45 – Edith: Pd 15 (ignoring, detracting) Edith is ignored when she tells the nurse she is feeling unwell

Pub – Eleanor: Pe 15 (including, enhancing) Eleanor is asked what she would like to drink and supported to feel part of the pub experience

15:45 – Eleanor: Pe 17 (fun, highly enhancing) the maintenance man and Eleanor have fun gently joking and flirting with one another

16:31 – Dorothy: Pe 16 (belonging, enhancing) carer involves Dorothy in conversation about her day

16:31 – Freda: Pe 16 (belonging, enhancing) carer involves Freda in conversation about her day

5. General points

- As a group, the behaviour most engaged in by the group was sitting in silence watching their surroundings. There were many instances where it was noted that individuals sat in silence for prolonged periods of time (over an hour):

Appendix xi - Group Care Summary Example (continued, page 5).

> *10:45 - […] very little has happened since I arrived on the floor 45 min ago. I have not seen any of my six residents engaged or interact with another person during the last 45 min. I have rarely seen a carer either, only as they passed through the lounge on their way from one wing of the home to the other*
>
> *11:05 - […] in over an hour I've only seen two out of the six of my participants interact with another human being and this interaction was very brief*

Often when staff members do interact with residents their interactions are very short:

> *12:00 – […] Interactions between residents and staff do not often transcend more than one time period, and very often resident staff interactions last less than 10 seconds*

- It was noticeable that despite the high staff/resident ratio staff were busy with task oriented care and did not have the time to spend sitting with residents and interact with them. When staff members did get a few moments free they would spend time with residents (although this could be was cut short to attend to other tasks):

> *18:31 – The carer engages Dorothy and Freda in conversation asking them if they have had a nice day and asking them what they have been doing […] The emergency buzzer causes her to break her conversation abruptly as she has to leave*
>
> *19:35 – The carer sitting with Dorothy offers her a head massage. Dorothy says she would like one and the carer begins to massage her head*

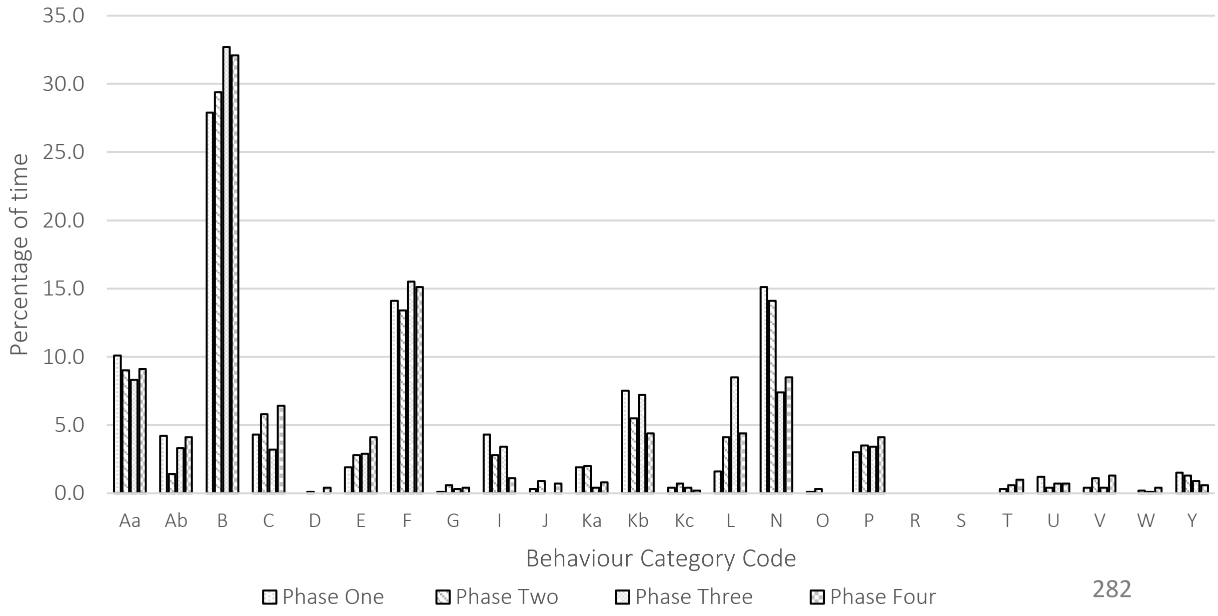
Late afternoons were the time when carers generally had more time to spend with the residents, during the morning there was very little interaction between carers and residents beyond what was necessary to complete care tasks.

- The activity coordinator and assistant were relied upon to provide the activities on the floor. When the residents were not engaged in the activities provided by the activities staff they were not engaged in any activity:

> *15:40 – Upon returning to the floor from the pub I find that Freda, Norma and Dorothy are sitting exactly as I left them, either asleep or passive engagement in their surroundings. […] EK has returned to the floor and sits alone by the nurses station occasionally looking around her. […] I ask a carer what residents have been doing while we have been out. She answers 'umm nothing really'.*

Appendix xii - Behaviour Category Codes: A breakdown by phases one to four

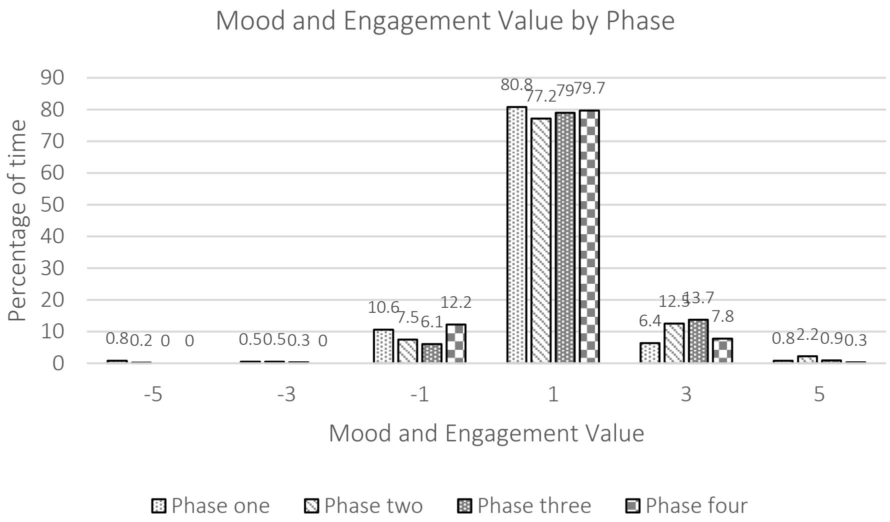
Behaviour Category Code	Percentage of time in BCCs				Av. Time in BCCs (phases 1-4)
	Phase One	Phase Two	Phase Three	Phase Four	
Aa	10.1	9	8.3	9.1	9.1
Ab	4.2	1.4	3.3	4.1	3.3
B	27.9	29.4	32.7	32.1	30.5
C	4.3	5.8	3.2	6.4	4.9
D	0	0.1	0	0.4	0.1
E	1.9	2.8	2.9	4.1	2.9
F	14.1	13.4	15.5	15.1	14.5
G	0.1	0.6	0.3	0.4	0.4
I	4.3	2.8	3.4	1.1	2.9
J	0.3	0.9	0	0.7	0.5
Ka	1.9	2	0.4	0.8	1.3
Kb	7.5	5.5	7.2	4.4	6.2
Kc	0.4	0.7	0.4	0.2	0.4
L	1.6	4.1	8.5	4.4	4.7
N	15.1	14.1	7.4	8.5	11.3
O	0.1	0.3	0	0	0.1
P	3	3.5	3.4	4.1	3.5
R	0	0	0	0	0.0
S	0	0	0	0	0.0
T	0	0.3	0.6	1	0.5
U	1.2	0.4	0.7	0.7	0.8
V	0.4	1.1	0.4	1.3	0.8
W	0	0.2	0.1	0.4	0.2
Y	1.5	1.3	0.9	0.6	1.1
Total	99.9	99.7	99.6	99.9	99.8

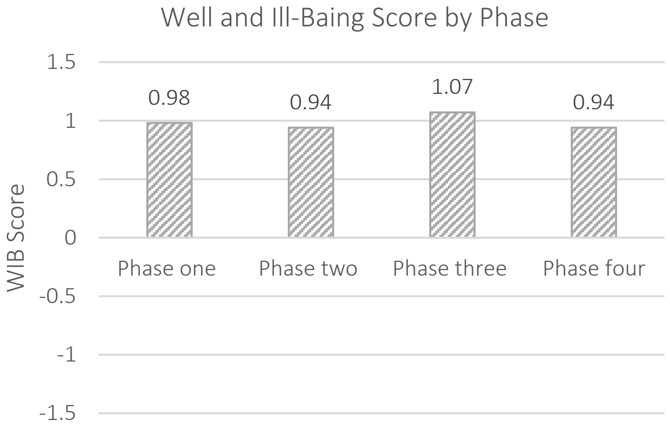


Behaviour Category Codes by Phase

Appendix xiii – Mood and Engagement Values: A breakdown by phases one to four

Mood and Engagement Value	Percentage of time in ME Value				Average time in ME value (phases 1-4)
	Phase one	Phase two	Phase three	Phase four	
-5	0.8	0.2	0	0	0.3
-3	0.5	0.5	0.3	0	0.3
-1	10.6	7.5	6.1	12.2	9.1
+1	80.8	77.2	79	79.7	79.2
+3	6.4	12.5	13.7	7.8	10.1
+5	0.8	2.2	0.9	0.3	1.1





Average WIB score by phase:

Phase one: +0.98
Phase two: +0.94
Phase three: +1.07
Phase four: +0.94
Average: +1.0

Appendix xiv - Plan for Activities Workshops with Staff

(Personal notes)

Sessions to run in the training room of FV from 14:00 – 16:00 with approx. 6 -8 care staff in each

Aim of session:
To discuss with staff how we might, as a team, begin to deliver self-chosen activities in FV

Previous knowledge:
Basic knowledge about person-centred care. Good knowledge of their residents as individuals and access to care plans detailing residents preferences for activities

Objectives:
To give information about which activities residents have reported that they like to do and discuss how to facilitate these with a view to making activity and care delivery more person-centred.

Support materials:
Large sheets of paper and pens, chocolate biscuits , PP presentation of DCM results, DCM handouts, P-CAT handouts

Detailed Plan

Time	Objectives & Details	Teaching Method
14:00	Welcome and introductions, housekeeping, ground rules etc.	/
14:05	Ask staff to fill in P-CAT tool	Researcher
14:15	Talk to the carers about what the terms ‘person-centred’ and ‘activities’ mean (emphasise that activity interventions are not only the responsibility of the activity coordinator). Give example: Dorothy and the head massage. Sitting having a cup of tea. These are quick and easy that anyone can do. Clarify what I mean by activity.	Researcher
14:20	Explain DCM and hand-out. Explain DCM. Give simple hypothetical examples. This is only a snap shot so I can only observe what I see when I’m there! Give examples of behaviours. Compare with activity session. Seems to show that activities can promote wellbeing. Feedback what I observed from my DCM and observations. Highlight where I saw good practice and where there might be room for improvement. It’s not just the role of the activity coordinator.	Researcher
14:30	Talk about the residents what they used to do / would like to do on a daily basis. Share my findings about what residents said they would like to do?	Researcher
14:50	Ask carers to think about the activities they could do with carers in their every day care delivery. Tell me who you cared for this morning, what did you do with them. Identify what is an activity. Try and change their mind set and approach. Might not appreciate the quality of what you are doing but it is good. Always look from point of view of the resident. Daily routine what is his day like? What happens when people don’t engage in the formal activities? Organised and spontaneous activities. Offer examples first (e.g. reintroducing the laundry corner where residents could take part in housework-like activities or asking residents to help hand out afternoon cake). What would carers like to see happen. Ask them not to talk about potential barriers at this stage, this will come later	Interactive group discussion
15:00	Summarise people’s ideas	Researcher
15:15	Ask carers to talk discuss any potential barriers to activity delivery and come up with ways to get around these problems. Challenges and solutions. Explore options.	Group discussion
15:20	Ask people to feedback their ideas	Group discussion
15:40	Jointly create a ‘plan of action’ specific to individuals and their preferences. This will show how care workers think they might be able to support residents to engage in activities within the constraints that they highlighted.	Group discussion
15:55	Summarise and close	Researcher

Appendix xv - Group Care Summary: 29th September 2015

Group Care Summary
29th September 2015

8.5 hours (11:00-19:30)
First Floor: Stanley, Peggy, May, Bill

1. Overview

There was a full quota of carers today; five in the morning (08:00 – 14:00) and four in the afternoon (14:00 – 20:00) plus one nurse all day. All of these were permanent members of staff (none from an agency) and the nurse was a highly experience mental health nurse who is evidently passionate about giving her residents the best experience possible. One of the members of staff on today was new and full of energy and enthusiasm for her work.

The activity coordinator and activities assistant were away on training on this day and it is probable that this made a positive contribution to the engagement and wellbeing as the care staff had been told that it was their responsibility to engage the residents and as a result they appeared to make extra effort to do so. There was a 45 minute long entertainment session in the afternoon which was attended by three of the five participants on the first floor and by 13 residents in total (22% of homes population). This was less participatory than other sing along groups and the singer sang modern songs such as Boy Zone which residents were unable to join in with. That said, residents still evidently enjoyed the experience and participated whenever they could.

What was special about this day is that carers tried to engage their residents in a way not yet observed. Bill was given his newspaper as usual but beyond this carers and the nurse tried to engage him in TV programmes that they knew he enjoyed and in playing noughts and crosses. Carers also sang and played games with Peggy and May and went to get the residents ice cream from the ice cream machine which they all sat and ate together in a party-like atmosphere. In addition to this, carers made sure they offered their residents some choice and control over their care. For example, Bill and Peggy were supported to eat in the lounge as they did not want to go into the dining room for their dinner; the residents were able to choose their own cake from a platter rather than the carer choosing it for them.

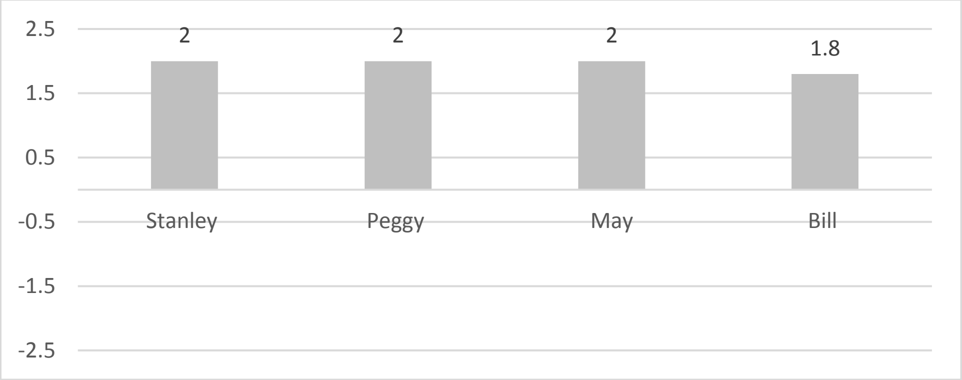
When carers were first told that they had to engage the residents today (the nurse, who is also the unit manager, kept reminding them that it was there job to ‘entertain’ the residents today) they talked together about how they were unsure what to do with people but their confidence appeared to grow throughout the day as they thought of more ways to engage people. That said, the morning was still a busy time as carers were trying to get all of the residents up and dressed before lunch and therefore they did not have much spare time to engage residents beyond their usual care.

Today’s mean WIB score was +2.0, the highest of any of the days so far and significantly higher than yesterday which was +1.0.

Appendix xv - Group Care Summary: 29th September 2015 (continued, page 2).

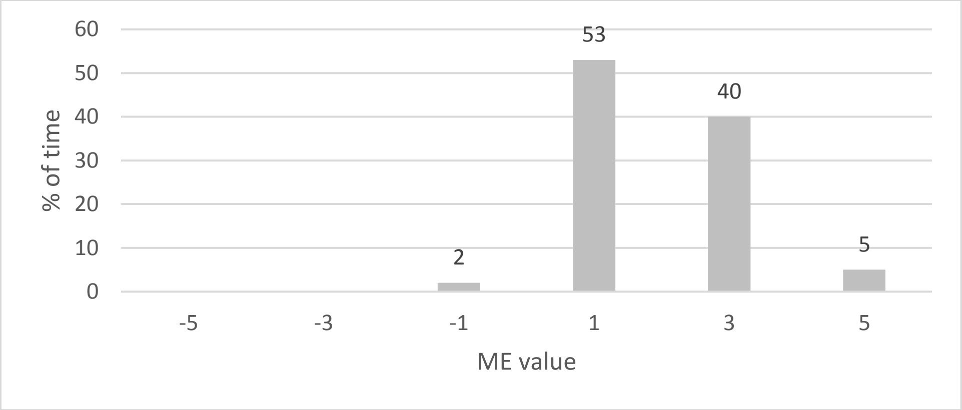
2. Well and ill-being scores

2.1 Individual WIB scores:



Mean WIB score: **+1.8**

2.2 Group WIB profile:



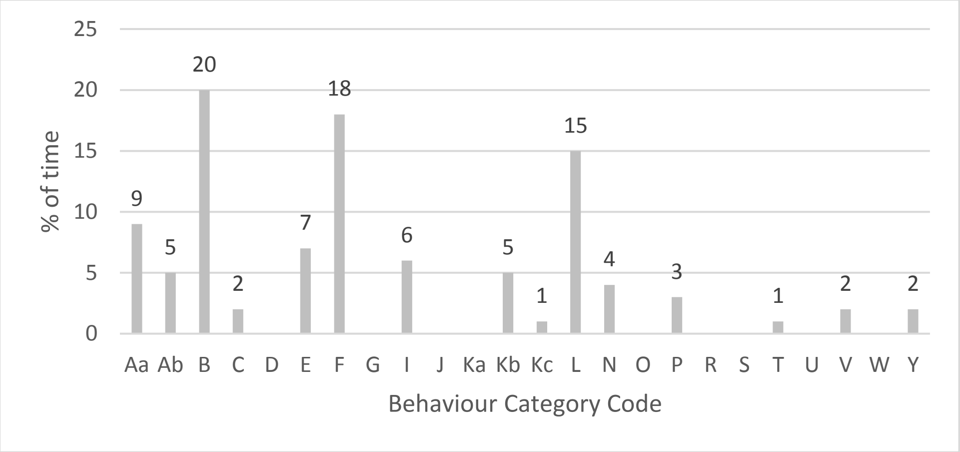
1.3 WIB summary

- Participants spent the majority of their time (64%) in a neutral mood showing no signs of well or ill-being and only intermittently engaged in activity.
- Participants spent 33% of their time showing signs of wellbeing and engagement, this was always when they were being positively engaged by staff members in activities such as games, singing, play, watching TV etc.
- In total participants spent 3% of their time showing signs of ill-being. In the case of Peggy and Bill this was when they became completely withdrawn from their surroundings and when Stanley appeared to be having an argument with someone who wasn't there.
- Peggy, May and Stanley had a WIB score of +2.0, Bill has a WIB score of 1.8. The Av. WIB score was +1.95 (+2.0). This is the most positive collection of WIB scores to date.
- More Personal Enhancers were observed on this day than on any other days, this is likely to have had a positive effect on WIB scores.

Appendix xv - Group Care Summary: 29th September 2015 (continued, page 3).

3. Behaviour codes

3.1 Behaviour Categories



Top 5 BCC: **B** -20 %, **F** – 18%, **L** - 15%, **Aa** – 9%, **E** –7%

3.2 BCC Summary

- The behaviour category which the group was engaged in for the greatest amount of time was B (20%).
- Residents sent 18% of their time eating or drinking and 15% of their time in leisure activities, 9% engaged in brief interactions and 7% in activities with an element of self-expression.
- In total, residents spent 26% of their time in behaviours associated with passivity, disengagement or distress (B,C and N), compared to 37% of their time engaged in a positive activity, in this case conversation (5%) self-expression (7%), intellectual activities (6%), walking for pleasure (1%) leisure activities (15%), sensory activities (1%) and work like activities (2%). This is a far more positive split than other days observed.

4. Psychological needs

4.1 Enhancing and detracting interactions

Psychological Need	Highly detracting	Detracting	Enhancing	Highly enhancing
Comfort				
Identity			1	
Attachment				
Occupation		2	10	2
Inclusion			2	2
Total		2	13	4

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4.2 Personal enhancers and detractors observed

Comfort

None observed

Identity

12:45 – May: PE 5 Acceptance, Identity, Enhancing. A carer goes over to May as she noticed she hasn't touched her lunch. She sits and talks to May for a while and while she does May begins to eat (May does not like to eat alone and Peggy isn't with her). The carer gets herself some food and sits and eats with May and chats to her. With the carer there, May eats too. She laughs and smiles with the carer while they eat together.

Attachment

None observed

Occupation

11:18 – Bill: PE 11. Facilitation, Occupation, Enhancing. A nurse notices Bill sitting alone in silence; she asks him if he would like his newspaper and when he says yes she goes to fetch it for him from the nurses' station. Bill begins to look at it and is engaged in reading it for the next 40 minutes.

12:07 – May and Peggy: PD 11. Imposition, Occupation, Detracting. A carer goes over to May and Peggy and tells them she wants them to go into the dining room for lunch. She speaks as though giving an order rather than asking them if they would like to go. Both women seem reluctant and do not move again so the carer says again 'come on its time to go into the dining room, let me help you up' and helps Peggy to her feet without her permission. After a few minutes in the dining room Peggy gets up and goes back to sit by the window.

12:26 – Peggy: PE 12. Enabling, Occupation, Enhancing. Peggy left the lounge and goes to sit back into the lounge, a carer goes to her and asks her if she would like to eat her lunch in the lounge, Peggy says she would and the carer fetches it for her and sets up a coffee table by her chair.

13:17 – May and Peggy: PE 13. Collaboration, Occupation, Enhancing. A carer is going around the room with tomorrow's menu asking residents what they would like for their lunch tomorrow. She is consulting with them in their care.

13:55 – May: PE 11. Facilitation. Occupation. Enhancing. A carer takes a jigsaw puzzle over to May and Peggy, she sits down with them for a bit and sorts the piece into piles with them. She has to leave fairly quickly but May continues to sort the pieces of the jigsaw into piles.

Appendix xv - Group Care Summary: 29th September 2015 (continued, page 5).

14:00 –May, Stanley and Bill: PE 12. Enabling, Occupation, Enhancing. A carer turns off BBC 1 and puts a Morecombe and Wise DVD on the TV. Immediately May and Bill become engaged in watching it and begin to laugh at bits. Stanley comes into the room and sits on a chair near to the TV, he too watches the DVD and smiles and laughs to himself occasionally. He tells a carer how he remembers Morecombe and Wise from when he was younger and how much he used to enjoy them.

14:16 – Bill: PHE 10. Empowerment, Occupation, Highly Enhancing. Bill seems to have stopped watching Morecombe and Wise. A carer approaches him with a wooden game of noughts and crosses and asks him if he would like to play (Bill used to enjoy playing board games in his lunch breaks at work). He says he would and she lays the game in front of him. Bill needs a lot of support to play the game but the carer is kind and patient and supports him well. Bill appears to be enjoying the game, he is laughing and evidently engaged and when the game finished he asks to play again.

14:30 – 15:15: Stanley, Peggy and May: PHE 15. Including, Inclusion, Highly Enhancing. During the entertainment session the entertainer encouraged residents to sing along to the songs they know and to dance to the music. Stanley and May sing and dance in their chairs but Peggy dances up and down the corridor for a while.

15:23 – May, Peggy and Bill: PE 12. Enabling, Occupation, Enhancing. The nurse puts a comedy DVD ‘Miranda’ on the TV. She tells me that the residents love it. When the DVD comes on May, Peggy and Bill all start to watch it, it is evident that they are enjoying as they laugh at the slapstick. Although Peggy appears to zone in and out of watching it, Bill and May appear to watch it on and off until supper arrived at 5pm. The DVD seems a far more appropriate thing to have on the TV than BBC 1 and programmes about crime, fraud etc.

15:30 – Group: PE 13.Collaberation, Occupation, Enhancing. Today the carers bring around the afternoon cakes on a platter so that the residents can choose their own cakes. In this way carers are working and consulting with residents rather than just making choices for them.

15:51 – May: PE 12. Enabling, Occupation, Enhancing. One carer sits beside May, she has a jigsaw with her and encourages May to join her in completing it. May sits with the carer happily sorting the edge pieces from the others. The carer and May talk together as they work.

17:07 – Peggy and Bill: PE 13. Collaboration, Occupation Enhancing. Both Peggy and Bill express a wish to eat their supper in the lounge rather than the dining room. The carers respect their decision to eat in the lounge and move some tables around to facilitate this. The carers have given Bill and Peggy choice and control over their care.

17:50 – Peggy: PHE 12. Enabling, Occupation, Enhancing. A member of the kitchen staff has come up to the floor to deliver some more food; she goes over to Peggy, strokes her back and talks to her. She then gets a balloon and the two women play a game with this

Appendix xv - Group Care Summary: 29th September 2015 (continued, page 6).

for approximately eight minutes. Peggy really enjoys the balloon game; she is smiling and significantly engaged in what she is doing. When the kitchen assistant has to leave Peggy strokes the balloon and smiles.

18:31 – Bill: PD 12. Disruption, Occupation, Detracting. A carer turns off 'Miranda' and puts on a CSI style drama. Bill, who has been watching Miranda and laughing becomes instantly disengaged and looks straight at the floor. He remains withdrawn until he is taken to bed at 7pm.

Inclusion

11:36 – May and Peggy: PE 16 Belonging, Inclusion, Enhancing. A carer walks over to May and Peggy who are sitting together looking out of the window, she asks them if they are alright, both women say that they are not. The carer spends some time sitting with them and talking to them about the view in the fields below and points out some rabbits, both May and Peggy seem delighted at this. She asks them if they would like a drink and goes into the kitchen to make them a cup of tea, when she returns she brings some magazines with her and the women sit together looking at the magazines, drinking tea and chatting. The carer spends about 10 mins with Peggy and May, when she left the two women sit in silence again.

16:01 – Peggy: PHE 17. Fun, Inclusion, Highly Enhancing. One carer walks over to Peggy who is no longer watching the DVD and appears to have become a little withdrawn, she asks Peggy if she would like to go for a walk, when Peggy says that she would she takes her by the arm and supports her to walk up and down the corridor. The carer and Peggy pick things up along the way; a hat which Peggy puts on the carers head and a feather that the carer places in Peggy's hair. The two women laugh and talk together. They go out of sight for a time frame but when they return the carer says that they have been playing 'Cowboys and Indians'. Peggy looks flushed and delighted, she had three feathers in her hair and a feather bower around her shoulders and a pompom, she is linking arms with the carer and smiling.

16:20 - Group: PHE 14. Recognition, Inclusion, Enhancing. A carer goes down to the ice cream machine to get the seven residents in the lounge some ice cream, she gets some for the other carers too. When she gets back onto the floor the residents and carers all sit together enjoying their ice cream. The carers are engaging with their residents as individuals and are acting as though they were a group of friends enjoying one another's company.

18:18 – Peggy and May: PHE 17. Fun, Inclusion, Enhancing. A carer is singing 'The Animals Came in Two by Two' with May and Peggy; they are laughing together as they sing. When they have finished the carer Peggy and May sit and chat together happily, they also play with the balloon and laugh.

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5. General points

- On this day, care and nursing staff took time to engage their residents in a number of activities which had a significant impact upon their overall WIB scores.
- There seem to have been a number of reasons why residents care was so therapeutic today. These are:
    - The fact that there was a full team on duty today (no staff shortage and no agency staff) and that no resident had additional needs (e.g. no one was very ill and requiring one to one care all day as is often the case – this leads to a staff shortage even if there are the right number of staff on duty)
    - The personality of the staff members on duty were conducive to delivering good care; the nurse/unit manager is a highly trained mental health nurse with many years of experience and is passionate about delivering high quality care, there was also one carer on the team who although new and inexperienced, approached her job with a passion and energy rarely seen in others and who has a genuine deep affection for the residents. The other carers were all good at their jobs and there was no ‘weakest link’
    - The activity coordinator and assistant were away and so staff were explicitly told it was their responsibility to ‘entertain’ the residents today, paradoxically, the absence of the activity coordinator probably improved the activity provision for residents as care staff knew they had the responsibility to deliver activities.

6. Recommendations

- The care home needs to ensure that they are appropriately staffed with permanent members of staff at all times. This also means that if, on one day, there are a number of residents that are ill and require one to one care or palliative care staff numbers are increased to cope with the extra pressures.
- The personality of staff appears to be important, more so than training and years of experience. Is there a way that management can ensure that they employ the right people who are passionate about giving their residents a good experience and who have the imagination to engage them in a variety of positive ways?
- Some of the carers were unsure how to engage the residents even though they said they wanted to, more guidance about how to engage individual residents would be helpful in this situation.
- Paradoxically, the absence of the activity coordinator and assistant was a contributing factor to the positive engagement of residents and their consequential higher WIB scores, this is because staff were told it was their duty to engage residents in activity today (usually they see it as the job of the activity staff). Staff need to be made aware that it is always their responsibility to engage residents.
- Today highlighted that the TV can be used in a positive way. When BBC 1 is put on every day (programs about crime, fraud, property etc.) few, if any residents engage with it but when the nurse put *Morecombe & Wise* and Miranda on, residents were observed watching the TV and laughing. Bill put down his newspaper to watch and picked up his paper again when he had had enough. This is one of two examples during the research so far where a resident has had a choice of more than one thing to do.

Appendix xvi – Thematic Analysis: Coding framework

Theme one: The Current Situation in the Home

Key for 'Data sets used' column:
Ws – Activities workshop
DCM – Dementia Care Mapping
Rev – Care and activity plan review
FG – Focus group with people with dementia
Ob – Unstructured observations
Con– Conversations with people with dementia
P-CAT – The Person-Centred Care Assessment Tool

Overarching (Key) theme	Synthesised theme	Underlying theme	Codes (layer one)	Data sets used
Theme one: The current situation in the home	Current levels of mood and engagement amongst individuals living with dementia in care homes *Note: provides rationale for improvement*	Prevalence of behaviour types	Positive and meaningful	DCM, Ob
			Tasks for care	DCM, Ob
			Passive/ withdrawn	DCM, Ob
		Levels of mood and engagement	Overall well and ill-being	DCM, Ob, Rev
		Engagement and wellbeing during participation in activity programme		DCM, Ob, Rev
		Engagement beyond the activity programme (the wider context of care	Positive engagement/ interaction	DCM, Ob
			Negative interaction	DCM, Ob
			Minimal interaction	DCM, Ob
			No engagement/ interaction	DCM, Ob
		How are activities supported?	Activities programme	DCM, Ob, Rev
			Staff supported	DCM, Ob, Rev
			Self-initiated	DCM, Ob, Rev
	Activity Preferences: (type and meaning of activity) *Note: inform strategy for improvement*	Activity preferences (type of activity)	Outdoor and physical activities	C, FG
			Creative activities	C, FG
			Playful activities (fun and games)	C, FG
			Normalising activities	C, FG
			Activities with a social element	C, FG
		The meaning of activity to people living with dementia	A sense of purpose / feeling useful	C, FG, Ob
			Personal achievement	C, FG, Ob
			Helping out / feeling useful	C, FG, Ob
			A sense of identity	C, FG, Ob C, FG, Ob
			A sense of inclusion and belonging Enjoyment and pleasure	C, FG, Ob
			Enjoyment and pleasure	C, FG, Ob
			Keeping busy	C, FG, Ob
		The importance of supporting person-centred activity	To suit individual abilities	DCM, Ob
			Complexities in group living	DCM, Ob
			Consider preferences / dislikes	DCM, OB, Rev

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Theme two: Identifying factors that affect engagement and developing a strategy to better support people living with dementia in care homes

Overarching (key) theme	Synthesised theme	Underlying theme	Codes (layer one)	Data set used
Theme two: Identifying factors that affect engagement and developing a strategy to better support people living with dementia in care homes	Factors affecting engagement amongst people living with dementia in care homes *Note: inform strategy for improvement*	Individual abilities (people with dementia)	Physical abilities	Ob, C, FG, Rev
			Cognitive abilities	Ob, C, FG, Rev
			Sociality	Ob, C, FG
			Capacity for self-initiated activity	Ob
			Motivation	Ob, C
		Physical environment	Architectural design	Ob
			Interior design	Ob
			Resources: ‘we don’t have the resources’	Ob, Ws
		The programme of activities	As improvement to engagement	DCM, Ob
			Offered limited opportunity for engagement	DCM, Ob
			Expendable part of care routine	Ob
			Separation of spheres of physical and psychosocial care	Ob
		Individual care workers	Care worker value base	Ob, Ws
			Past work experience	Ob, Ws
			Relevant training	Ob
			Motivation for undertaking role as a care worker	Ob
		Care worker perceptions	Perception of role	Ob, Ws
			Perception of people living with dementia	Ob, Ws
		The culture of care	The philosophy of the care home ‘people will think we’re shirking our work	Ob, Ws, P-CAT
			Management influences	Ob, P-CAT
			Prioritisation of needs	Ob, P-CAT
		Time constraints	Staff ratio and the use of agency staff	Ob, DCM
			Prioritisation of need physical over psychological: ‘we don’t have the time [for psychosocial care]’	Ob, W
	A strategy to better support engagement amongst people living with dementia in care homes	Care workers need to take responsibility for engaging residents in activity and quality interaction. For this to happen:	Activities need to be quick to initiate and sustain	Ws
			Activities need to fit into every day care tasks	Ws
			Additional considerations: 1. A physical environment and appropriate resources. 2. A reconstruction of the role of a care worker. 3. The recruitment of care home staff who value the wellbeing of their residents. 4. Appropriate staff training. 5. A culture of care that values activities and that is underpinned by strong leadership. 6. A reduced resident to staff ratio. An activity programme of structured activities to facilitate group activities (needs to be carefully managed so as to dispel the notion that activity’ refers to an activity organised activity.	Ob, Ws

Appendix xvii - Thematic Analysis: Map of coding framework