UTILITY OF PIECE-dem AS A PRACTICE TOOL

A tool focusing on the perspective of people with advanced dementia in residential aged care

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Summary

It has been suggested that 'dementia challenges our assumptions about what it means to be a person' (Woods, 1999:35). If there is little or no regard for a person's self-expression, by whatever means, then effectively many people with dementia become excluded from any form of participation in, or influence over the support and care they receive, other than as a passive, objectified recipient.

The aim of this research was to trial the tool, PIECE-dem, in the Australian context and evaluate its application by practitioners to better support people living with advanced dementia. PIECE-dem, which is underpinned by person-centred principles, was designed by researchers for use by researchers in a UK study. This current research explored the potential for use of the framework by practitioners.

The research took place within one residential aged care (RAC) home, with five staff participating in the training and subsequent observations using PIECE-dem. It was a mixed method research design with the Individualised Care Inventory (ICI) (Chappell et al., 2007) staff-based measure used in the survey as the quantitative component, and observations, interviews and field notes made up the qualitative component.

The tool provides a framework for structuring observations to capture resident efforts at social interactions, supporting observers to look for small and subtle nuances of movement and gestures. The focus of the observations is on the resident and how they are experiencing the care environment. At the conclusion of each observation session there was guided reflection (Johns, 2013) on how the person with dementia was experiencing the care environment and to identify possible trends or patterns in responses and expressions of agency.

The findings provide a positive indication that PIECE-dem would be valuable as a practice tool for staff in RAC homes as a framework to support critical interpretation of observations. Spending time observing and then reflecting on observations gave staff an awareness of patterns of gestures they had not seen. Also, by observing and reflecting on what actions might mean for the person with dementia provided staff with insights into demonstrations of capacity and agency not recognised before. The staff participating found they gained awareness of expressions of wellbeing and illbeing as well as a greater understanding of embodied communication. These findings suggest that PIECE-dem has the potential to advancing an understanding of person-centred practice. PIECE-dem offers a strong foundation for building an awareness of autonomy and expressions of agency as it enables an exploration of how the person with dementia is experiencing and influencing their immediate environment, and provides a framework for reflecting on what is observed.

Key words: Person centred care, guided reflection, agency, observations, embodied communication, dementia.

“I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where reference is made in the text”

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CHAPTER ONE

Exploring an observational process to capture the perspectives of people with dementia living in RAC homes.

Before there is an exploration of such an observational process, it is necessary to look at dementia and developments which lead up to the need to identify such a process.

1.1 Dementia, what is it?

Dementia is not one single definite disease, but rather a general term which describes a condition associated with more than 100 different diseases, with the most common being Alzheimer’s; about 50-70% worldwide (AIHW, 2015). All these diseases are characterised by impaired brain function which may affect memory, problem solving, language, perception, understanding, and reasoning. Although the type and severity of symptoms and their trajectory varies with the type of dementia, and the individual, dementia is usually progressive in nature, of gradual onset, and irreversible (AIHW, 2011).

The condition of Dementia is caused by damage to brain cells. The ability of brain cells to communicate with each other is interfered with by this damage. When brain cells cannot communicate normally as they are designed to do, cognitive processing, behaviour, moods and personality can be affected. There is no known cure.

The range of symptoms associated with dementia will affect mental and social responses to situations severely enough to interfere with daily life. As the condition develops, it can be highly disabling, physically and socially, and can result in a need for extensive care in the long term. While dementia is a chronic condition that can cause death, many die from other causes first (AIHW, 2010).

1.2 Why study dementia in the Australia context.

In forthcoming years as the population in Australia ages there will be a need for significantly more RAC home and community care places to support the ageing population. One of the drivers for this increase in demand for services and support will be the cumulative incidence of dementia, and an accompanying requirement for high-level support and care. In 2009–10 about 53% of all permanent residents in Australian Government subsidised RAC homes had a diagnosis of dementia. Of those residents, almost 87% (9 in 10) residents with dementia in subsidised RAC homes had an ACFI classification indicating their need for high level of care (AIHW, 2011).

Australians today generally live longer and have healthier lives than previous generations. 50 years ago, life expectancy at birth was 74 years for females, and 67 years for males. Life expectancy has increased by a decade according to the latest mortality data, indicating that females born in 2013 can anticipate reaching 84 years of age and males to 80 (AIHW, 2015). Life expectancy is increasing both at birth and over the life course, as most Australians now experience better standards of living and improved access to healthcare. What these figures also mean is, the percentage of people aged 65 and over in the Australian population is growing. Over the last fifty years, people aged 65 and over have more than tripled in numbers, rising to 3.4 million in 2014 (AIHW, 2015). Older people account now for a swelling share of the Australian population, with 15% of Australians aged 65 and over in 2014, compared to 8% in 1964. Furthermore, the number of people aged 85 and over, has increased ninefold, up to 1.9% of the population in 2014 (ABS, 2015; Australian Demographic Statistics, Dec 2014).

Young people do develop dementia; however, it does primarily affect older people. Dementia is not an inevitable part of ageing, but the incidence does increase with age. Consequently, one of the anticipated concerns regarding the growth and ageing of Australia's population is an increase in the number of people with dementia over the coming decades. This projected increase in the incidence of dementia poses a substantial challenge to planning and positioning of aged care and health services along with social policy. Although methods used for population projections do vary, there is general agreement that there will be a significant increase in the number of people living with dementia, anticipating a possible tripling of numbers between 2011 and 2050 (AIHW, 2012).

Dementia has been identified as having profound consequences for the quality of life and health and for the individuals with the diagnosis as well as their family and friends. We know dementia is a progressive disease and is currently the second leading cause of death in the general population in Australia and identified as the primary cause of death for 7.4% of all deaths in 2013 (AIHW, 2016). It is significant to note that in 2012, the Australian Health Ministers recognised dementia as a National Health Priority Area (AIHW, 2016). Australia was one of the first countries in the world to have listed dementia as a national health priority. The implication of this being that it has been identified as a significant health and social issue, requiring attention.

1.3 Dementia within RAC homes

With an ageing population and an ensuing growth of physical and cognitive frailty amongst older people, there have been discussion nationally regarding the best ways of safeguarding provision of services for the projected ageing population are of high-quality. RAC homes offer support to the most vulnerable older members of society and, in the 2013-2014 financial year 7.8% of the Australian population aged over 65 were living in RAC homes at some point (AIHW, 2016). The traditional image of aged care is often associated with RAC homes however the majority of people as they age do actually remain in their home, stay independent and connected to family and community. The current government policy is supporting people to remain within the community for much longer by offering a range of services and supports. It is worth noting that 67% (2 in 3) older Australians, aged 65 years and over (2.4 million) did not use aged care services during 2014–15 (AIHW, 2016). These figures are encouraging; however, it is the small percentage of more frail and vulnerable people living in RAC homes that this research is concerned with.

When talking about a RAC home it is necessary to note that it sits somewhat awkwardly within different orientations/positioning for the different collections of people who inhabit the 'place'; home for the resident, workplace for the staff, visitation venue for family and friends; compliance for the CEO and Board. As an organisation it has documentation, audits, risk management, compliance requirements, as a workplace it has rosters, routines, occupational health and safety requirements and as a home to a number of people who are strangers many of whom would rather be somewhere else. Wilkerson and MacDonell (2003) noted that 'at the heart of the issue is the fact that virtually no one chooses long-term care as a way of life'. The challenge, hence, is how to construct a sense of community and a domestic like environment in a place where no one really wants to be (Boyd, 2003). Such is one of the key challenges for a RAC home; the role, identity, purpose for being there, is so very different for many of the people involved in the 'place', therefore what different people requires of the 'place' is different, which may make for awkward engagements if there is a clash of needs.

It is also worthy to note the somewhat ironic situation that people with dementia, who often find it difficult to learn, are required to make adjustments at the end of their lives to a model which would be difficult for most people. RAC homes by definition are group settings. This model requires residents to spend the majority of their time with a group of strangers. This can be personally demanding; physically, socially and emotionally. Communal settings can suit some people well, especially if they are highly socially skilled or more extrovert by nature. However, it can also be confronting and emotionally exhausting for others to attempt to be on their best behaviours and make small talk for most of their waking day (Marshall, 2001).

RAC staff work very intimately with many residents in RAC homes, often completing tasks and interactions in private spaces with residents', particularly bathrooms and bedrooms. Such occasions are more prolific if there is an increased level of disability or dependence which would be the situation for most residents with advanced dementia. Within this paradigm of care, where there is a distinct power differential, the person with advanced dementia is vulnerable to less than optimal care interactions, it is worth considering the concepts of 'dignity of identity' (Stevens et al., 2013) and personhood (Kitwood, 1997). The maintenance of personal identity can be made more vulnerable by some of the consequences of increasing chronological age, such as changes to involvement in the workforce or retirement and increasing need for assistance with personal care. Such developments can affect self-perceived identity and potentially reduce one's sense of autonomy. If cognitive impairment, reduced comprehension of language and slower processing of information is added to this situation, there is an increased opportunity for a compounding of factors resulting in diminished dignity of identity, sense of self and the undermining of personhood. The degree to which residents are able to participate in creating the style of care offered and in creating their own space, especially regarding more intimate care, such as toileting and bathing, can either enhance or diminish the dignity of personal identity and personhood. If there is a task-oriented work culture, the completion of the task is likely to preside over any invitation to participate in choices and styles of action? Unfortunately, there has been language heard used in RAC homes which firmly places residents in a diminished and totally submissive position such as ‘can you do him too, he’s a straight forward feed’, or ‘don’t forget the purple pad in room 45’. Where the power sits within this paradigm is rather obvious as is language use to reinforce such a paradigm.

Provision of opportunities for participating in the caring interactions may be limited if there is positioning of the older person with care needs as less capable or less worthy of collaboration and interaction and somehow less of a person (Sabat, 2007). Unfortunately, such patterns of positioning and use or interpretations of language can not only diminish personhood and identity, but more broadly lead to the creation of an organisational culture which reinforces societal factors such as ageism. This is one example where macro scale features such as routines of practice, social inequalities or styles of management can influence, and be influenced by micro-interactions that fashion the foundation for the care interactions and environment.

There is a challenge for RAC homes to develop and maintain a care environment which feels psychologically safe where all persons can flourish; this is bound up closely with self-respect, and wellbeing. To embed such values within an organisation, it needs to be across the entire organisation (Brooker, 2005).

1.4 Developments over the last 30 years

1.4.1 Observational tools for how the person with advanced dementia is experiencing their world

Interest in the quality of life of long-term care for residents with dementia has resulted in there being many measures that provide windows to explore the presence or degree of quality of life. Examples of these include Quality of Life in Dementia (QOL-D) (Albert et al., 1996); Quality of Life in Alzheimer's Disease (QOL-AD) (Logsdon et al., 2000); Alzheimer Disease Related Quality of Life (ADRQL) (Rabins et al., 2000); Dementia Quality of Life (DQoL) (Brod, Stewart, Sands, and Walton, 1999); Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS) (Lawton, 1994; Lawton et al.,1996); Resident and Staff Observation Checklist—Quality of Life Measure (RSOC-QoL) (Sloane et al., 1991; Sloane et al., 1998; Zimmerman, et al., 2001).

In a review of QoL measures (Sloane, Zimmerman, Williams, Reed, Gill, and Preisser, 2005) it is asserted that no single instrument can claim supremacy, and, further, no sole instrument has the breadth to adequately capture the wide-ranging coverage of quality of life. They suggest the field is still underdeveloped as one area that needs further exploration is to better understand the experiences of persons with dementia.

There are several observational methods which include regarding different aspects of quality of life in dementia and include observing engagement with participants; (McFayden, 1984); the Short Observation Method (SOM) (MacDonald et al., 1985); Dementia Care Mapping (DCM) (Kitwood and Bredin, 1992); the Quality of Interactions Schedule (QUIS) (Dean et al., 1993); the Patient Behaviour Observation Instrument (PBOI) (Bowie and Mountain, 1993); DS-DAT (Volicer, 1999) ; and The Affect Rating Scale (Lawton, 2001).

All of these observational methods provide a controlled way of observing the experience of people with dementia who live in RAC homes. The observations are generally applied in public or communal areas where the observer has a greater chance to blend into the background and observe a number of people at the same time. Most of the tools have complex coding of behaviour and thus require a period of training to become adept in their application.

It has been argued that DCM may come closer to seeing the perspective of the person with dementia and their experience of QOL than many other available measures (Sloane et al., 2007), and consequently has widespread clinical appeal and use in dementia care practice. The weaknesses of DCM however lie in the time-consuming nature of the method (Fossey, Lee, and Ballard, 2002; Sloane et al., 2007) and questions about its cost-effectiveness (Chenoweth et al., 2009). Another difficulty with DCM is regarding it being a commercial product (Bradford Dementia Group) available for use only by people who have paid for and attended courses. It has been suggested that a condensed version of the tool would be a positive way forward to reduce the time demands DCM places on the user (Fossey et al., 2002; Sloane et al., 2007). Without there being a condensed version of DCM yet to be developed, PIECE-dem may have the potential to come some way toward filling this void as an observational framework to capture information on how the person with dementia is experiencing their environment.

A more recent observational tool, AwareCare measure (Clare et al., 2012), provides a structure for identifying signs of awareness and responsiveness in people with severe dementia and understanding the patterns of responsiveness shown by individual residents. Awareness has been defined in their research as ‘a reasonable or realistic perception or appraisal of a given aspect of one’s situation, functioning or performance, or of the resulting implications’ (Clare, Rowlands, Bruce, Surr, and Downs, 2008*)*, expressed in words or actions. Staff who took part in the study completed on average over 20, ten-minute observation sessions, and stated they felt that they ‘benefited from the training, appreciated the opportunity to devote time to observing and interacting with individual residents, and gained a greater understanding of residents’ behavior and responsiveness*’* (Clare et al., 2012:136*).*The study demonstrated that care staff are able to use the AwareCare measure effectively as a practice tool, and that they feel this is useful in enabling them to identify and understand residents' needs.

> 'I feel I can do my job better now through learning how to observe individuals' (Claire, 2012:133).

> 'She does respond. . . A lot of eye movements and turning her head, and if you suddenly touch her and she hasn't seen you she jumps. . . She is very aware.*'* (Claire, 2012:134).

At the time of developing the proposal for this research study, the AwareCare measure (Clare et al., 2012), was not publicly available. At this stage it is not possible to compare and contrast AwareCare and PIECE-dem as practice tools, however there does appear to be significant convergence in process (observational framework for resident responses) but divergence in orientation of outcome (how the resident is engaging/responding and what supports this). This may be interesting to explore in a future study.

At this point in the field of observation tools for working with people living with dementia, it appears that PIECE-dem may be a useful tool for practitioners to support reflection on how residents living with dementia are experiencing their care environment. Before proceeding any further, it is important to understand the origins of the tool and the development of the PIECE-dem process.

1.4.2. Development of PIECE-dem

As is evident from the above tools, there has been a deal of work done in the field of observational tools over the last 30 years. Many of the tools mentioned above have been used in research into quality of life. There is an established body of knowledge regarding the value of observation for in depth research data. A UK research team, headed by Professor Dawn

Brooker had significant expertise in the development and application of observation tools with people with dementia such as DCM (Brooker, 2005; Brooker and Surr, 2006) and the Short Observation Framework for Inspection (SOFI) (Commission for Social Care Inspection, 2008). This research team completed a research study funded by Preventing Abuse and Neglect in Institutional Care of Older Adults (PANICOA) with an aim:

> 'to develop an observational process to capture the perspectives of people with significant cognitive impairment who are living in care homes; People vulnerable to the risk of abuse, neglect and loss of dignity. A further aim of this research was to develop the observational framework to capture examples of excellent care.' (Brooker, De Vries, La Fontaine, Porter, and Surr, 2011:11)

The original team stated an awareness of the potential chance to develop a tool that, had primary use in research, and could be adapted for use by practitioners as a way of refining the quality of care to this same vulnerable group of residents.

It was identified by the original research team, that none of these current tools were useful for observing potential neglect and abuse, the emphasis of their original study. Even though DCM does provide rich data it is a multifaceted tool which requires in-depth training to become familiar with the coding and procedural rules. SOFI, although less complex, was designed specifically for the English 'inspection and regulation of care homes' and thus needs to be used within that context.

In developing the PIECE-dem tool, the original research team stated their focus was on those residents who had been identified as being mostly hard to reach due to their compromised cognition, language difficulties and diminished ability to self- advocate. Given the original research team had a wealth of experience from DCM and SOFI observational tools, this experience was used to develop a tool that unambiguously focussed on capturing the experience of very dependent people with dementia living in RAC homes. In the development of the tool, they considered questions such as: What were the signs that could be directly observed that people in these situations may be experiencing poor care, neglect or abuse? What were the signs that people were experiencing care that was supporting their wellbeing?

Extensive collaboration and consultation, uniting practice and academic expertise with active participation of older people and their carers was undertaken in the development of the tool. There was awareness also that the original team were looking to develop a tool for use by researchers (and practitioners in the longer term) with minimal but realistic training. Even though the tool was being developed for use by researchers, there was recognition that such a tool could be very useful for practitioners, given the research teams' experience with developing and extensive use of observational tools in informing care practices. The research team were well placed regarding practical experience with working with people with cognitive impairment and observational tools to develop a robust and sensitive tool that could be used to capture the care experience of people with compromised cognitive capacity. The focus of the tool for the PANICOA project was on observable signs of neglect, abuse and or associated risk factors. However, there was a parallel recognition that positive features in RAC homes can exist which make mistreatment less likely to occur. Thus, the tool has the capability to capture instances of positive care culture, social interactions and examples of excellence in care supporting wellbeing.

The original UK study found that there were no observational tools available designed for use with vulnerable population groups looking at neglect and abuse. The literature review in the original UK study looked at the databases Psychinfo, Medline, Web of Knowledge and PubMed using key search terms in different combinations - neglect, abuse, identification, observation, older, elder, child and learning disability. The literature review did identify themes which informed the development of their PIECE-dem framework. There is a critique regarding the transfer of research from one population, such as child abuse, into understanding abuse and neglect in another population such as elders (Fulmer et al., 2004). This critique was largely based on the differences in roles, life experience and general contextual difference which can make direct transfer of ideas less robust. This may be correct; however, there are also strong parallels such as increased vulnerability to the direct influence of others on dignity and wellbeing.

The PIECE-dem framework was trialled by the researchers in 28 UK care homes. After each of the trials in there was a compilation of data; observation results; the researcher reflections on the procedure and observation experience; information from earlier focus groups and interviews. The PIECE-dem process (of which the framework was one component) was finalised after seven RAC home trials. Additional visits to three RAC homes were done to carry out initial inter-rater reliability.

As a result of the consultation and research, a manualised tool (a tool supported by a manual of instructions for implementation), the PIECE-dem Observational Process, was built. PIECE-dem is an acronym for:

People

Interaction

Environment

Care

Experience

In

Dementia

In the original study, when using PIECE-dem, four residents were selected as participants (residents, referred to hereafter as participants) to be observed in detail. In addition to having dementia, PIECE-dem participants selected had other characteristics or high levels of need placing them potentially within at higher risk of mistreatment with an inability to self-advocate. The conduct of observers using PIECE-dem need to be exercising inclusionary consent (Dewing, 2007) and the process was clearly outlined in the practice manual developed to support the implementation of PIECE-dem. It is important that participants are relatively comfortable with the presence of the researcher during observation. The manual clearly states that observations are to be discontinued if participants show signs of discomfort associated with the observations.

In the original research during a PIECE-dem observation session, one researcher worked with two participants during the same time period, spending time observing each participant alternately in 15-minute observation blocks over a two hour period. This was done for two days, across a typical waking day. There was an attempt to observe how different staff impact upon the experience for each participant, therefore observations were recorded over a two day period, to capture any differences which may be due to staff impact. In each one minute time frame the researcher records observations of the participants' experiences of the world around them. What is recorded in each one-minute time frame is a choice of three 'activity' a resident is involved with; interacting, engaged or disengaged. In addition, a narrative is written to record what is actually occurring with or around the resident at the time of observation, and what is occurring within their immediate environment.

Observations occur in communal or public areas such as lounge, dining rooms and in hallways. Given that the aim of PIECE-dem is to identify an individuals' experience of care there may be some observations done in or immediately outside the person's bedroom. If the participant was bed bound or spending long periods in bed this was necessary. However, no intimate personal care activities were directly observed.

Observations are summarised every 2-3 hours on behalf of each participant. Brooker et al. (2011, 10) state, the summary for observation involves:

> 'Actions (and their possible intention) that may be observed/expressed by the **Person** with dementia. This includes their facial expression, body posture, bodily movements, attempts at communication and vocalisations;
>
> Direct actions of others as they relate to the participant. This includes the nature of the **Interaction** and how this appeared to be experienced by the person with dementia. Recording includes the posture, tone, content, apparent intent and use of touch occurring in the interaction;
>
> The immediate physical and psycho-social **Environment** surrounding the participant.'

The initial idea was that the PIECE-dem would be trialled in 15-20 locations. However reduced availability of care homes resulted in only 11 trials being concluded. Initial inter-rater reliability of the tool was good but does need further testing. Validity testing was not possible on such a limited number of trials.

A full manual was developed to assist research teams in using the tool in the subsequent PANICOA in-depth study of RAC home culture. It is planned for the manual to be adapted for use by care practitioners as a practice development tool to improve their care of people with dementia and high dependency needs. The findings from this exploratory study will be made available to inform future developments of the adaptation.

1.4.3 Adaptation of orientation for this study

PIECE-dem was selected to be used in this study due to the demonstration of capacity to capture the experience and perspective of the person with advanced dementia and how they are experiencing their care environment. This exploratory study has a different although related orientation to the original UK study. There is not a focus on elder mistreatment as with the original UK research. This study has a focus on use of the tool by practitioners, to explore the potential to inform quality care practice. The tool was designed specifically for use by researchers, however, there was awareness of the potential for it to be used by practitioners for improving care to this vulnerable group of residents. The lead of the UK research team kindly gave permission for me to explore the utility of PIECE-dem as a practice tool.

To establish a knowledge and theoretical context for this study, Chapter 2 will look at contextualising dementia and Chapter Three will establish the theoretical framework and key concepts central to this study.

CHAPTER TWO

2. Contextualising dementia and recognising the unique experience of the disease.

In this Chapter, different types of dementia and individual variances will be considered. Knowing what diagnoses a person has will indicate which part of the brain has been affected and thus what functions are likely to be compromised. Nevertheless, even with the same diagnosis, every person will have a unique experience as they have a distinctive set of personal circumstances surrounding them.

Dementia is a term that is commonly used to describe a syndrome associated with a wide range of different neurocognitive disorders and their associated symptoms. Dementia is not a normal consequence of ageing, however one of the anticipated concerns of an ageing population in Australia is an increase in the number of people with dementia over the decades, with projections estimating numbers may increase three-fold by 2050 (AIHW, 2012).

Even though there are projections based on current trends, there is a major data gap with no robust data on the prevalence of dementia. There have been questions raised regarding how the diagnosis of dementia (ABS, 2015) is captured in recent reviews (Bradford et al., 2009; Koch and Iliffe, 2010). The reviews also investigated possible reasons for delays in diagnosis. It was found within the literature, that there were complex combinations of obstacles to diagnosis at the earlier stages, which contribute to a suggested under-diagnosis, as well as the under-disclosure, of dementia. As a result, data sources reliant on respondents reporting the existence of health conditions are less reliable when it comes to dementia compared with other chronic illnesses.

Thus, there is a question regarding the robust nature of existing data sources, which cannot accurately describe the prevalence of this condition (ABS, 2015). In the absence of more rigorous data, they can however provide an indication and contribute to useful projections (AIHW, 2012). Even though there is a lack of national epidemiological data in Australia that can provide reliable estimates about the actual number of people in Australia with dementia (AIHW, 2014), projected trends can be extrapolated based on the projected ageing of the population. The likelihood of developing dementia does increase with age; one in ten Australians over 65 years of age had a diagnosis of dementia in 2015 which increased to three in ten over the age of 85 (AIHW, 2015).

Currently there is no cure for dementia. The type and severity of symptoms along with their pattern of development and trajectory varies as each person's experience of the disease will be different even within the same type of dementia (Smits 2015). However, dementia is usually of gradual onset, irreversible and progressive. It is a condition people will die from if they do not die from some other condition first.

2.1 Different types and symptoms

Even though there are different types of dementia, there are common symptoms. Memory loss and problems with finding familiar words may be observed in the early stages of the condition. Problems with familiar tasks, such as driving, handling money, the shutting of gates or errands, may appear as symptoms in the mid-stages. Then during the latter stages, activities of daily living may become more challenging, such as self-care, including dressing, personal hygiene and eating. Depending on which parts of the brain are affected, people may also lose the knowledge they had regarding social protocols and socially acceptable behaviour.

Dementia can affect not only mental capacity but also social behaviours enough to significantly restrict functioning within daily life. People with dementia eventually become dependent on their carers in most, if not all activities of daily living (ADLs), resulting in people with dementia becoming increasing dependent on others to assist with the functions of daily life. This developing inability to perform activities of daily life is one of the major causes of dependence, disability, and ultimately death in older people (AIHW, 2015).

It is important to know what type of dementia a person has. This provides an indication of which part of the brain is damaged, what functions are more likely to be affected, and what symptoms may be exhibited. Having this knowledge will also support care staff in having a more informed capacity to differentiate between personality and condition influenced responses. That is not to suggest a reductionist approach or a straightforward causal relationship between neuropathy, dementia and behaviour, but it is helpful to be aware of the part of the brain that has been affected by the disease and therefore which functions may have been affected for the individual. This again is not a straightforward causal relationship, but rather possible aetiological connections; keeping in mind that each person will have a unique experience and trajectory of their condition?

2.2 Common types of dementia:

There are over 100 different types of dementia (Alzheimer’s Australia, 2017), each with different causes, symptoms and treatments. However, there are four types which are the most common, these being:

- Alzheimer’s dementia, caused by Alzheimer’s Disease, accounts for 50–75% of dementia worldwide
- Vascular dementia, which can occur as a result of stroke or alternative internal bleed, accounts for 20–30% of dementia

- Frontotemporal dementia, caused by various diseases including Pick disease, accounts for 5–10% of dementia
- Dementia with Lewy bodies (up to 5% of cases).

While these are the four most common types of dementia, there are other less common dementias, including:

- Dementia caused by other diseases (such as Parkinson disease, Huntingdon disease and Creutzfeld-Jakob disease)
- HIV/AIDS-related dementia
- Trauma related dementia
- Mixed dementia cases, where a person may have more than one type of dementia

(Alzheimer's Disease International World Alzheimer Report, 2009)

2.2.1 Alzheimer's Disease

Alzheimer's disease is the most common form of dementia, and accounts for between 50 – 75% of all diagnosed cases (ADI, 2009). This form is associated with the characteristic protein plaques and neurofibrillary tangles in the brain. Typical early symptoms include memory loss, apathy and depression. As the disease progresses, symptoms can include:

- Difficulty with short term memory and persistent and frequent memory difficulties
- Imprecision in routine conversation
- Difficulty speaking, swallowing and walking.
- Outward loss of interest for activities formerly enjoyed
- Needing more time to do routine tasks
- Be unable to remember well-known people or places
- Incapacity to process information, questions and instructions

- Decline in social skills
- Emotional changeability

(Chiu, Chen, Yip, Hua and Tang, 2006)

2.2.2 Vascular Dementia

Vascular dementia, which results from inadequate blood flow to the brain, is the second most common form of dementia, (also known as multi-infarct dementia). The cumulative effect of a series of small bleeds or blockages in the brain over time or a single significant incident such as a major stroke can result in changes in the brain associated with the condition. There are several different types of vascular dementia. Two of the most common are Multi-infarct dementia, caused by a number of strokes that damage the cortex of the brain; and Binswanger's disease, caused by high blood pressure, thickening of the arteries and inadequate blood flow. A person with Multi-infarct dementia is expected to maintain more insight in the early stages of their disease than people with Alzheimer's disease, and parts of their personality may remain relatively intact for longer (Smits, van Harten, Pijnenburg, Koedam, Bouwman, Sistermans, Reuling, Prins, Lemstra, Scheltens and van der Flier, 2015).

Symptoms of Multi-infarct dementia may include mood swings, severe depression, and epilepsy. Symptoms of Binswanger's disease often include difficulty walking, emotional ups and downs, slowness and lethargy, and lack of bladder control in the early stages of the disease. Most people with Binswanger's disease have a history of high blood pressure

Symptoms depend on the severity of the impact on the blood vessels and which area of the brain is affected but can include confusion, disorientation, difficulty speaking, learning, memory and language or understanding speech and vision loss. (Chiu et al., 2006)

2.2.3 Mixed Dementia

This is an increasingly prevalent category of the disease, and as the name suggests, usually involves brain changes of more than one type. The most common form of mixed dementia is Alzheimer's disease and vascular dementia and can include a range of symptoms typical of both forms of dementia (Alzheimer's Australia, 2017).

2.2.4 Frontotemporal Dementia

Frontotemporal dementia (FTD), as the name implies is the name given to dementia when there is progressive damage to the frontal and/or temporal lobes of the brain.

Both the left and right frontal lobes are involved processing information which informs social behaviour, attention, judgement, planning, mood, and self-control. Damage to the frontal lobes can result in reduced intellectual abilities and variations in emotion, personality, and behaviour.

Both the left and right temporal lobes, located at the two sides of the brain are involved in processing auditory input, understanding, and sight. Damage to the temporal lobes can result in reduced ability in recognising objects and understanding or expressing language.

The symptoms of FTD depend on which parts of the brain are damaged. One distinct difference in symptomology to Alzheimer's disease, is that memory often remains relatively unaffected in FTD, especially in the early stages. When the frontal lobes are first to be affected, the main changes are in behaviour and personality. This development is called behavioural-variant FTD. When the temporal lobes are the first affected, language skills are lost or severely compromised.

Common symptoms of FTD can include any one or combination of:

- Immovable mood and behaviour, which can appear to be selfish
- Inability to adapt to new or unfamiliar situations
- Loss of emotional warmth and demonstrative responses
- Indifference or limited motivation; past hobbies abandoned and social contact avoided
- Diminished social inhibitions
- Trouble in rational thinking, decision making, organisation and planning
- Easily distracted and impetuosity
- Deviations in eating patterns
- A waning in attention to personal hygiene and self-care

(Chiu et al., 2006)

An early symptom is reduced ability to perform daily activities. As the disease advances, obsessive behaviour, or repeat patterns of movement or behaviours may develop. Often people with FTD are accused of being selfish and intentionally being obstructive or resistive as they don’t exhibit common characteristics of dementia such as memory loss; they can appear ‘normal’, but to people who know them well, changes are more obvious.

FTD can affect anybody; however, it more often affects people at a younger age than Alzheimer’s disease, with symptoms beginning in the 50s or 60s, and sometimes younger.

It has been found that approximately a third of people with FTD have a family history of dementia. Nonetheless, only about 10-15% of cases have familial FTD, in which a gene mutation is passed on that cause the disease. (AA 2015)

2.2.5 Dementia with Lewy Bodies

Lewy body disease is produced by the death and disintegration of nerve cells in the brain. This form of dementia is characterised by the development of masses of abnormal protein in the brain called ‘Lewy bodies’. When they develop in the cortex, dementia can result. Memory loss and cognitive difficulties associated with Alzheimer's disease can be present but there are also very specific symptoms early in the disease such as disturbed sleep, graphic visual hallucinations and muscle inflexibility similar to Parkinsonian movement types. Vacillation in mental state may also occur so that the person may be coherent and articulate and then confused, disoriented and bewildered. Archetypally such vacillation occurs over a period of hours or even minutes and is not owing to any physiological or acute illness. (Chiu et al., 2006)

2.2.6 Alcohol related Dementia (Wernicke Korsakoff Syndrome)

Thiamine (Vitamin B) deficiency is the major cause of this form of dementia and is most frequently caused by alcohol misuse. Memory loss is the primary symptom and unlike other forms of dementia, many other cognitive functions remain relatively intact.

Commonly symptoms will include:

- Reduced ability to absorb new information
- Changes in personality
- Difficulties with memory
- Struggle with logical discerning that require planning, organising,
- Difficulties with common sense judgement and social skills

- Difficulties with balance
- Diminished initiative

Usually old habits and skills learned earlier in life such as language incline to be reasonably unaffected.

Dementia is considered a progressive and irreversible disease as most changes and damage to the brain that cause dementia are permanent and accumulate over time. However, cognition difficulties resulting from the following conditions may improve when the condition is treated or addressed:

- Depression
- Side effects of medication
- Excessive alcohol intake
- Thyroid problems
- Vitamin deficiencies

(Source Chiu et al., 2006)

There is a broad range of variation in presentation of symptoms. When working or caring with someone with dementia, it is important to know what type of dementia they have, as that provides a general idea of potential symptoms commonly associated with the diagnosis. Having knowledge of the diagnosis provides a broad basis for understanding the potential neuropathology for each type of dementia, the functions effected and associated symptoms (Chiu, Chen, Yip, Hua and Tang, 2006). It is important for care staff to have an understanding of the different types of dementia to support them in providing appropriate care and support for residents (Brooker, 2012).

However, each person will experience their condition differently and knowing the diagnosis is only one part of the information you need. You also need to know the individual and their circumstances, life history, likes, dislikes and passions. It is critically important to be aware that every person will have their own unique experience of the disease. Dementia affects each person in a different way. The severity and trajectory of the disease will vary with each person and the person's personality and personal context before becoming ill impacts on how they will experience the disease. The person needs to be considered within their personal context as well as their medical diagnosis.

2.3 Individual experience of the disease

Where is the person in all of this discussion?

It has been suggested that 'dementia challenges our assumptions about what it means to be a person' (Woods, 1999, 35). Kitwood in his influential text *Dementia Reconsidered* (1997, 3), writes of the prevailing view of dementia as being a 'death that leaves the body behind'. If this orientation is considered within a Western culture with a tendency to split mind from body and to position the former as superior to the latter, this dichotomy proposes a necessary passivity of the body (Kontos, 2004). There has been a long-standing debate within philosophy concerning how the mind is related to the body and matter more generally. This debate became well known with the seventeenth century French Philosopher René Descartes, who concluded that he did actually exist from his conclusion that 'I think therefore I am' (Cogito ergo sum) (*René Descartes, 1596–1650).* This clearly places the mind as the dominant and defining feature of being 'a person', as compared with 'non-person'. This way of thinking appears to have been the dominant discourse over the centuries (Kontos, 2004). This way of thinking is reflected in comments overheard in nursing homes: 'She's lost her grip on reality', 'I'd rather be dead than demented', 'He's off with the fairies', 'and he won't care what you say cos he won't remember'. These kinds of statements reveal how, in Western cultures, intellect appears to be the major cornerstone of being perceived as a valued and useful member of society. It also suggests that ‘selfhood’ becomes compromised as primarily it is cognition that is held to be essential to selfhood. This leads to an assumption that cognitive impairment infers a loss of selfhood (Kontos. 2004; Kontos, 2013; Katz, 2012).

In *Dementia Reconsidered* (1997), Kitwood examines potential for common ground that dementia brings into the discussion on being a person. The term ‘personhood’ is explored with relationships as central, along with the absolute uniqueness of each person and embodiment as providing each person a distinctive experience. The definition of personhood used in his discussion is:

> ‘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, 1997: 8).

One of the key points within this definition is the notion that personhood can be ‘bestowed upon one human being by others’ or withheld. The term personhood also emphasises social status as a social being, worthy of respect. For personhood to be bestowed it is necessary that there be recognition, respect and trust.

Each person is profoundly different from others. Some of those dimensions of differences include gender, culture, social status, temperament, age, interests, tastes, values, opinions, politics, and obligations. Added to these dimensions is a person’s life story as every person has had different combinations of factors influencing their lives to affect the person they become?

Given the unique nature of each and every person, how then can it be suggested that an approach of 'one size fits all' would be appropriate to any situation. In addition to the uniqueness of each individual, there are also differences in each presenting case of dementia. There may be typical symptoms, but as with all conditions there are individual variations in how they experience the condition, the severity, combination of factors and their trajectory. Thus, there is no prescription for what 'a person with dementia' looks like or acts like. Each person will have a unique partnership and relationships would benefit from knowing the person as a fellow human.

2.4 The risk of overlooking the person with advanced dementia

If there is little or no regard and credibility for individuals' self-expression, by whatever means, then effectively people with dementia are excluded from any form of participation in, or influence over the support and care they receive, other than as a passive, objectified recipient. Overlooking the person with advanced dementia could be argued to be exercising social exclusion. If this was to occur on an ongoing basis, and was the main context for care practices then such routine exclusion could represent 'cognitive disablism, and is an example of the discrimination faced by people with dementia in their everyday lives' (Ward et al., 2008: 645). Rather than labelling the person with dementia as unable to communicate, an incomplete person who has nothing to say and therefore is not worth talking to or interacting with (Sabat, 2007), the challenge is to seek out the means by which to recognise, support and facilitate their input (Ward et al., 2008).

One of the keys to understanding their self-expression is to know the individual and have an awareness of their bodily expression and gestures. They might have lost most of their vocabulary and capacity for coherent verbal expression, but they can still communicate through their body; embodied communication (Kontos, 2004).

2.5 Dementia and compromised communication

Throughout normal ageing, the facility to communicate and comprehend is not necessarily impaired. However, communication capabilities may be decreased by pathological disorders, which may, or may not, be associated with the ageing process (Hugonut-Diener and Husson, 2007). There may be impairment to sensory capabilities or a frailty provoked by environmental or social circumstances or possibly discrete disease pathology such as dementia, depression or an aphasia following a stroke.

Ageing has conversely been linked with diminishing sensory capabilities. There is evidence to suggest that from the age of 20, changes in vision start to occur with diminished sensitivity to light, reduction in the ‘smoothness’ to colours and a reduced range of vision. There is generally also a ‘progressive, bilateral symmetrical hearing loss …which occurs with age’ (Hugonut-Diener, and Husson, 2007: 93).

Dementia however can affect a person’s capability to communicate in a number of different ways, commonly manifested as a lack of unified discourse, divergent content, word-finding difficulties, and the excessive use of pronouns (he, she, and it) where the subject is not clearly identifiable. The person’s ability to communicate may also be compounded by any pre-existing difficulties, such as sensory impairment. (Hugonut-Diener, and Husson, 2007). Every person is unique, and thus each person will experience their dementia differently according to their personal circumstances, the stage of the disease and the pathology (eg Alzheimer’s disease, frontal-temporal dementia, Lewy body dementia, or vascular dementia). However, it is critical to note that verbal communication, which relies on words and sentence structure, becomes increasingly difficult for people with dementia, as their brains become more affected by the disease.

At this point, it is important to note the different dimensions of communication, verbal (words) and non-verbal (gestures, facial or body expressions). Charles Darwin's *The Expression of the Emotions in Man and Animals* (1872) planted the seeds of non-verbal usage in messages. One significant piece of published work in the area of non-verbal communication is Albert Mehrabian's *Silent Messages* (1971). Mehrabian found that the aggregate effect of a verbal message is about 7 per cent verbal (words only) then 38 per cent vocal (including pitch, the tone of voice, and other vocalisations) and finally 55 per cent was non-verbal. He found the main vehicle we rely on to convey our messages, words, accounts for less than 10% of communication which is understood by others. Facial expressions, gestures, tone, pitch and general body language account for approximately 90% of the communication messages received successfully by others. Hence, any nonverbal methods such as waving and other arm gestures, nodding, smiling, calling out, humming, eye contact or avoidance, use of body as a physical barrier should be noted as communication. As word finding becomes more difficult, people with dementia increasingly rely on their body language for communication. There is growing appreciation of the significance of non-verbal practices of communication and self-expression used by people with dementia (Ward et al., 2008). A study conducted in a Canadian RAC home found that:

> 'Slight head nods, eye and small lip movements, chin thrusts, shoulder nods, hand and finger movements, as well as leg and foot shifts were intentional, informative, communicative and interactive.' (Kontos, 2004: 835)

It appears too easy to assume that because there is cognitive deterioration, people with dementia are not interested or able to interact or engage with others (Sabat and Lee, 2012; Kontos, 2004; Kontos, 2005; Kontos, 2012; Mok, 2014). However, whether the individual with dementia partakes or not in interaction may also be influenced by the existing contextual factors. The deleterious features of institutional care have long been recognised (Goffman, 1961). It is sometimes presumed that context is of limited importance in relation to people with dementia as they lack awareness of their situation, but there is evidence which robustly suggests otherwise (Clare, Rowlands, Bruce, Surr, and Downs, 2008). It is therefore important to consider the context of the interactions, since the partner in the communication interface can greatly influence the ability of the person with dementia to create dialogue (Sabat, 1991). Understanding non-verbal communication is as much a part of the caring relationship in a RAC home as personal hygiene. Indeed, Ward et al. (2008) argue that it is often the changes and modifications to self-expression and gestures communicated by people with dementia that offer the most essential information and insights into their experience of the environment and wellbeing. Watch, observe and learn.

2.6 Evolution of language and context of dementia.

When contextualising dementia, it is valuable to look briefly at the regard dementia has had historically. It begins with its etymology: Dementia (noun) 1806, from Latin *dementia* ‘madness, insanity’, literally ‘a being out of one’s mind’ from dement, a stem of *demens* ‘mad, raving’ (see dement) + abstract noun suffix of *ia*. It existed earlier in an English form *demency* (1520’s) from the French *demence*. (Etymology dictionary, https://www.etymonline.com/).

Berchtold. and Cotman (1998) in their investigation of the evolution in the conceptualization of dementia suggest that it is clear that age-related cognitive deterioration was recognised as early as the 7th century B.C through the works of such major historical figures as Pythagoras, Hippocrates, Aristotle, Plato, Cicero, and Galen. They present historical evidence supporting that in the Greco-Roman period, mental deterioration was considered by most, as an inevitable consequence of ageing, and that ageing itself was considered a disease process. Age-related cognitive decline was a common feature of life.

Awareness of dementia as this subject has also made regular appearances in literary descriptions. Chaucer [ca. 1343– 1400] remarked on the inescapability of dementia: ‘with old folk, save dotage, is namore’ (153), and Shakespeare [1564–1616] made frequent acute portrayals of dementia through his characters in a number of plays, most famously in King Lear and Hamlet. Dementia made its official appearance however in French law between 1794 and 1799, regarding a case of a woman who affected insanity to evade trial. The ‘losing of one’s mind’ was akin to insanity it seems.

In the medical field, Esquirol [1772–1840] made specific refinements in how to think about dementia, particularly regarding categories of dementia. One key refinement was making the central otherness between ‘dementia’ and ‘amentia,’ where dementia was:

> *‘the loss of mental faculties consequent on disease, and Idiocy. . . is not a disease, but a condition in which the intellectual faculties are never manifested; or have never developed sufficiently to enable the idiot to acquire . . . knowledge’* (Hunter and Macalpine, 1982, 732 as cited in Berchtold and Cotman, 1998: 178).

Up until Esquirol, there had not appeared any distinction between dementia as a medical condition and ‘idiocy’; people born with compromised cognitive abilities.

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) of the American

Psychiatric Association offers a contemporary example of the evolution of the conceptualisation of dementia in the United States. The impetus for developing a classification of psychiatric diseases in the U.S, the DSM, was to collect statistical data. It is noteworthy at this point to mention that a recording of ‘idiocy/insanity’ was made as early as 1840 (Torack, 1983). However, the first DSM was developed only after the publication in the late 1940s of the sixth edition of the International Classification of Diseases (ICD-6). In this edition of the ICD, a section on ‘mental disorders’ was included, for the first time. This early edition of DSM did not reference dementia but rather used the term ‘Organic Brain Syndrome’ (OBS), as a chronic and ‘more or less’ irreversible condition. This term were strongly criticised (Gupta, de Jonghe, Schieveld, Leonard and Meagher, 2008) but the term officially lasted until 1980 and is still used by some clinicians (Ganguli, Blacker, Blazer, Grant, Jeste, Paulsen, Peterson and Sachdey, 2011).

In 2008, the Neurocognitive Disorders Work Group of the American Psychiatric Association's (APA) DSM-5 Task Force began work on recommending revisions to the criteria for the disorders referred to in DSM-IV as Delirium, Dementia, Amnestic and Other Cognitive Disorders (Ganguli et al., 2011). The revised manual (DSM-5) released by the APA, has replaced the term ‘dementia’ with ‘major cognitive disorder’ and ‘mild cognitive disorder’. The choice of the term, ‘neurocognitive disorder’ is an attempt to help reduce the stigma accompanying the term, dementia. Another, possibly greater change to the new DSM-5 is a focus on a decline, rather than a deficit, in function.

This change in language and thus orientation moves the emphasis from memory impairment allowing for more variables allied with conditions such as FTD, which often begin less with memory alterations but more with deteriorations in speech and language. An additional noteworthy language development within this new version for classification is the emphasis on independence and autonomy. For example, it is suggested that exhibiting cognitive deficits that interfere significantly with independence is consistent with major neurocognitive disorders, while persons with mild neurocognitive disorder may retain the ability to be independent. (Warchol, 2013) This is an important distinction, and demonstrates a significant shift in focus. It leads to questions such as; is it still safe for the person to drive? To live alone? Does the person have the capacity to seek medical help for injuries and infections? These alterations in the language and orientation come from a different functional perspective, one which honours independence and autonomy over a deficit orientation.

Over the last 30 years Professor Tom Kitwood's work has been influential in challenging the predominant biomedical approaches, offering an alternative social–psychological context of the individual. Kitwood's conceptualisation of dementia highlights the dialectical interplay between neuropathological and the social-psychological context of a person, establishing a paradigm beyond the reductionist linear causal relationship between neuropathy and dementia. In some of Kitwood's writing (1989, 1990, 1992, 1993) he focused on the process of dementia rather than on the end state; highlighting dementia as a journey rather than the destination.

Undoubtedly, Kitwood's work has opened many avenues for rethinking dementia. Two key areas for reframing how we see the person with dementia is the genuine consideration of the value and influence of the social nature of human interaction regardless of situation, and the maintenance of authentic relationships supporting the individual and personhood. One example of Kitwood's discussion regarding the value and influence of the social world is as follows:

> '..human beings are far more deeply affected by the social psychology that surrounds

> them than is commonly recognised. In particular, the maintenance of self-esteem is essential for good learning, efficacy and constructive relationships with others. Conversely, when self-esteem is lacking or damaged, a person is disastrously incapacitated in many ways and easily falls into a cycle of discouragement and failure' (Kitwood, 1990: 181).

Building on these earlier works, Kitwood contributes further to the conceptualisation of dementia care. Guided by the 'I-Thou' relationship work of Buber (1937), Kitwood explored strategies for supporting the 'personhood' of individuals with dementia. Looking at relationships and how they could enhance or undermine personhood by their engagement and interaction approach (Kitwood and Bredin, 1992; Kitwood, 1997). This reconceptualising of dementia and focusing on the process and person rather than the condition and state, have reframed the thinking within the dementia field of study; within the broader psychosocial framework rather than the reductionism of biomedicine.

Of recent times, there has been increased articulation of the need to conduct research in partnership and collaboration with people living with dementia (Dupuis, Gillies, Carson, Whyte, Genoe, Loiselle, and Sadler, 2012). Work conducted in Canada on authentic partnerships looks to 'actively incorporate and value the diverse perspectives and includes all key stakeholder's voices directly in decision making' (Dupris et al., 2012: 436). The emphasis is on working with rather than for others.

This notion of 'authentic partnerships' is highlighted in the current social context by many people with dementia who have become very active advocates, (Richard Taylor, Terry Pratchett, Christine Bryden) including their use of the social media such as Facebook, Twitter and YouTube uploads (Kate Swaffer, Terry Pratchett, Alan Beamer). This relatively recent media phenomenon has bought about a much more immediate and greater public voice for people with dementia; further influencing how dementia is conceptualised and understood as a lived phenomenon. The developing mantra of 'nothing about us, without us' has taken the thinking about dementia and how one lives with dementia to another level. People like Kate Swaffer are certainly challenging the view of dementia as being a 'death that leaves the body behind' (Kitwood, 1997, 3) and has recently written about how a disturbing diagnosis (of dementia) rather than falling into despair and giving up, has triggered a deep resolve to keep living:

> 'I am living every day as if it's my last, fitting in as much as I possibly can, and squeezing all the juice out of every lemon. Now I see dementia as a gift. It's given me a clarity about life I didn't have before.' (Swaffer, 2016).

Undeniably, dementia is a condition people will die from if they do not die from some other condition first. However, this reconceptualising of dementia and focusing on the process and person rather than the condition and state, highlights that there is a lot of living to do before death. This is particularly the case if dementia is located within the broader psychosocial framework rather than the reductionism of biomedicine.

A tool that could be used by practitioners in RAC that facilitates their awareness of residents as people and strategies to support selfhood along with self-expression and gestures communicated by people with dementia would be a value.

Personal and social interactions, relationships and 'authentic partnerships' from the framework for our social selves appears to be central to maintaining identity. How the social 'self' is supported or otherwise is something that will be explored in the following chapter on the theoretical framework of symbolic interactionism.

CHAPTER THREE

3. Theoretical framework and Key concepts

3.1 Theoretical framework

3.1.1 Symbolic interactionism

All human beings are social beings, and from a symbolic interactionist perspective, the ‘self’ is considered a socially constructed entity resulting from interactions with others (Blumer, 1969; Sabat, 2001). This social dimension of life as a human being, challenges the assumption that neurodegeneration alone is responsible for the depersonalisation experienced by people with dementia.

The micro-level theory of symbolic interactionism (Blumer, 1969) provides a means of understanding how human behaviour is shaped by social interaction in a particular situation and context. With a goal of understanding behaviour and the meaning people give to their experience, Chenitz and Swanson (1986) suggest that conceptualising human behaviour in its context helps researchers gain perspective on the shared meaning of objects in human interactions. Thus, symbolic interactionism has been used as a theoretical framework for this research. Building on the theoretical framework of symbolic interactionism, I have used positioning theory (Davis and Harre, 2007) to explore how people with compromised cognition can be placed in a negative and compromised social position by well-meaning others.

To begin this theoretical discussion, we will look briefly at the evolution of symbolic interactionism as this offers some foundation for understanding the key concepts within the theory: I and me; self and mind; meaning; the ‘looking glass’-self as an object; ‘generalised other’ and definition of the situation.

Early in the 20th century with the growth of industrialisation and urbanisation came social problems not seen previously. This new social situation inspired scholars of the era to advance a discrete theoretical perspective for the systematic study of human social behaviour. This theoretical perspective which had its roots in social psychology (Meltzer et al., 1975) later became known as symbolic interactionism (Blumer, 1969). It is suggested that the thoughts of Scottish moralists of the 18th century and of some German idealists of the 19th century (LaRossa and Reitzes, 1993) were among the intellectual precursors of symbolic interactionism. The early moralist concepts of `I' and `me' provided the fundamentals for the development of symbolic interactionist thought connected to the `mind' and `self' as social products. From these idealists, the view that people construct their world based on individual perceptions of that world was drawn on in the evolution of symbolic interactionist theory (Benzies and Allen, 2001).

Mead (1925; 1934) advanced the concepts of the `mind' and the `self' suggesting that the mind resulted from an interchange of social acts, emphasising language as the most complex social action in which people participated. Mead distinguished the `self' into two components; a spontaneous `I' and a socially determined `me'. The `I' is the primary spontaneous propensity in individuals, while the `me' embodies the considered expectations of others; ‘Me’ as the social self and that develops through social interactions with others. Hense the ‘me’ is the categorised arrangement of values, characterisations and expectations of others, which from Mead’s symbolic interactionist perspective constitutes the ‘generalised other’. The ‘generalised other’ influences percieved social expectations of others, and in turn human attitudes and responses. Who or what constitutes a generalised other is suggested as being quite broad encapsulating ‘individuals, social groups or sub groups, the organised community or social class’ (Mead, 1934, 154). The central point being that ‘generalised other’ develop out of social interaction, and that each human being has more than one single ‘generalised other’.

Mead considered the `self' being understood as a process of interface between the `I' and the `me; self being a balanced interpretation of the spontaneous ‘I’ and the socially determined ‘me’. What is important to add into the discussion here is that Mead also suggested that human beings can control their behaviour from the position of the ‘generalised other’. However with compromised cognition, this could be very challenging as it requires interpretation and understanding of the differences in the generalised other (as each human being has more than one single ‘generalised other’). In addition, social interaction is seen as contributing to the development of the self concept, however this does not necessarliy result in social interaction always being positive in its impact. Where an individual has difficulty in the interface between the `I' and the `me’, the self may not have a balanced interpretation, especially if the social me is struggling to identify the appropriate generalised other for the situation.

Cooley (1902) like Mead (1925; 1934) focused on the opinions that significant others hold about the self. From Cooley’s work, significant others were mirrors in which one saw reflected back opinions others held of self; the ‘looking glass self’, seeing self as an object. Significant others held the role of social mirrors as the perceived opinion of others is reflected back to an individual. These opinions of others became incorporated into one’s sense of self, and self-worth. Thus, if there is approval of self by others, there is positive impact on self-esteem. Conversely, if others are disapproving of self, the individual will see themselves as a person of less worth with a negative impact on self-esteem.

Cooley contended that the development of self is what we perceive others opinion of us to be, what we imagine others think of our appearance, values, activities, character. However, Cooley observed that an individual with ‘balanced self –respect has stable ways of thinking about the image of self that cannot be upset by passing phases of praise or blame’ (1902, 201). This is a critical point to note when considering individuals with compromised cognition such as dementia whose ‘balanced self’ or interpretation of balanced self may be challenged by functional deficits.

Mead elaborated on the themes identified by Cooley with a stronger emphasis on the role and importance of social interaction and the use of language,

> ‘we appear as selves in our conduct in so far as we ourselves take the attitude that the others take toward us. We take the role of what may be called the ‘generalised other’. And in so doing this we appear as social objects, as selves.’ (Mead, 1925: 270).

This concept of ‘generalised other’ role, suggests that individuals responds in their behaviour and interaction, to the expectations of others. In so doing they are orienting themselves to the perceived values and norms of the others. The ’generalised other’ refers to an individual’s recognition that others hold values and expectations about behaviour. A theoretically and historically embedded interpretation of the generalised other reveals that both the personal and the social evolve and each is open to activities that bring about change. There may develop a situation where an individual’s internalised impression of societal norms and expectations is reinforced by others at the expense the particular individual as society determines human action and behaviour through the ‘generalised other’ (Blumer, 1986) as social objects.

Another dimension of symbolic interactionism talked about by Mead in his analysis of the theory was the presence of two levels of social interaction ‘the conversation of gestures *‘(*non-symbolic interaction) and ‘the use of significant symbols’ (symbolic interaction). Non-symbolic interaction takes place when an individual responds automatically to a situation, such as raising a hand to catch a ball heading for their body or face; a reflex response. Symbolic interaction by contrast requires consideration of the action or object and interpretation of the action, event or object. Interpretation of a ball coming toward an individual would have different meanings in different contexts; playing a game of cricket, playing with others in a game, being a spectator at a game, or walking down the street deep in conversation. In everyday association there are many non-symbolic interactions occurring as people respond to different stimuli, bodily movements, tone of voice, but human's characteristic mode of interaction is on the symbolic level as people seek to understand the meaning of each other's actions (Blumer, 1986).

Mead's idea of the 'the conversation of gestures' *is* an important cornerstone to his analysis of symbolic interactionism. The presentation of gestures and a response to the meaning of the gestures is often the initiation of social interaction activity. A gesture is often an indication of forthcoming action by the person presenting them. The person who responds does so in a way which recognises what meaning the gestures have for them. The person who presents the gesture does so as an indication of intention. Thus, the gesture has meaning for both the person who made it and the person at whom it was directed. When the gesture has the same meaning for both parties, then the parties understand each other. When the gesture has different meaning for both parties then communication breakdown occurs. For example, a seemingly simple gesture of holding out a hand in front of your body, when another person is standing facing you may have different meaning for the two parties. The person making the gesture is doing so with an underlying meaning of friendship, however the gesture may have different meaning to the person observing the gesture. From their process of interpretation they see the gesture as a sign of wanting something, not recognising the local social protocol of shaking hands on greeting.

This understanding of gestures leads to another component of symbolic interactions talked about by Mead, and that is parties involved in social interaction taking each other's role. 'Mutual role taking is the *sine qua non* of communication and effective symbolic interactionism' (Blumer, 1986: 10). By role-taking people adjust and adapt in exchanges based on social gesture-response action sequences. Self-consciousness is developed through action in the social domain that is completed in personal reflection. Through this process, the personal and the social, of Mead's theory of the generalised other, is located within the framework of intersubjectivity and role-taking.

Blumer (1986) is recognised with building on Mead's work and creating the term `symbolic interactionism' in 1937 (Meltzer et al., 1975; Charon, 1995). Blumer's work explores three basic premises underpinning symbolic interactionism; people, independently and jointly act on the basis of the meaning that situations have for them; meaning ascends through the process of interaction among individuals; and meanings are given and modified through an interpretive progression that is ever changing, as adaptation occurs within the context of their environment (Blumer, 2001). There is general agreement regarding the first premise that people act on the basis of the meaning situations have for them. The point of difference between symbolic interactionism and other social theories is the source of that meaning. In symbolic interactionism, meaning rises out of a process of interaction between people. The meaning of an object or a situation develops out of the ways in which significant others act toward the individual with regard to the object or situation. The actions of significant others defines the object or situation for the individual. Consequently, symbolic interactionism understands meaning as social products which are formed from and created through the defining activities of people as they interact within a social context. The third premise of symbolic interactionism mentioned above further differentiates it. While meaning is formed in the context of social interaction, the use of meaning occurs through a process of interpretation. This process of interpretation is a two-step process involving an internalised social process where the individual communicates internally identifying the meaning. Subsequent to the internal communication and interpretation process the individual then reflects, checks and reappraises the meaning in the light of the situation they find themselves in. Thus, the process of interpretation is not an automatic response based on prior knowledge, but rather a formative process, where meanings are called upon and revised as an instrument to guide action.

In exploring the meaning of situations for individuals, Thomas (1978) developed ‘the definition of situation’ concept. This concept contends that throughout their life course, humans examine and interpret the situations they encounter and define and create situations according to the symbols of their environment. The environment is thus represented symbolically to the self within which a response is framed. This concept suggests that humans respond to a given situation according to how they define the situation rather than to how the situation is objectively. Applying this ‘definition of situation’ contributes to consideration of why humans respond as they do to a given situation.

As outlined above, the micro-level theory of symbolic interactionism, considers humans as self-conscious beings, possessing selves and minds. Through the mind, humans are able to select out and indicate to others the meanings of certain environmental stimuli to which they respond. Through the concept of the mind, individuals are able to acquire control over meanings. ‘For interactionists, the mind is functional, volitional, teleological process serving the interest of the individuals’ (Herman and Reynolds, 1994: 2). Just as the mind is considered as a social product, so too is the self. The self is not present at birth, but rather develops within a social process and evolves across the lifespan of an individual (Blumer, 2001).

Environment is also seen as an important component of symbolic interactionism. Not surprisingly then, that Darwin's theory of evolution influenced symbolic interactionism (Benzies and Allen, 2001). The theory of evolution which claimed the dynamic nature of environment influenced behaviour as there was adaptation to the environment (Charon, 1995). Symbolic interactionists garnered the idea that each individual and his/her environment are intricately linked through conjoint relationships and adaptations from the theory of evolution. Individuals respond to and influence their environment and their behaviour and response is in turn influenced by their environment and how they interpret their world. This is a dynamic and adaptive process as ideas and behaviours are constantly shifting contingent on the individual interpretation of their world. However, this process of change and adaptation has limits established by the characteristics of the individual and the environment.

Perhaps one of the most significant tenets of symbolic interactionism is the notion that the individual and the environment (their context) in which that individual exists are inextricably linked. Truth is uncertain and never unconditional since meaning fluctuates contingent on the context for the individual. Theoretical inquiries regarding the concept of ‘being’ are best comprehended via individual construal of reality in a social context. So, this conversation needs to be prefaced then by why symbolic interaction theorists talk about the definition of the situation. Research framed within a symbolic interactionist theory explores the nature of individual and collective social interaction; to comprehend the importance of a situation from the perspective of the individual and the context they are in. Intrinsically, the social world subsists as a construction of human interactions. Thus, symbolic interaction offers a theoretical perspective for reviewing how individuals understand entities and significant others as part of their lives and how the social process of interpretation leads to responses within certain situations.

Fine (1993: 69) suggests that ‘few issues are as central to the symbolic interactionist perspective as personal agency’ when looking at an interactionist approach to social order. Given the prominence of interactions and the importance of context within this theoretical framework, there appears to be a balancing dilemma between agency and structure as ultimately social order is dependent on how individuals interact, negotiate, manipulate and create their ‘place’.

Symbolic interactionism recognises that much of the world an individual inhabits is not of their making (such as class systems, societal attitudes, and institutional structures) and can only really be understood in terms of the context and circumstances where these social realities are expressed. In this milieu of mediation, there is consideration of how social institutions take individuals into account.

> ‘Social organisation as a framework inside of which acting units develop their actions. Structural features, such as ‘culture’, ‘social systems’, ‘social stratification’ or ‘social roles’, set conditions for their action but do not determine their action.’ (Blumer, 1969: 87)

Thus for individuals living within social institutions, such as RAC homes which ‘set the conditions for actions’ raises the question of how does an individual with diminished verbal language maintain their social position in this social situation requiring negotiating and mediating. If diminished cognitive capacity is influencing only one person in an interaction, there may be an imbalance of influence exerted on the outcome of interactions. Of potentially greater concern for individuals unable to exert control over outcomes to interactions, may be compromised sense of self, agency and ultimately identity.

When considering social institutions, such as RAC homes, it is important to consider the complexity of contexts which exist within the composite environment of a facility. There are four broad contextual settings which exist within a RAC home. Each of these four broad contexts provide different orientations/positioning for the different collections of people who inhabit the space; home for the resident, workplace for the staff, visitation venue for family and friends; and regulatory compliance for the CEO and Board. Within an institution which 'set the conditions for actions', appreciating the difference in context can influence the perceptions of individuals capacity to exert control over outcomes to interactions.

The application of the symbolic interactionist theoretical analysis of the experiences and social outcomes for people with advanced dementia signposts that social interactions can be depersonalising if they are deemed to be occurring with an empty shell devoid of a living self. However, this idea of people with advanced dementia are devoid of self and resemble the living dead is challenged (Sabat and Harre, 1992; Kitwood, 1997). The Swedish Council on Technology Assessment in Health Care (2006) on the care for people with dementia found that, people with dementia were more awake, had less responsive behaviour, and exhibited increased levels of wellbeing when they were interacted with as autonomous individuals (cited in Edvardsson, Winblad, and Sandman, 2008).

So, in summary, symbolic interactionism_as the theoretical framework for this study is concerned with the social interaction among individuals and significant others. Communication, self-reflection and the interpretation of meaning through language and symbols, is believed to be the way in which people make sense of their social worlds. Theorists Herman and Reynolds (1994) note that this perspective sees people as being active in shaping the social world rather than simply being acted upon. This is of particular interest in this study as through observation, there is the goal to explore how a person with dementia is experiencing their world; how they are influencing their social world, and what meaning might be behind their responses to situations.

3.1.2 Positioning theory

Positioning theory is founded on a macro sociological theory of social constructionism, which has a relationship with symbolic interactionism (a micro-level sociological theory). Social constructionism gives prominence to the notion that society is dynamically and productively shaped by human beings, portraying society as being invented and constructed and our social worlds as interpretive networks of individuals and groups. The similarities with symbolic interactionism are the interactive and interpretive aspect of the theories. This is not surprising when it is considered that the term social constructionism first entered the domain of sociology in *The Social Construction of Reality* (Berge and Luckmann, 1967) which explored further the ideas of Mead (discussed above) and Durkheim. In this publication, the social order is determined within the principle that society is a product of human activity and humans are a social product. (The Oxford Companion to Philosophy; a dictionary of sociology).

There has been a discussion about symbolic interactionism, and how we use symbols and the interpretation of meaning to communicate and interact. With social constructionism, and how society constructs abstract principles and concepts (like time) we will discuss how people with compromised cognition can be socially constructed into a compromised social position.

The contemporary performance-dominated health care systems make it difficult to practice person-centred care as tensions and challenges exist within that context (Dewing, 2008). Stevens, Biggs, Dixon, Tinker and Manthorpe (2013) look at tensions which may be present within the institutional settings of RAC homes. They investigate how interpersonal features interrelate with organisational or institutional characteristics, through an analysis of positioning theory. Positioning theory has been applied in other similar areas such as facilities for older people with dementia (Sabat, 2001; Sabat 2007; Kelly 2010).

Positioning theory takes as its opening position the notion that language is the 'prime instrument of thought and social action' (Harré, 2008: 29), as Mead (1934) contributed language as our most complex social act and central to social interactions. However, as Stevens et al. (2013) point out, even though language is understood as the primary form of social interaction, it is not only language as expressed verbally which need to be considered. Non-verbal interactions, such as eye contact, or avoidance, are subtle and can be open to interpretations of meaning (Bakker, 2011). In reviewing the literature, Stevens et al. (2013) suggest that such subtle nuances of communication often result in misunderstandings, for example between older people and care staff, particularly if care staff are from a different culture. It is important to note also that the environmental and social context surrounding the person with dementia will affect their scope for registering sensory features and behavioural responses (Quinn et al., 2014). As stated above, each interaction is an interplay between people within a given context, and success of any interaction is influenced by both parties (Sabat, 2001).

If positioning theory is used as a tool for analysing the dynamics of conversations, Harre (2005) suggests there will be three main components recognised: a storyline consisting of a narrative; a fluidity of 'positions' as the different participants contributes to the storyline: and acts of speech (verbal and non-verbal) exercising illocutionary force (Austin, 1955) which reinforce social actions and presumed positions of participants. These three components of the storyline, the position and the act of speech are conceptualised as an interacting 'positioning triad' all interrelated and reciprocally determining the processes in each and every social exchange (Harré and Van Langenhove, 1999: 18).

To supplant the idea of the 'role' in social science, as discussed in the work of Goffman (1969), psychologists Davies and Harré (1990 and 1999) offer the idea of the 'position' when looking at social interactions . If positioning theory is used as a tool for analysing the dynamics of conversations as suggested by Harre (2005) involving people living with dementia and care givers, it can be revealing. Consider this 'positioning triad' with the following simple scenario:

> The time is 15:30, there has been a very active and noisy group of primary school children visiting the RAC home. One of the residents, Mrs B, is exhausted and disoriented and just wants a hot cup of tea and some quiet time. One care staff wants to make sure all residents have been to the toilet before she finishes work in 30 minutes and is taking residents one by one, Mrs B is next…
>
> The care staff walks up to Mrs B.
>
> Staff: "Come on Mrs B, time to go to the toilet"
>
> Mrs B: doesn't respond, but looks up at the staff member and gives a big sigh
>
> Staff: Bending down, places her hand under Mrs B's elbow, and says, "Come now, time to go".
>
> Mrs B: gently pulls her arm out of the staff members grasp and glares up at her
>
> Staff: "Come on Mrs B, we don't have much time. Let's go"
>
> Mrs B: Sighs and sits back in her chair crossing her arms. "No"
>
> Staff: "Mrs B, why are you being so difficult. Come on", and proceeds to try to raise Mrs B from behind her chair.

Mrs B: Throws an arm back over her head and makes contact with the staff member.

The staff member calls out to her fellow staff to come and help her with Mrs B, who is being difficult and aggressive.

There appears to be two different narratives, about the ‘positions’ of the different participants contributing to the storyline, there is a difference in power and this imbalance of power governs which storyline is likely to prevail. Acts of speech to reinforce positions again is not being exercised or understood equally. The resident may not like the ‘position’ she has been placed in. If the resident does not wish to get up and go to the toilet, then they may be thought of as resistive, uncooperative, when all they are doing is exercising their act of speech (maybe non-verbally) but from a position of minimised power. Thus, a person with compromised cognition who is challenged by word finding has difficulty rejecting the way the she is being negatively positioned by the well-intentioned care staff. Such ‘malignant positioning’ (Sabat, 2004) of the person with dementia may have their social identity constructed by others as dysfunctional, uncooperative or resistive and their personhood significantly compromised.

Through the perspective of social constructionism as our social worlds get constructed via interpretive networks of individuals and groups, beliefs and values get constructed by the dominant people within the situation. Thus, in an institutional setting such as a RAC home, the social world has many established expectations and limitations pre-constructed. Where language is the main means for influencing the construction of social worlds, or for negotiating an understanding of self, individuals with compromised cognition are in a compromised social position even before any social interactions occur.

Identity, self and people living with dementia has been a topic of debate over recent decades (Harris and Sterin, 1999; Sabat, 2001; and Surr, 2006). Historically, it was presumed that with dementia came an inevitable loss of identity and sense of self, or whether the self after diagnosis remained ‘intact’ or was perhaps ‘compromised’ before being altogether ‘lost’ to the disease (Caddell and Clare, 2011). This view has largely been replaced with a more progressive view that recognises a person’s identity is unique and co-constructed (Kitwood, 1997: 84; Sabat, 2004; Kelly, 2010), thus suggesting that any loss of identity is a potential hazard rather than unavoidable consequence of dementia (Bruce and Schweitzer, 2008).

Using Symbolic interactionism, from which social constructionism evolved, as a theoretical framework for research involving people living with dementia is not a new idea. Rodriquez (2013) based his study within a perspective rooted in symbolic interactionism, where the premise was the self is thought of as a fundamentally social process that emerges in the course of everyday interaction. This study showed that people diagnosed with dementia used narratives not only to construct a self, but also to ‘salvage a self’ in relation to a community; bringing pieces of self together through facilitated story telling.

Rodriquez (2013) found the value of storytelling as a component of the self, particularly among those living with dementia of the Alzheimer’s type. The self is constructed in interaction and, as in this case, is expressed through the stories people tell about themselves. The question of whether Alzheimer’s disease and dementia erode, degrade, or compromise the self misses the narrative dimensions of self that are constructed in interaction (Turkle, 2011).

There is research evidence that supports the use of symbolic interactionism as a framework to better understand human behaviour. Evidence also supports the role that having an approach to interactions what is enabling and supportive of the individual helps develop and maintain individual's identities but also to salvage a self in their environment. This leads us into our discussion on person-centred approach as a key concept within this study.

3.2 Key Concept: Person-centred dementia care

3.2.1 Development of the Concept of Person-Centred Care

Globally, the concept of 'person-centred care' or 'person-centredness' is a term that has become convergent within social and health care (Kitwood, 1997; Brooker and Latham, 2015). The term alludes to a standard of care that confirms that the person is the focus of care interactions. (Brooker, 2004). It is therefore not surprising that the body of literature relating to person-centred care has grown over the last three decades, alongside an academic debate and critical dialogue concerning the concept (Brownie and Nancarrow, 2013). Person-centredness is not an original concept. It has its roots in humanistic psychology through the work of scholars such as Rogers (1961) and Heron (1992). However, it is relatively new to the area of dementia studies (Kitwood and Bredin, 1992; Kitwood, 1997).

A review of the literature indicates that research in this area has focused largely on endeavouring to clarify the terms 'person-centredness' and 'personhood' (Brooker, 2004; Edvardsson, Fetherstonhaugh, and Nay, 2010; Slater, 2006), investigating the associations of the term in practice (Dewing, 2004), and determining the contextual and cultural challenges to implementing a person-centred approach (Binnie and Titchen, 1999; Medvene, 2006; McCormack and McCance, 2010). Over the last decade, there has been significant theoretical and conceptual development within the area of person-centredness as evidenced by the growth of a number of frameworks; such as the Authentic Consciousness Framework (McCormack, 2003), the Senses Framework (Nolan, Davies, Brown, Keady and Nolan, 2004), the Person-

Centred Nursing Framework (McCormick and McCance, 2006 and 2010) and Authentic Partnerships (Dupuis, McAiney, Fortune, Ploeg, and de Witt, 2014).

Despite the noteworthy developments surrounding person-centred care, there are features that would benefit from further development. One area where there has been substantial deliberation is regarding the precise concepts that underpin person-centredness (Dewing, 2008; Australian Commission on Safety and Quality in Healthcare, 2010) and secondly how appropriate of person-centred models and their implementation are (Nolan et al., 2004; Australian Commission on Safety and Quality in Healthcare, 2010). One proposition is that 'current understandings of the concept largely rest on abstractions, conceptual synergies and personal opinions' (Edvardsson et al., 2010 and 2012).

3.2.2 What is person-centred care?

The origins of the term person-centred care rests in client-centred psychotherapy and the work of Carl Rogers (1961 and 1980). Rogers began by referring to 'client-centred' counselling which was replaced over the years by the term 'person-centred counselling'. This deliberate change in language had an important consequence of considering the person pursuing counselling is the expert on themselves, and the counsellor in the role of facilitator in the individual's search for the achievement of their full potential, and understanding their real world (Rogers, 1980).

The idea of person-centred approaches was first used in the dementia care field by Professor Tom Kitwood in 1988 to distinguish them from other approaches seen in aged care that emphasised the behavioural and medical approaches and thinking in regards to working with people living with dementia. The term as used by Kitwood brings together ideas and approaches of working that emphasised relationships and communication. The term as referenced to Rogerian psychotherapy also has an emphasis on authentic relationships; being present and in the ‘now’ in both communication and engagement.

Even though the use of the concept has been extensive over the last three decades, the concept of person-centred care or person-centredness has no clear definition. There have been several analyses conducted in an attempt to define core attributes of person-centredness (Brooker, 2004; Nolan et al., 2004; Slater, 2006; Dewing, 2008; McCormack 2010). The concept of ‘person-centred care’ may differ in meaning depending on your perspective and personal context; as a practitioner, researcher, a person with dementia or as a family member of someone with dementia.

The first attempt to look at identifying some common definition of the concept was conducted by Professor Dawn Brooker. Brooker was invited to review research to identify common themes in research around dementia studies in an attempt to identify ‘what is person-centred care?’ From the results of that literature search came the conclusion that any definition of person-centred care was not straight forward but rather, as it relates to people with dementia, it needed to be a composite term encompassing four major elements (Brooker, 2004):

1. **V**aluing people with dementia and those who care for them; upholding rights, entitlements and citizenship,
2. **I**ndividuality is respected; recognising the unique personal history, personality, mental and physical health, and social context of all people with dementia.
3. The **P**erspective of the person with dementia is valid; appreciating the psychological validity of each person and that people with dementia act from
4. **S**ocial environment nurtures a person’s psychological needs; relationships are the

foundation of all human life, and a stimulating and enriched social environment will support the wellbeing of a person with dementia.

These four components (VIPS) are referred to Brooker as the ‘elements of person-centred care’. These elements can and do exist autonomously, however when they are bought together they ‘define a powerful culture of person-centred approach to care’ (Brooker, 2004, 13).

Six years on, McCormack et al. described person-centredness as:

> ‘An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development’ (McCormack et al., 2010: 13)

McCormack also suggests there are four components of person-centred care from a different perspective, focusing on person-centred nursing: being in relation, being in a social world, being in place, and being with self:

- ‘Being in relation’ highlights the prominence of relationships and the interpersonal processes that support the growth of relationships as having ‘therapeutic benefit’.
- ‘Being in a social world’ regards a person as being connected with their social world, thus meaning is created by their being in the world.
- ‘Being with self’ is closely linked to being in a social world as it *emphasises* the prominence of a person ‘knowing self’ and the ideals they have about their life, how they make sense of their world and what is happening for them.

- ‘Being in place’ suggests close attention to ‘place’ and to recognise the impact of context and thus the care environment on the care experience.

(McCormack, 2004, 33):

There appear to be significant convergence between the values underpinning both Brooker and McCormack’s core components of what constitutes a person-centred approach. However, McCormack, refers to ‘therapeutic relationships’ which seems to limit the concept to a certain paradigm where therapeutic relationships occur for ‘therapeutic benefit’, rather than as an approach to all interpersonal interchanges.

Carl Rogers' person-centred approach (1961) also informed the earlier work of Mearns and McLeod (1984) development of their person-centred methodological research framework. Mearns and McLeod (1984) saw the framework Rogers developed for therapy could be applied to research practice. They suggested that a list of key characteristics, which overlap, as associated with a person-centred approach to research; all participants are seen as equal and shown respect accordingly; respect for different frames of reference; respect for the dynamic process of relationships; maintain congruence and a sense of authenticity in self and others and be non-judgemental and accepting of the values of others.

Even though there is no clear and singular definition of person care or person centeredness, at an elementary level, we can identify similarities with these orientations. Respecting people as individuals and recognising their place as co-creators in the care partnership appears to be the consistently applied notion across the different perspectives, as does the focus on building authentic relationships. Thus, even without a clear common definition, there does appear to be strong agreement on underlying values and principles of mutual respect, acknowledging the social nature of all interactions as building relationships and that relationships are an interplay and multidirectional.

3.2.3 Person-centred dementia care: Personhood

Although it is valuable to have knowledge of the different dementias and associated characteristics, what each individual will have in common is the need of support from others to maintain a robust sense of self (Sabat, 2001) and personhood (Kitwood and Bredin, 1992; Kitwood, 1997) as their cognitive capacity to hold onto their memories and personal timeline diminishes, where they may find themselves struggling to hold onto their sense of identity; ‘who am I’?.

The term ‘personhood’, has had an historical and cultural passage (Kitwood, 1990; Singer, 1993; O’Connor, Phinney, Smith, Small, Purves, Perry, and Beattie, 2007; Dewing, 2008), but is generally used as a fundamental attribute of a human being; a person (Kitwood, 1997). Kitwood defines 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, 1997, 8).

Kitwood (1992 and 1997) maintained that recognition of personhood is essential for the physical and emotional wellbeing of all persons. However, for people who have dementia, support is needed from others to uphold and maintain their personhood as their memories which support the self are damaged and eroded by the disease. The above definition is based on a broad conceptualisation that can apply to a person with severely compromised cognitive function as it does to any other person. Much of Professor Kitwood’s work (1989, 1990, 1993, and 1997) opened up possibilities for positively influencing the perception of how dementia might be experienced through the implementation of person-centred practices. It has been suggested that the attention he drew to personhood has been welcomed as one of the most significant advances in understanding dementia from the perspective of the person living with dementia (Woods, 2001; Brooker, 2004). Scholars who are critical of the concept of 'person-centred care' (McCormick, 2001 and 2004; Nolan et al., 2004), do however recognise the intrinsic value of the concept of 'personhood'.

Despite the importance for this study of this academic debate, it is the awareness of the connections between the subjective experience and in what way it is socially constructed, both within the immediate environment and the broader social context that is of primary concern. Unfortunately, too often, it is the 'dementia' which assumes priority positioning over other aspects of an individual's life.

Kitwood states;

> 'a person in the fullest sense: he or she is still an agent, one who can make things happen in the world, a sentient, relational and historical being' (Kitwood, 1993: 541).

Regarding each person as such may support practitioners to recognise and support expression of selfhood through bodily movement and gestures. Being more aware of the visual and verbal expressions of the self of the person with dementia may support opportunities for viewing residents and engaging with them. This may encourage recognition of residents as:

> 'purposeful, sentient people and encourage (staff) to recognise and respond to aspects of the (residents) selves as they carry out care, which would foster more meaningful

> interactions and ultimately improve residents wellbeing' (Kelly, 2010: 121).

These perspectives are central premises to person-centred dementia care, and pivotal to the theoretical framework and research design of this study.

3.2.4 Debates and criticisms of Person-Centred Care

Internationally Person-Centred Care (PCC) has gathered momentum and popularity over the last 30 years (Verbeek, 2009). Even though it has been prevalent in the last 20 years in dementia studies (Koren, 2010; Rahman and Schnelle, 2008), evidence suggests this has occurred without a strong research base (Brownie and Nancarrow, 2013). Even though there has been an appearance of person-centred approaches and philosophies of care in RAC homes, this development has not been based on robust evidence, with little known about the impact of such approaches on residents and staff wellbeing. Brownie and Nancarrow (2013) systematically reviewed studies based on PCC approaches and only found seven studies which met their inclusion criteria: experimental study design; person-centred interventions; subjects and setting were residents in long term care and publication type being peer reviewed articles in scholarly journals published in English. Only one of these studies was considered robust in its research design (Chenoweth et al., 2009). The remaining six were considered to have weak methodological design thus limiting their generalisability (Brownie and Nancarrow, 2013). Additionally, Brownie and Nancarrow (2013) found conflicting findings about the benefits to residents of person-centred care. Two studies from Brown and Nancarrow's (2013) review found that a greater incidence of falls happened with residents in receipt of PCC in comparison with residents receiving traditional or usual RAC (there was no explanation other than a suggestion for further study).

It has been suggested that PCC has become popularised and politicised to now be synonymous with Politically Correct Care (Brooker, 2004). This has become the language required to be in policy and documentation because it is current rhetoric of ‘best practice’. Similarly, McCormack (2001) concludes, it is the presentation of ‘consumerism to health care’, and the elevation of a viewpoint that considers the individual that has caused the development of the ‘contemporary speak’ of person-centred care. McCormack (2001) goes on to suggest that the concept of autonomy, a core element of person-centred practise, becomes ‘untenable’ in health care settings for older people because it is based on individualism and independence, particularly in a hospital setting. There are some people within dementia care, who have opened up doubt as to whether person-centred care can actually be achieved, and suggest that it is basically an evangelical ideal (Packer, 2000).

Nolan et al. (2004) suggests that it may well be misguided to focus any definition of person-centred care on autonomy and individualism and even meeting individual need. They present an alternative way of looking at the care of older people than autonomy and individualism, based on Mulrooney’s (1997) investigation of person and relationship-centred care. Mulrooney (1997) proposes three prerequisites that principally regulate the quality of care received by older people. These prerequisites are that care staff: (i) show respect of personhood, (ii) demonstrate the value of interdependence and (iii) embrace providing care as an active choice. Nolan et al. (2004) explored an investigation of person and relationship-centred care based on Mulrooney (1997) to suggest what they consider, a more suitable underpinning for improving the care of older people other than that of autonomy and individualism. The ‘Senses Framework’ (Nolan, 1997; Davies et al., 1999; Nolan et al., 2001, 2002 and 2004) attempts to capture the subjective and perpetual dimensions of the caring relationships dynamic and reveals both the intrapersonal experiences and interpersonal processes involved the care partnership.

The focus of this framework is on relationships underpinned by the conviction that each party involved in the relationship will experience a sense of belonging, continuity, security, purpose significance and achievement (Nolan et al., 2004).

An interesting conceptual argument regarding person-centred care is discussed by Dewing (2004) looking at the potential for there to be a double-bind in this PCC caregiving situation. The appeal of PCC has led to tensions between how practice could be and how it seems to be. Dewing suggests that as a framework it is too general and doesn't inform practice, however if it was too specific it would limit its applicability in certain practice situations. Thus, it seems an unmanageable undertaking to create a detailed framework that still has the space for the diversity of persons and contexts. It has been suggested that within the context of contemporary and performance-dominated health care systems, being person-centred brings significant challenges and tensions (Dewing, 2004).

Within a performance and task focused care environment, personhood may well be compromised. The principles applied within a practice context may also influence an individuals' personhood. The concept of personhood within the discussion of dementia care arose from Kitwood's (1990 and 1997) discussion of person-centred approaches and how interactions support or undermine personhood. The concept of personhood can be challenging for conventional thinking as Heron (1992) and Kitwood (1990 and 1997) both refer to transcendence (outside the everyday usual existence) as a required component in their descriptions of personhood. This transcendence supports the potential for personal development and life experiences to influence one's personhood. This in turn suggests a dynamic concept which exists in the immediate time as well as having the potential to evolve.

Such a dynamic presentation of the concept of personhood is consistent with social constructionism (Sabat and Harre, 1992) as the social context (environment and interactions) influences a person’s response to a situation. It has also been suggested that there are in fact interconnections within the social context between three domains which influence an individuals’ personhood; these being personal, interactional and socio-cultural (Sabat and Harre, 1992). Recognising the interconnections between personal experience and how it is socially constructed, both within the immediate environment and the broader societal context may offer a more holistic conceptualisation of personhood (O 'Connor, Phinney, Smith, Small, Purves, Perry, Drance, Donnelly, Chaudhury, and Beattie, 2007).

There have been some discussions and criticisms of Kitwoods’ theory of personhood based on the perceived social inequality of the theory; suggesting it is unidirectional in its focus on the person living with dementia and not recognising the mutual aspect of relationships where the person with dementia is able to give back to others and thus influence the relationship. This unidirectional construct of the concept may make them more vulnerable and dependent on the vagaries of others (Nolan et al., 2002; O’Connor et al., 2007). It has also been suggested that traditional approaches to personhood, which focus on a person as a status rather than a person leads to a preoccupation with exploring when status starts and ends, and if indeed it can be withheld or withdrawn (Dewing, 2008). It has also been argued that there is a dilemma in Kitwoods’ definition of personhood, where moral concern for others is emphasised but in doing so, inadvertently attention is drawn to people who do not have dementia placing an inferior status of personhood on people living with dementia (Dewing, 2008).

An additional criticism is that it is essentially a non-political concept consequently limiting its scope and impact (Bartlett and O’Connor, 2007). A further criticism is relating more to family members, where the support of personhood creates additional emotional burden and grief for family members who are unable to grieve their loss due to the altered relationship (Davis, 2004).

Bartlett and O'Connor (2010) advocate for broadening the debate regarding the status of people with dementia and personhood and extending it to include citizenship. They suggest that the concept of social citizenship be applied, which would provide a fresh 'lens … to promote the status of discriminated groups of people as equal citizens with similar entitlements and rights to everyone else' (Bartlett and O'Connor, 2010: 12). They go on to suggest that by broadening the debate toward social citizenship, whilst not losing sight of the centrality of impairment, allows for greater insights into how individuals manage their experience. It is suggested that broadening the debate allows for consideration of individuals experience to be placed within their overall experience of their life course as opposed to their disease trajectory.

One question which arises from these critiques is what purpose does a concept such as person-centred care serve; as a concept, an idea underpinned by an approach to relationships that can be applied flexibly to different situations depending on the context? Given a concept is not directly informing direction or structure for practice (Dewing, 2004) might it be more suited to structuring reflection on practice? It's not a model of care and doesn't claim to be. If the concept is based on a set of principles, can principles be prescriptive or are they rather for guidance? A critique of the critique is that we are expecting prescriptive direction rather than thinking for ourselves and how the principles might be applied and implemented into our own practice context.

Many of the criticisms levelled at PCC appears to be criticising it for not being sufficiently prescriptive ‘tell me what to do and I’ll do it’. However, as part of the theoretical framework discussion, it offers building blocks of knowledge and a challenge for people to recognise that being person-centred is something that you are rather than something that you do.

3.2.5 Why a Person-Centred approach is the basis for this study

A significant legacy that Kitwood gave to the thinking regarding dementia was to generate consideration of the social aspect of the experience, in addition to the neuropathology (1989, 1990, 1992, and 1993). Indeed, Kitwood’s conceptualisation of dementia emphasised the dialectical interaction between the social–psychological context and the neuropathology of the individual (Kitwood, 1989 and 1990). This was the beginning of the development person-centred care within dementia care. This conceptualising provided a broader psychosocial framework for approaches to work in the field of dementia care, defending against the existing reductionism of biomedicine. This work has expanded academic and practice thinking and paved the way for others to build on and adapt. There are many new areas of work emerging, such as adequately involving persons with dementia in decision-making concerning their individual care (Dupuis, 2012).

Person-centred principles are grounded in social interactionism recognising the two-way interplay that occurs in interactions and the influence perspective and context has on how each environment or situation is interpreted and given meaning by individuals. The routine and task oriented, medical model of care is widespread in RAC homes and is arguably a model still prevalent in Australia (De Bellis, 2010; Parker, 2011). When such a biomedical model is the focus for the provision of care, all functional complications and emotional circumstances are credited to brain damage. Any ‘behaviour’ is attributed to the neuropathy, and the social context in which the person with dementia lives and responds is often minimised or overlooked completely (Cheston and Bender, 2004).

This perspective can contaminate thinking and minimise all expressions of distress being due to the disease and not attributable to expressions of personal need. This orientation significantly limits the capacity for residents' psycho-social needs to be supported (Dewing, 2000; Sheard, 2010). With all the best intentions, a person-centred approach is difficult to realise in a biomedical model of care which is task and routine oriented (Dewing, 2004, Brooker, 2004). By contrast, the uniqueness of each individual and their personhood is respected when perceived through a person-centred lens. Their efforts at social interaction are then respected and supported.

The application of principles of person-centred care in RAC homes can provide a foundation for a workplace culture aimed at refining outcomes for resident and reducing responsive behaviour (Koren, 2010) and understanding communication efforts (Ward et al., 2008). When working from a premise of PCC an attempt is made to understand residents in terms of their unique personality, preferences, abilities, needs, and life experiences (Chenoweth et al., 2009; Koren, 2010; Leutz, Bishop, and Dodson, 2010). This knowledge supports a more holistic approach to the care relationship. This approach is significantly different from hierarchical management strategies and structured routine practices prior to the mid-1990's, which muted personal expression and the potential for more individualised care (Brune, 2011).

The attention given to person-centredness illustrates society's interest to equalise the current imbalance in the care environment, moving toward a care ethos that is relationship focused, collaborative, and holistic and away from one that is disease positioned, medically oriented and dominated, and often fragmented. A person-centred approach to research has been explored

(Mearns and McLeod, 1984) and found to be suitable as a foundation for a methodological foundation; appropriate as a foundation of an inclusionary consent process (Dewing, 2008); and has the attributes of a framework for exploring the utility of PIECE-dem as a practice tool. The challenge of providing operative, person-centred care, though, is often in how it is translated into practice. Even though the notion of person-centredness is understood at a rudimentary level, the test is often recognising it or translating it into practice (Dewing, 2008).

Reflective practice has been suggested as one possible vehicle for assisting the translation of knowledge into practice across a number of academic disciplines. The understanding of the geneses of reflective practice may vary contingent on a persons' context (discipline and the perspective), however, many authors (Fook, 2002; Fook and Gardner, 2007; Johns, 2005; Redmond, 2006) concur that it was the early work of Dewey (1910 and 1916), that was built upon by Schon (1983), Argyris and Schon (1996) and Mezirow (1990) that established the fundamentals of reflective practice. Dewey was a practical educator and a rationalist philosopher (Rolfe, 2014). He does use the words 'reflection' and 'thinking' more or less interchangeably (Dewey, 1916), which may have contributed to why reflection is frequently viewed as little more than simply thinking. However, his notion of thinking is intricately connected to doing 'Mere activity does not constitute experience'. Rather:

> 'To learn from experience' is to make a backward and forward connection between what we do to things and what we enjoy or suffer from things in consequence. Under such conditions, doing becomes a trying; an experiment with the world to find out what it is like; the undergoing becomes instruction—discovery of the connection of things.' (Dewey, 1916: 107).

Hence, to learn from experience was an active process that involved forming premises and trying them; doing them, or trying them and experimenting become informative and self-educative. In a process of developing person-centred practice it is reasonable to suggest that times of reflecting on practice would support the evolution of practice; ‘how could I have done that differently to have had a more positive outcome’?

Reflection is a central activity to the interventions in this study. There are guided reflections after each observation with the goal of understanding what was observed and gaining a shared view of how the person with dementia was experiencing their immediate environment.

The notion of reflection appears to have gained momentum in the last few decades. Some of these developments will be discussed in Chapter Four of this document. It was interesting to note that the Nursing and Midwifery Council (NMC) in the UK have reflection stipulated is a competence that must be established before gaining entry onto the register as a Mental Health Nurse. This is requirement for all new preregistration nursing programmes from September 2011 (Clarke, 2014); reflection as a competence.

Reflection is considered not only as a supportive activity to translate theory into practice, but also to be a good tool for self- education. It is also a keystone activity for this study.

CHAPTER FOUR

4. Reflective practice

4.1 Reflection in learning and developing practice.

The notion of reflection is not a new phenomenon. Socrates (469/470-399 BCE) talked about living the 'examined life', (Plato's Apology (38a5-6) to meet the moral dilemmas of the world with ethical, compassionate and humane engagement; encouraging critical self-examination. Of more contemporary times, Fook, White and Gardner (2006) conducted a literature review of on reflective practice and critical reflection and found there had been enormous attention over the last several decades in reflective practice and critical reflection exercised. Possibly this is an indication of a resurgence in seeking some foundational knowledge in this fast-changing world we live in.

The volume of written literature attested to the popularity of the notion of reflection across a variety of fields such as allied health, social work, law, human resources and management, nursing, medicine and education (Fook et al., 2006: 4). The concept of critical thinking is also present as part of a broader process in allied areas for example transformative learning (Mezirow, 1991) and action research (Reason and Bradbury, 2001). In the field of social theory, critical reflection is talked about as a feature of 'reflexive modernity' (Beck, 1992). Fook et al. (2006) suggest that the literature review was difficult and complex due to the vast range of application situations. A further compounding factor was the customary disciplinary precincts and collective standards of academic rigour were applied differentially. However, even with these compounding factors, the literature fell broadly into three categories based on three different purposes reflective practice was used for: primarily educational in its focus; located within the methodology of research; or focused on the development of theoretical frameworks to fathom the occurrences in social life and/or applying them in professional or education practice (Fook et al., 2006). One area identified in their review as lacking was robust empirical research which demonstrated an evidence base for supporting the practice of reflection. A counter argument on this point is put forward by Rolfe (2014), who claims that where the dominant health care model which stresses all practice needs to be informed by evidence-based research, largely resulting from quantitative data, then this paradigm limits the potential for experiential knowledge to be taken seriously (Rolfe, 2014).

There is a vast range of literature and streams of thought around the notion of reflection. As with most fields in academia, there develop strains of thought and activity from foundational work. Kolb (1984) incorporated reflection into his learning cycle as he considered learning from life experience as differentiated to classroom and lecture learning. The accent with experiential learning is frequently on personal experience and action occurring in-context as the principal basis of learning, regularly playing down a role for analysis and academic knowledge (Kolb, 2015). For Kolb learning has its foundation in epistemology. He quotes Piaget's position that 'it is impossible to dissociate psychology from epistemology . . . how is knowledge acquired, how does it increase' (Piaget, 1978 cited in Kolb, 1984, 37).

Even though many of the ideas of Kolb's 'experiential learning' are intrinsically appealing, Miettenen (2000) has criticisms of Kolb's learning cycle in several areas. Firstly, he questions the efficacy or authenticity of pulling together doctrinaires from diverse backgrounds, causes and dissenting origins as originators and `supporters' of experiential learning. This takes place when Kolb pieces together Carl Jung, Kurt Lewin and John Dewey with humanistic psychologists (Carl Rogers and Abraham Maslow), as originators and creators of experiential learning. Miettenen questions Kolb's motive as less for critical appraisal or interdisciplinary collaboration but rather an effort 'to construct an 'attractive' collection of ideas that can be advocated as a solution to the social problems of our time and to substantiate the usefulness of his learning style inventory' (Miettenen, 2000: 56). The second significant criticism is the separation of learning from a cultural and social environment. This presents a dilemma for individuals and poses the query of how a more socially aware learning can be conceived. This dilemma was posed by Holman and his colleagues (1997). They discussed the use of activity theory concept as 'mediational means'. By these means they argued that any thinking occurs as an 'internalisation of interpersonal transactions', and continue on to say: 'people create and are created by their social conditions' (Holman et al., 1997: 140).

From the perspective of a symbolic interactionist it would be reasonable to suggest that it is unrealistic to disaggregate the experience of an individual, from the relational and social processes that make any action of experiencing personally meaningful. The relational and social processes are inextricably linked to their personal context. An important issue here is that all our means of knowing are socially generated as there is no universal measure (Woolgar, 1996). In addition, there are certain work place habits or practices that seem 'right' and natural at an unspoken level, in a local ontology, where people feel permitted to take certain 'truths' for granted (Ramsay, 2005). Such a situation can inhibit the uptake of reflective learning from practice in two key areas; if much of the local ontology is implicit and taken for granted then there is less room for criticism of those applying reflective learning; and if reflective learning is concentrated on individual knowledge this may jeopardise the all-important social processes in constructing the shared context. (Ramsey, 2005).

As can be seen from the brief discussion above, the notion of reflection in learning and developing practice has been applied in many different ways. To provide a solid theoretical foundation on reflective practice, the work of John Dewey and David Schon, the founders of reflective practice in contemporary times will be discussed.

4.2 What is reflective practice?

To get a solid understanding of the concept of reflective practice, there needs to be some grounding in the origins of the concept. John Dewey (1859-1952) was an American psychologist, philosopher, social critic, educator and political activist (Field, 2016). It appears that all through his long career and life and across all his areas of interest, Dewey maintained his contention that the human individual is at the very essence, a social being; the environment is not passively perceived but actively manipulated through interaction. His conceptions of reflective learning and thought are offered most plainly in his works on logic and thought: *How We Think* (1910 re-released 1933), *Essays in Experimental Logic* (1916) and *Logic, Theory of Inquiry* (1938). Dewey (1910 and 1933) outlined first what reflective inquiry wasn't (most beneficial given the shortage of definitional problems and clarity related with the concept of reflective practice): it is more than just pondering thoughts of interest, which regrettably appears to be a common understanding of reflective thinking. Dewey saw reflective inquiry as;

> 'active, persistent, and careful consideration of any belief or supposed form of knowledge in the light of the grounds that support it and the further conclusions to which it tends (that) constitutes reflective thought' (Dewey, 1933: 16*).*

Routine thinking concerned Dewey. If activities are directed by habit, tradition, impulse, or authority, and individuals don't trouble to consider their work intelligently then there is the potential to become slaves to routine. Dewey wanted people to not only think, but to think in context. 'While we cannot learn or be taught to think, we do have to learn how to think well, especially how to acquire the general habits of reflecting' (Dewey, 1933: 35); reflection on experience to inform practice. The catalyst for reflective thinking for Dewey appears to come from the feeling of conflict or doubt where the situation encountered doesn't fit with the routine response. Five main phases of reflective thought were suggested. They were not intended to be necessarily in a linear order but rather as more fluid:

1. Suggestion: Presenting circumstances are viewed as problematical, and several imprecise possibilities are considered.
2. Intellectualisation: Presenting circumstances are felt and intellectualised into a problem to be resolved.
3. Guiding Idea: One idea is presented as a primary proposition, or hypothesis, followed by other propositions; the primary proposition can serve as a working hypothesis to start the thinking and monitor other activities in the gathering of alternative material.
4. 4. Reasoning: Linking present and past propositions is achieved by reasoning and this step aids elaboration of the options that reflective inquiry has arrived at, as well as extending the supposition as an idea or the mental elaboration of the idea.
5. Hypothesis Testing: There is a cultivated proposition reached, this hypothesis is tested; this testing can be in thought (imaginative action) or by overt action

(Farrell, 2012: 10)

Dewey's approach to understanding thought genetically was controversial for his time. To consider thought as the creation of the interaction between the individual and environment, and subsequent knowledge as exercising practical instrumentality in the control and guidance of that interaction was new thinking. From this point Dewey adopted the term 'instrumentalism' as an appellation that was descriptive for his new approach; 'instrumentalism maintaining: a doctrine (where) ideas are instruments of action and that their usefulness determines their truth' (Merriam-Webster dictionary, https://www.merriam-webster.com/dictionary/instrumentalism)

Subsequent to Dewey's avant-garde views on reflective practice, there appears to be no academic discussion around reflective practice until the 1980s and the work of Donald Schon (1983 and 1987). It is noteworthy that Schon concentrated his dissertation on Dewey's theory of inquiry (Farrell, 2012), which may well have influenced his pragmatic framework and influential book, *The Reflective Practitioner: How Professionals Think in Action*:

> 'We are in need of inquiry into the epistemology of practice. What is the kind of knowing in which competent practitioners engage? How is professional knowing like and unlike the kinds of knowing in academic textbooks, scientific papers and journals?' (Schon, 1983: vii).

Donald Schon was an insightful academic. His considered opinion was that in the 1980s, the educational needs of the practice disciplines such as nursing were not being met by higher education. He was suggesting that traditional means of gaining knowledge did not support practitioners in learning; 'what aspiring practitioners need most to learn, professional schools seem least able to teach' (Schon, 1987: 8). Provocative but quite possibly true, as learning institutions were not able to impart what practitioners needed most to acquire; since what they most needed to acquire was basically not learnt from teaching but learnt in practice, on the job. Practice knowledge was typically learned on-the-job and typically tacit and through trialling, not in a lecture theatre or through reading. Schon, like Dewey and Rogers before him, alleged that the part the educator plays in learning was not to teach but rather to facilitate learning (Schon, 1987), encouraging active and thoughtful thinking.

Thus, for Dewey and Schon, thinking is a dynamic and fluid process. It is a process that includes forming hypotheses and trialling them in practice. Reflection or thinking is consequently a form of investigation. For reflective practitioners, reflection is not an activity for the armchair, it happens in practice; reflection, in Dewey's words, involves ‘doing something overtly to bring about the anticipated result, and thereby testing the hypothesis.’ (Dewey, 1916: 115)

This may seem a counter intuitive understanding of the term reflection, considering reflection as an action and doing rather than more a passive activity as a way of thinking. However, there are many similarities between Dewey's description of reflection and what Schon four decades later referred to as ‘reflection-in-action’ or basically as reflective practice. Reflective practice Schon described as ‘a reflective conversation with the situation’ (Schon, 1983: 163). Reflective practitioners reflect in the here-and-now, on- the- job and the outcome of their reflections are trialled in practice; an ongoing learning with a spontaneous and continuous interplay between thinking and action (doing), in which possibilities are framed, trialled and reviewed.

By putting forth the notion that practitioners can reflect-in-action, Schon tries to redress the ‘rationalist-technicists’ time-based break between action and reflection in the process discussed by Dewey. For Dewey’s reflective inquirer, time and action is suspended when challenged with a problem and return to action when the reflective model has gone through the phases and reached its conclusion. Schon’s reflective practitioner appears to reflect during action, in what Schon referred to as the ‘action present’. The action present is ’a period of time, variable with the context, during which we can still make a difference to the situation at hand- our thinking serves to reshape what we are doing while we are doing it’ (Schon, 1987: 26). Thus, the environment is not passively perceived but actively engaged with and manipulated through interaction.

Building on the work of the idea of a reflective practitioner, Johns (2013) outlines his typology of reflective practices, and suggests that reflective practices extent across doing reflection to being reflective (Table 1.) Doing reflection is indicative of an epistemological approach using reflection as a device or tool. He suggests that reflection is more than this and that being reflective expresses an ontological approach about ‘who I am’, rather than ‘what I do’ more relevant to a practice setting where the primary contact is the self, such as nursing, or care staff.

Table 1: Typology of reflective practices

Reflection – on experience	Where the practitioner reflects on a given set of circumstances after the event to learn and enlighten future practice	Doing reflection
Reflection – in action	Where the practitioner retreats, reframes the practice circumstances so as to proceed to sought after result	
The internal supervisor	Where the practitioner has an internal discussion, whilst conversing with another in an attempt to make sense and respond appropriately	
Reflection – within the moment	Where the practitioner is aware of their pre-existing patterns of feeling and thinking and respond spontaneously whilst maintaining the intent to achieve appropriate practice	
Mindfulness	Viewing the situation for what is there without misrepresentation	Being reflective

Source; 1 Johns, C. (2013) Becoming a reflective Practitioner P: 3

In the process to becoming a reflective practitioner, Johns (2013) suggests that through writing and reflecting on their work practices, practitioners learn to be aware of self within practice; patterns of feeling and thinking, responding spontaneously to situations. As shown in the progression of Johns’ typology of reflective practice, the definitive manifestation of this awareness is mindfulness, where the self is seen clearly without misrepresentation. As Wheatley and Kellner-Rogers write;

> ‘The more present and aware we are as individuals and as organisations, the more choices we create. As awareness increases, we can engage with more possibilities. We are no longer held prisoner by habits, unexamined thoughts, or information we refuse to look at.’ (Whealey and Kellner-Rogers, 1996: 26).

Certain qualities of mind were identified by Fay (1987) as prerequisite to reflection: commitment, curiosity and intelligence. Commitment can be a type of energy which tends not to be present if the practitioner has become blunted or numb through working in an unsupportive and generally stressful or boring environment, where work satisfaction is gained through finishing the shift with minimal disturbance. Such people tend not to enjoy reflection, as they don’t like what’s mirrored. Being curious the practitioner is not protective but rather open to fresh prospects. These qualities of commitment curiosity and intelligence are important to counter the other adverse qualities of the mind associated with ignorance, habit, resistance and defensiveness, (Johns, 2013).

Just as Fay (1987) identified prerequisites to reflection, there were also barriers identified that influence the practitioners’ aptitude to respond otherwise to workplace practices even when there is awareness of more appropriate ways to respond. These barriers fall broadly into three categories: tradition, the ontology of the workplace, the customs, norms, patterns ‘that’s the way we do it here’; force, the construction and maintenance of relationships via the use of force or power; and embodiment, represented by work colleagues normally feel, think and react to the world, where change is not welcome (Fay, 1987).

An everyday reality of practice for RAC staff is thinking on one's feet and acting accordingly. What Walker (2012), found was the need to embed opportunities for reflection into daily schedules and practices so as staff could construct their own learning- from reflecting on their practices, developing the capacity for ‘reflecting -in-action’, and learning on the job. Reflective practice here is not secluded introspection but rather, it is strongly evidence based, where information is systematically collected and decisions/conclusions (instructional and otherwise) are made founded on evidence. Reflective practice therefore becomes ‘a compass that allows us to stop for a moment or two and consider how we can create more learning opportunities’ (Farrell, 2012, 15). As John Dewy (1933) stated ‘We do not learn from experience … we learn from reflecting on experience.’

The framing of reflective practice is in part determined by the context of its application. As Fook et al. (2006) found, the literature in their review fell broadly into three categories based on different applications of the concept: an educational focus; research methodology; or understanding the nature of social life in education or professional practice. I am contending that reflective practice was used across all three purposes within this study; during the training pre-observations, reflection was part of the interactive sessions; in the methodology as debriefing and reflecting on observations was a key component; and understanding the social life of residents and how they constructed and influenced their care environment.

4.3 How can reflection influence person-centred care in practice

How can staff in RAC homes be supported to appreciate the context and many subtleties they encounter on a daily basis within their work place? As was discussed in Chapter Three (page 63) there is no clear common definition of person-centred care, however, there does appear to be strong agreement on the underlying values and principles of mutual respect, acknowledging the social nature of all interactions as building relationships and recognition of the importance of relationships. Reflecting on situations and thinking about what happened and what the meaning might be for the person, may assist a more authentic appreciation of the person and facilitate a genuine person-centred approach. It has also been suggested that the trust and openness of a person-centred approach can be an effective enabler of research participants to explore more openly areas of vulnerability which may be restricted by a more measured and structured method (Mearns and McLeod, 1984).

Many situations practitioners in RAC find themselves in may be in unchartered waters for them. They may find themselves in problematic situations in which they are unclear what to do and how to respond. Problematic situations occur in many different settings, and answers therefore are more likely to be found within the specific contexts in which the problematic situations occur and are thus framed. In an oft quoted passage written by Schon:

> ‘In the varied topography of professional practice, there is a high, hard ground where practitioners can make effective use of research-based theory and technique, and there is a swampy lowland where situations are confusing `messes' incapable of technical solution….in the swamp are the problems of greatest human concern.’ (Schon, 1987, 42*)*

Hence empirical science and evidence-based knowledge may not support them in their problem solving and decision-making process. Schon (1987) claimed that for practitioners who go into the `swampy lowlands' unvaryingly would be using their intuition, `gut feeling' and trial-and-error in managing unknown situations considered as uncertain and unique. In these situations, Schon (1987) suggested that practitioners reflect, and in so doing, apply tacit knowledge, in which the `theory' enlightening action is rooted in the action itself.

In a practice discipline such as nursing or personal care, it is reasonable to expect that people learn through doing. There may be theories of how to do ‘it’ but that doesn’t mean people know what ‘it’ is. Learning in blocks of theory, then blocks of clinical practice can result in a practice-theory gap, where there are quite different perceptions of the situation. Reflection of experience on clinical practice can be used as a microcosm of the culture of caring interactions. Within each experience significant aspects of the caring interaction can be pulled out as a focus for attention, yet always set against a background of the whole culture of caring interactions. Different aspects of the story can be pulled out from the story canvas and explored against the story’s contextual and wider theoretical, philosophical and background – engaging in a dialogue of the particular with the universal. Johns (2013) suggests that where there is this interplay between ideas about practice and practice as experienced, the practice-theory gap is diminished.

It would seem reasonable that a practice discipline has practice at the core of its program of study and professional development. If there is a position taken that considers practice as an apprenticeship and the learning of the craft is mentored by others within the practice environment, there is the ongoing opportunity and openness to learning. Within such a paradigm, reflection on experiences can result in ongoing professional learning (Walker, 2012; Johns, 2013). Reflection on practice can occur individually in what Schon (1987) called the ‘action present’ or through guided reflection (Johns, 2013). In guided reflections, the guides don’t set out to teach people. The intention is to open a learning space so practitioners can learn from themselves. Guided reflection requires skilled guides. The guide points the way forward, sometimes leading from the front other times taking a back seat, always mindful of the groups’ performance and learning outcomes. Guidance demands a wide range of knowledge yet without setting oneself up as expert. Guides will also need an understanding of the community of inquiry within which the guided reflection is taking place - organisational and situational context are significant factors to be aware of during reflections. This can be achieved by establishing teacher –guided reflection groups initially expertly facilitated and subsequently peer led, where each person takes responsibility for their own performance of the outcomes reached by group as a whole (Johns, 2013). This was the model used in this study.

It has been suggested that through guided reflection there is an opportunity to appreciate the differences in context (staff and resident) and to consider different interpretations (Johns, 2013) of what staff encounter and see on a daily basis within their work place. Person-centred care is broader than having the person at the centre of thinking. It is also about respecting people as individuals and recognising their place as co-creators in the care partnership and unique individuals who are capable of building authentic relationships. PIECE-dem was selected for use in this study as it appeared to have the potential to support RAC practitioners to develop a greater understanding of the unique character of the individual and an appreciation of the exercise of agency. Also, there appeared to be the, potential, through guided reflection to develop a deeper appreciation of person-centred approach.

4.4 PIECE-dem potential for building reflective practice

Reflective practice is the cornerstone of PIECE-dem. The raw data collected during PIECE-dem observations is quite meaningless as it tells only the amount of time spent interacting or engaged. It is only when the data is examined in relation to the narrative recorded during observations that a picture emerges. The picture that is constructed comes to life when there is a discussion about what all of this information and reflection on what the actions might mean to the person being observed; what does it tell us about the agency exercised by the person;

patterns or trends; activity that indicated capacity; influence exerted on their environment. It is only through reflection that the picture begins to have a story, and for the observers an appreciation of the activity within its social context.

Reflection on observations is a critical component to understanding and making sense of what was observed. Reflective practice was evidence based, and the information was systematically collected via PIECE-dem discussed and conclusions made based on this information. This component of the study was clearly centred on the notion that ‘We do not learn from experience … we learn from reflecting on experience.’ (Dewey, 1933) All of the learning from the observations resulted from reflecting on the story revealed. This indicates the potential for ongoing use of the PIECE-dem process to embed reflective practice into practitioners’ work practices.

CHAPTER FIVE

5. Method

5.1 Rationale and Research Objectives

In the residential care setting, people living with dementia, particularly advanced dementia, face particular barriers when attempting to communicate their needs and experiences to others. This often occurs through no malice or ill intent on behalf of the staff, but in a model of care focused on task completion, the person is often overlooked. The consequences of misunderstanding of the needs of people with dementia expose these people to receiving inadequate and often less than appropriate care.

The overall aim of this research is to pilot the PIECE-dem as a tool for practitioners to use in the Australian RAC homes setting.

A subsequent research question is:

Can PIECE-dem increase understanding and observational skills of practitioners to inform quality care to residents with dementia?

Objectives:

1. To examine the value of PIECE-dem as a tool for use by practitioners
2. Develop a set of recommendations to inform the adaptation of the original PIECE-dem manual for use by practitioners.

5.2 Research design

5.2.1 Site selection

This research is a pilot study to determine the utility of a tool, to ascertain the potential value and use for practitioners rather than the original researchers. As such the decision was taken to select a field site which would provide optimal opportunity to trial the tool and minimise organisational obstacles and issues to undermine the trial.

The research field site was a RAC home well known to the researcher from previous work and research projects. This facility had 73 Commonwealth licensed RAC beds and had an ‘ageing in place’ policy where possible. During previous work and research projects, this facility demonstrated a person-centred approach across their organisation. This approach was evident in organisational documentation, management practices and staff resident interactions. Nevertheless, it was important to measure the culture of care as part of the research design, particularly in the light of a recent change to senior management. Management and facility staff (including RN’s, care staff, domestic and ancillary staff) verbally indicated their support of the research study and the researcher’s presence in the facility. In addition, there was a letter of support from the management of the facility which accompanied the ethics application.

A research plan with timelines and scheduling was agreed to between the researcher and the management of the facility. An information sheet was distributed to all staff. Included in this information sheet was a date for the general briefing session to be held at the facility. To ensure no staff member missed receiving the information, the sheet was attached to each staff members pay slip. In addition to the information sheet, was a copy of the survey comprising the Individualised Care Inventory and an envelope for return of survey was also attached.

Three weeks after the distribution of the information sheets a briefing session on the research project occurred within the facility. All staff, inclusive of care staff, domestic and ancillary staff, were invited to attend. The facility manager introduced the research and student researcher. An outline of the research, purpose, timelines and expected implications for the workplace was provided; what was proposed and why it was occurring. There were information sheets available for staff to take away with them at the conclusion of the briefing session (Appendix 2).

5.2.2 Recruitment of individual study participants

5.2.2.1 Residents

Research participants were identified by clinical leaders in each of the two wings participating based on clear inclusion criteria. Inclusion criteria for participants incorporated cognitive impairment resulting from a dementia. Exclusion criteria included lack of significant cognitive impairment, having past paranoia, residents who were admitted within the last six months before the study or residents whose mental and physical health was deemed by the charge nurse to be particularly unstable.

Residents were identified as eligible to participate in the research due to their Psychogeriatric Assessment Scale score and Cognitive Impairment Scale (PAS-CIS) and Modified Barthel Index scores; low scores which indicate high dependency. Scores were documented as part of everyday practice and the care planning process and thus were readily available for the researcher. As well as a diagnosis of dementia, eligible residents needed to demonstrate one or more of the conditions below;

- Verbal communication is compromised
- May be in a withdrawn state

- Are documented to have high levels of responsive behaviour
- May be overly agitated or mobile
- Have significant sensory loss, such as sight or hearing

Residents, who met the above criteria, but currently experiencing acute physical or mental health problems as identified by the charge nurse, were excluded from participating. Care interactions with recruited residents, whose legal representative consented to the study as proxy, were observed at each observation session (when consenting on the day).

5.2.2.2 Staff- mentors

All staff, inclusive of care staff, domestic and ancillary staff, were invited to attend a briefing session on the research project at the facility selected as the research site. At this briefing session the researcher provided an outline of the research, purpose, timelines and expected implications for the workplace so there is a clear understanding of what is proposed and why it is occurring.

At the conclusion of the session, all staff were invited to write down names of staff they believe were clinical leaders in the two RAC nursing home units participating in the research. Envelopes and a locked mail box will be placed by reception for staff to post their nominations. Senior management personnel were also asked to provide a short list of names who they believed were clinical leaders within the two participating wings. Both these sources of names were collated by the researcher.

Nominated staff were approached with an information sheet outlining the time commitments, activities and roles and responsibilities expected of mentors for the duration of the study. This information sheet for mentors clearly stated that participation is voluntary and by personal choice. Staff members nominated as mentors who agreed to the commitments and signed a consent form were invited by the researcher to be trained in person-centred care and the application of PIECE-dem. To determine the utility of the tool for practitioners, these mentors who are practitioners will continue as rostered staff and continue to work alongside their colleagues when not involved with observations, except for the one-hour observations.

Staff members who consented and agreed to participate as mentors participated in one on one interviews pre and post the trial, and completing the general survey. After completion of the survey, these staff members attended a seven-hour training on person-centred dementia care, before attending the seven-hour training on how to use the PIECE-dem tool.

5.3 Ethical approach to the Research: Person-centred principles

5.3.1 Researching in a person-centred charter

Carl Rogers', person-centred approach (1961) informed Mearns and McLeod’s (1984) development of their person-centred methodological research framework. There was a belief that the framework Rogers developed for therapy could be applied to research practice, providing a framework for more comprehensive understanding of people behaviour within which existing research practices could be located.

Mearns and McLeod (1984) suggest that a list of key characteristics is concomitant with a person-centred approach to research. There is suggested overlap, but to clarify the characteristics considered central to the approach to a research participant taken by a person-centred practitioner, the researcher needs to:

1. See the other person as an equal, with their own perceptions, feelings and preferences being respected
2. Reflect the phenomenological nature of person-centred philosophy in highlighting the aim of the research is a sensitive exploration of the other persons frame of reference;
3. Respect that the reality of research participants and the relationship present between participants and the researcher, is conceptualised as always being a process, dynamic, not static in nature;
4. Seek to preserve congruence and genuineness in self and others;
5. Be non-judgemental and accepting of the values of others

There is the suggestion that characteristics, when taken as a whole, define a distinctive and powerful perspective on the research act (Mearns and McLeod, 1984: 372-373)

By acknowledging the individual as an active contributor in the research process, potentially reduces the power imbalance that could transpire between researcher and participant.

> ‘The primary objective of the person-centred researcher is to give an account of the frames of reference or perspectives of research participants. In practical terms this objective will often be fulfilled by constructing detailed descriptions of their perspective.’ (Mearns and McLeod, 1984: 388).

There is great diversity in how person-centred philosophy has been perceived over the decades; however, these key characteristics Mearns and McLeod developed in 1984 as a framework, is consistent with the principles of person-centred practice suggested by Alzheimer’s Australia in 2016. Person-centred philosophy provides a concept to work within from whatever perspective, researcher, practitioner or family member, based on key principles of person-centredness (Dementia Australia, 2016):

- Valuing people and considering all people with self-worth and respect by an awareness of and supporting personal values, beliefs, perspectives, and preferences;
- Autonomy and the provision of choice and ensuing respect for choices made- thus balancing risks, rights, and responsibilities;
- Life experience being acknowledged and sense of self being supported by acknowledging a person's past, present and future anticipations;
- Collaborative relationships, and appreciation of the importance of social connectedness and opportunities to engage in meaningful activities.

These principles recognise the key role the environment has on enabling independence and autonomy of all stakeholders.

The characteristics or principles of person-centredness underpin ethical practice and research. That is why they were selected as a key element of this study design, method and implementation. Conducting research underpinned by person-centred principles leads into a discussion of inclusionary consent to establish the methodological basis for the decision.

5.4 Consent and ethics

This study being underpinned by person-centred principles required careful consideration regarding consent for participants with compromised cognitive capacity. Given the complexities of this environment, guidance for ethical research conduct was sought from the Australian Government National Health and Medical Research Council (NHMRC) guidelines, Australian Code for the Responsible Conduct of Research (The Code) and the National Statement on Ethical Conduct in Human Research. These guidelines and codes govern the ethics of all research involving humans in Australia. These guidelines and code of conduct underscore the core principles of person-centredness; respect for the inherent value of human beings, of concern for the wellbeing of study participants, and of the obligation to treat people with equal respect and consideration. Additional guidance was sought from experts in dementia care research, particularly from Dewing's (2002 and 2007) 'Process of Inclusionary Consent'; a way for researchers to engage with persons who have dementia. This study received ethics approval from the Flinders University, *Social and Behavioural Research Ethics Committee* Project Number **6541.**

5.4.1. Consent - Ongoing Consent

Considering the emplaced nature of study participants, in that they live in the places selected as a research site and are unable to move freely out of the environment, ongoing consent was a process employed. In keeping with the person-centred principles underpinning this research, consent was not only considered in its written form, but also as embodied and oral, and as an ongoing and negotiated process (Dewing, 2007).

'Institutional ethics' (Butterworth, 2005) appears to seek consent for specific episodes of care such as surgery or other procedures. Consent is not sought for the daily episodes of care and treatment for those receiving long term care (Butterworth, 2005). However, for people living in long term care situations ongoing consent is a process. Context and personal situational variations are relevant, no person is static in how they experience their environment or context. Thus, consent should not be considered a one-off event. 'The seeking and giving of consent is usually a process rather than a one-off event' (Butterworth, 2005: 40). Therefore 'institutional ethics' is inconsistent with this study's ethical and theoretical framework. 'Situated ethics' (McKee and Porter, 2009) is more dynamic, diverse and context bound because it is constructed by current context and the immediate situation. McKee and Porter claim that for a researcher to comply with the general ethics principles when making ethical decisions, they should:

> 'attend to the complexities of context, of place, of situation, … of methodologies, and of ……persons/players/residents*'* (McKee and Porter, 2009: 47)

This also implies that the researcher plays an active role in constructing an ethical approach by reflecting on guidelines and negotiating with the research participants. This section describes how consent for observations was negotiated and secured (or not) from multiple players. Potentially competing interests is also considered.

5.4.2. Inclusionary consent

In legal terms, the resident participants of this study would be deemed to not have the capacity to consent (Hall, 2009) as they would not meet either of the traditional approaches to capacity decision making; the 'cognitive' requiring reasoning, comprehension, and communication; and 'status' broadly based on 'certain characteristics or impairments with a loss of legal capacity...on the basis of an individual having a particular diagnosis' (Australian Law Reform issues paper, 2016).

Capacity is a legal concept and incapacity is thought to extend from an individual's condition or status in contrast to their situation or context (Hall, 2009). In common law, legal capacity refers generally to individuals organic or internal capacity to make an informed choice which regard to a certain decision. So where does this leave an individual who has fluctuating cognitive comprehension and concentration? From a fundamentalist common law perspective they may well be deemed to be incapable of giving informed consent.

There has however been some consideration given to how people with compromised cognitive capacity could be actively included in giving consent. A methodological process developed by Jan Dewing (2007) provides a comprehensive pathway for researchers to follow with the 'process consent method'.

The method designed by Dewing (2007) to be applied with people who have compromised capacity for informed consent and who would otherwise be considered by others to be incapable of legally informed consent. The process consent method suggests that through observation, people with advanced dementia can actually communicate and express their wishes, consent and assent/dissent to be involved in research. This inclusionary consent process, strongly grounded in person-centred principles was therefore consistent with the ethical principles underpinning this study.

The process consent method is ongoing, dynamic and multidimensional. It is not simple and linear and relies heavily on the skill and capability of the researcher in two key domains; ability to include people who have dementia in engagement; and applying critical reflection skills (Dewing, 2007). Both the domains need exercising by the researcher in order to consider the fundamental questions;

'Is this person consenting? Does this person have (informed) appreciation of their consent? Is any lack of objection genuine?' (Dewing, 2007, 13).

The 'method consent process' discussed by Dewing is comprised of five principles which will be briefly discussed. There is not a linear progression through the principles from one through to five, as their relationship is rather more fluid depending on the context. This inclusionary consent process, based on person-centred principles was therefore consistent with the ethical approach to research applied in this study.

5.4.3 Inclusionary consent within this project

5.4.3.1 Consent - Resident Participation and Monitoring Assent/Dissent

In this study, consent was negotiated with resident participants who were in advanced stages of dementia. In legal terms, the resident participants were deemed to not have the capacity to consent (Hall, 2009; Australian Law Reform issues paper, 2016). As such, for legal resolutions, written consent from the resident's legal representative (proxy) was sought. This process required consideration of what the proxy was being asked to consent to. However, securing consent from legal representatives was not sufficient to proceed practicing person-centred principles. Persons who lack legal capacity to make decisions regarding informed consent are still able to express their wishes regarding participation in meaningful ways (Dewing, 2002 and 2007) Consideration of this as an ongoing process is particularly relevant to ethical research practices when working with people with dementia; to respect the person's choice to assent or dissent in research. However, there is little consensus as to how to do this in practice (Black, Rabins, Sugarman, and Karlawish, 2010). In this research study, Dewing's process consent method was applied, and residents were given the opportunity to voice their assent/dissent at each scheduled observation. It was explained to each resident participant, that I was visiting, and asked permission to observe for a while, and make some notes on what was happening, 'Was that Ok with them'? This process was carried through with each new observation. Due to limited or no verbal capacity of the residents in this study, close attention was paid to their vocal or embodied expressions for indications of dissent. As each observation session was done with a staff member of the unit I also consulted with them regarding cues of assent or dissent normally expressed by the resident. To respect the privacy of participants, all observations occurred in public spaces only, such as dining, lounge room and hallways.

5.4.3.2 Consent - Staff Participation and negotiated Consent

The consent process for staff participation was similar to that of residents. Staff in the two wings where the observations took place were invited to sign a consent to participate, in the knowledge that they would be asked again on the day of observations for their verbal consent as well; providing them with choice and minimising the risk of perceived undue pressure to participate. In addition, similar to observing embodied expressions of resident participants, staff's body language was observed to discern if they were indeed consenting as sometimes words of consent are at odds with a body that is voicing dissent.

5.4.4 Potential Competing Interests

With informed consent, there needs to be consideration of whether there is 'the potential for domination (being) inherent in the relationship itself' (Hall, 2004, 127). To avoid any unintentional undue influence to participate, negotiating consent with staff was ongoing even after receipt of a signed consent. Sensitivity to the relationship between staff, management and the organisational culture (Kirkley, 2011) is crucial. An awareness of how information was exchanged between care staff and management and in particular how messages about the research project were conveyed to the staff. During an introductory staff meeting, management introduced the research saying that observations *will* occur in particular wings of the facility. Such authoritative statements such as 'will occur' can potentially give rise to competing priorities of the organisation, the staff, and the researcher. The organisation's managers may feel they have the authority to direct staff in terms of their participation in facility-based activities (such as research); however, in so doing, care staff's right to exercise autonomy in this situation is taken away (Puurveen, 2008). This choice was offered back to staff each time before observations took place.

5.4.5 In-Situ Research Practice

Respectful inclusionary consent of multiple participants in the research process was essential to adhere to the principles of person-centred philosophy and embed them through all aspects of this research. Thus, there was the need to keep the conversation about consent alive throughout the research process, securing consent from multiple participants, and monitoring their assent/dissent. Additionally, consent, ongoing consent, and monitoring assent/dissent were primary drivers for observations to occur or not (Dewing 2007). Having a staff from the unit involved in each observation session was valuable as they had pre-existing knowledge of the residents and staff and their embodiment expressions of assent and dissent. In addition, as part of the preparatory work before observations there were pre-Observation summary questions completed for each resident participant. Mentors were also asked to indicate what they knew of each staff member involved and how they would indicate their dissent if it was expressed before or during observations.

It is relevant at this point to indicate that by applying my own aptitude, skills and experience, I became in effect a research tool critical to facilitating the success of this study.

5.4.6 Positioning the researcher in the research

Extensive experiences with DCM led to how I positioned myself in the research. Over a four-year period from 2009 to 2013, I was working within a research team in collaboration with 24 RAC homes implementing person-centred dementia practices. My role was one of educating staff in person-centred principles and practice as well as facilitating the implementation of a range of process and tools to create a more enabling environment for people with dementia;

enabling physical environment for independent movement, and social environment for spontaneous interaction opportunities. During this period of time I completed the basic and advanced courses in DCM. DCM is grounded in a person-centred theoretical perspective. DCM turns the philosophy of person-centred care, into concrete observable actions (Kitwood and Bredin, 1992), and provides a practical guide using real life experiences for observing people with dementia in RAC settings. As such, it becomes obvious when looking at the data from mapping, what constitutes person-centred practice and practices which do not. In the course of this four-year period, I completed 225 hours of DCM observations. It was during this time when I became aware of the notion of inclusionary consent, as it seemed ethically incorrect not to ask each person I was going to be observing if it was ok with them for me to be in their environment. Even though there was formal signed consent from the legal representative, each time before a scheduled observation period of DCM, I would talk with each resident, show them my paperwork and seek their consent. It became evident that through observation, there is a rare opportunity to enter another person's world and observe the direct and immediate impact interactions had on them, both positive and negative. The effect of these interactions lasted for some considerable time after the interaction ceased. It was a humbling experience to enter into another person's world, and the insight gained about how physically, emotionally and socially vulnerable people with dementia are was profound.

5.5 Tools used in the research

5.5.1 Individualised Care Inventory; a staff-based measure of individualised care for persons with dementia in residential care settings

The concept of individualised approaches to care which are inclusive of the psychosocial aspects is a complex idea as it suggests a holistic approach accommodating and including complex relationships such as organisational and operational factors, cultural influences and the broader societal influences (Calkins, 2001) as well as resident choice and autonomy (Chappell, Reid and Gish, 2007). To capture the culture of the RAC home in which the PIECE-Dem would be trialled in Australia, the 'Individualised Care Inventory' (ICI) (Chappell, Reid and Gish, 2007) was selected as the survey instrument (see Appendix 1 for survey). The ICI is a staff-based measure of individualised care for persons with dementia in residential care settings established through a review of the literature, direct observation of care and consultation with an expert panel (Chappell et al., 2007).

Since Chappell et al. (2007) developed the ICI tool, it has been used in numerous Canadian studies (Caspar and O'Rourke, 2008; Caspar, Cooke, O'Rourke, and MacDonald, 2013), in Finland (Charalambous, Chappell, Katajisto and Suhonen, 2012) and to measure person-centred practice in several major projects in Australia (Davis and Campbell, 2011; Davis, Shanahan, Campbell, Hegarty and McCarthy, 2011; Davis and Campbell, 2017). The ICI has been found to have high internal consistency (Charalambous et al., 2012; Caspar et al., 2013; Davis and Campbell, 2017) and good structural validity (O'Rouke, Chappell and Caspar, 2009).

The ICI provides data that is an indicator of staff subjective perceptions and not actual care provided. However, as a tool with good internal consistency and reliability, and that has been shown to be useful in the Australian context, it provides information about the culture of care that reflects the person-centred principles that are the framework of this study. The scale comprises three domains measured by four sub-scales (Chappell et al., 2007). The following provides a review of the ICI domain sub-scales and the raw scores in this study for each sub-scale:

1. Knowing the person (resident); [IC-KNOW]

This domain comprises the personal patterns and preferences and unique needs of the person with dementia, and the concept of self-identity as a universal value. The emphasis is on staff knowing what is significant to the individual; the cultural and spiritual needs as well as knowing the norms of that person. In addition, knowing the person includes knowledge of the person's many roles in life such as an individual, family and community member. The higher the score the more knowledge staff perceive they have about the residents they care for as persons. This sub-scale of thirteen items has possible scores of 13-52.

2. An opportunity for autonomy and choice for the resident; [IC-AUTO]

   Resident autonomy and choice reveal an acceptance that independence is vital to the self-worth of a person. It requires staff to encourage people with dementia to be provided with opportunities to make decisions for themselves. Decision incapacity in one area of life, such as locating their bedroom, is not generalised across all areas, as people with dementia have capacity to make decisions, especially when consistent with their past. Thus, assessment of capability needs to be undertaken by caregivers, prior to performing care to assess opportunities for self-care. This requires a redefining of achievement or 'success' as with regard to different residents as well as with the same resident over time in different contexts. This sub scale has fifteen items which relate to the general institutional environment in which care staff work. A higher score signposts that staff believe the facility where they work countenances and supports autonomy for residents living with dementia.

3. Communication between staff and residents [IC-COMSR]:

   The first of the two Communication domain sub-scales is important because communication concerning staff and residents involves equally verbal and nonverbal communications. Communication necessitates staff to be observers and interpreters of language, behaviour; watching and listening carefully to determine what the person is at ease with across all care related areas inclusive of individual and social aspects of life (Chappell et al., 2007). This sub scale consists of seven items which measure the extent to which staff members employ different forms of communication. Scores of 7–28 are possible

4. Communication between staff members [IC-COMSS]:

   The second of two Communication domain sub-scales, identifies the aptitude of care staff to solve problems collectively and to understand the meaning that drives certain behaviour and to discuss options for how best to work with the behaviour (Chappell et al., 2007). The focus is on sharing information, not only about clinical issues but across key areas of everyday life that are pertinent to knowing more about residents to better support the wellbeing of the person with dementia. This sub scale consists of eleven items and reflects both communication with other staff and with supervisors in the institution (Chappell et al., 2007). Possible scores are 11 – 44.

These sub-scales represent domains that make up the Individualised Care Inventory complete scale. Although these raw scores have been identified at the domain level in this introduction, as each sub-scale has a different number of items constituting the different scores noted, the data from the ICI and each of the domains has been standardised to make it easier to interpret the data overall. Raw scores have been converted into ratio scores, where 1 is a perfect score. The purpose of using this measure of individualised care was to determine the culture of care within the study site in which the trial was to occur. An examination of the ratio scores provides such insight and provides a context for the qualitative data obtained through the trial of PIECE-dem.

The researcher entered the raw data from the surveys into the Statistical Package for the Social Sciences (SPSS) version 23 which was used to analyse the data. Data cleaning and preparation was completed by the researcher and ICI scores and sub-scale dimension scores were calculated using a pre-existing syntax file (used in earlier studies eg Davis and Campbell, 2011 and developed by Dr Davis in consultation with Professor Neena Chappell, lead on the development of the ICI). Frequencies for all items on each dimension were created. Additional statistical analysis used included cross tabulations, correlations and T-tests, some of which are reported on in the results section to illustrate the culture of care.

5.5.2 PIECE-dem Manual adaptation

An adaptation of the practice manual *Exploring the utility of the PIECE-dem Observational process for practitioners* was done prior to the training in PIECE-dem. This adaptation was done as the original manual (Brooker, De Vries, LaFontaine and Porter, 2010) was for a target audience of researchers. This study required the manual to be suitable for use by practitioners to explore the potential to inform care. The bulk of the manual is material from the original PIECE-dem manual (Brooker, De Vries, La Fontaine and Porter, 2010), as the framework for capturing the residents experience remains unchanged.

Three of the original templates of PIECE-dem were altered to better suit them to the purpose of this study; the pre-observation summary sheet (Appendix 14 for original and Appendix 3 for revised), the raw data sheet (see Appendices 13 and 4) and the reflection summary sheet (see Appendix 15 for the original and Appendix 5 for the revised refection summary sheet). An addition of *prompt questions* (see Appendix 11) was designed to support mentors in facilitating reflection sessions. The pre-observation sheet had one inclusion added which asked: ***How does the person usually demonstrate consent within their daily life:*** *Knowledge of the person's* *usual self-presentation and usual level of wellbeing /illbeing*. This information was necessary to maximise the probability for perceiving ongoing consent of the person with dementia when approached before observations, and for observing indications of continuing or withdrawing consent during observations. Alterations were made to the raw data sheet layout by expanding the one minute data collection points from 15 to 30 on one page. This was requested by mentors so they only had one sheet for data collection per 30 minute observation set. Several alterations were also made to the reflection summary sheet to be more easily understood by and useful for practitioners.

Two items were changed in wording:

1. *Original wording*: Summarise your perception of the person's predominant experience of their world during this time period.

   Revised wording: How do you think the individual was experiencing their world during observation? Where they in a positive or negative state during observation?
2. *Original wording*: When do interactions occur, who is the interaction with, what appears to be the purpose of these interactions and what impact do they have upon the person with dementia? Was knowledge of the person used in the interaction?

   Revised wording: What appeared to be the purpose of any interactions which occurred and what impact did they have on the person with dementia?

There were three items added to the reflection summary sheet which evolved during the study as the mentors used PIECE-dem and discovered areas where they thought the information would be useful for them in their care practice. These three items included:

1. Did you discover anything new, or surprising about the resident?
2. How could we improve quality of life for this person?

3. How can we use this information?

In addition, there were three items removed from the reflection summary sheet as they were seen to have more relevance to a research orientation than as a practice tool. The items removed were:

1. Was an empathic connection made during interactions between staff and resident? (describe how this was achieved and if not, why it appeared not to occur)
2. What emotions did you experience during this period of observation and why?
3. How do you think the staff experience this person?

This pilot study was not looking for signs of abuse or neglect. It was rather to see if the PIECE-dem framework was useful to inform quality care to residents with dementia and to increase the knowledge, understanding and observational skills of practitioners when working with dependent people with dementia living in RAC homes. That is what informed the alterations made to the original templates.

5.5.3 PIECE-dem implementation

As the researcher, I assumed the role of participant observer during observational sessions in which the PIECE-dem was used by mentors and I completed observations of the same residents. Extensive field notes were taken by the researcher during observations and during reflection sessions, and at the end of the day to support the data collected. Mentors were encouraged to make field notes to capture their thoughts throughout the study. These field notes contributed significantly to the development of discussion regarding the research question; can PIECE-dem increase understanding and observational skills of practitioners to inform quality care to residents with dementia?

Before any observations were undertaken, there was a pre-observation summary completed for each participating resident (see Appendix 8 for a completed pre-observation summary). This summary was completed by the care staff and mentors within the unit the resident lived in collaboration with the researcher. This summary considers the physical, psychological, social, spiritual, and communication needs along with the participants history, diagnosis medication and usual self–presentation. In addition, there is discussion and documentation on how the person usually demonstrates consent within their daily life. The pre-observation summary assisted in understanding how to approach the resident given their usual presentation, assess for signs of wellbeing or illbeing whilst engaged with them, and later during observations.

During observations, data was recorded on the general engagement of individuals, individual actions, interaction and the general environment, identified as follows:

- Actions as observed or expressed by the **Person** with dementia, (the potential intention). Actions may include expressions of face or body, gestures, posture, or movements, and any attempt at communication and vocalisations;
- Others actions in relation to the person with dementia. Others actions may include any **Interaction** and how the person with dementia appeared to experience interaction. Aspects to be recorded include apparent intent, tone, content, posture and use of touch if it occurred during the interaction.
- The immediate **Environment** surrounding the participant including both physical and psycho-social environments.

Before any observations occurred, there was a role play during training, using the PIECE-dem framework and discussing the language used in the raw data sheets, to facilitate an understanding of the subtleties in what was being observed; what constitutes and action; an interaction; and what to look out for in a person immediate surrounding environment.

5.6 Data collection procedure

This ethnographic study used mixed methods. Ethnography is defined by Brewer as:

> ‘the study of people in naturally occurring settings or ‘fields’ by methods of data collection which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally.’ (Brewer, 2000, 6)

Data collection comprised several components: survey of all staff and mentors, pre-post interviews of mentors, data collected through observation and reflection sessions during the trialling of PIECE-dem and researcher field notes.

5.6.1 Survey and dissemination

At the introductory briefing session held in the participating RAC home, all staff were invited to complete a survey. Three weeks after the briefing session, surveys were attached to each staff members pay slip along with an information sheet about the study. An envelope was proved with each survey and a ‘mail box’ was placed outside reception of the RAC home for staff to return the surveys. The surveys were collected by the researcher and were anonymous. Mentors were requested to write *Mentor* on the front page of the survey so their results could be collated and analysed separately.

5.6.2 Interviews with mentors

Care staff (mentors), who consented after knowing the roles and responsibilities expected, participated in one on one interviews on their understanding of personhood and working with people with dementia pre and post-trial with the researcher. After the first interview, mentors then attended a seven-hour training day on person-centred care and an additional seven-hour training day on the application of PIECE-dem. Staff were not financially disadvantaged by attending training as they received their regular pay.

Recording of one-on-one interviews was done so the expressed thoughts and opinions were correctly captured. Transcripts were sent to mentors for collaboration on correct expression of their responses. Recordings were destroyed after transcription as per ethics application.

5. 6.3 Ethnographic Observations

After training, each mentor was involved in observation session ranging through 15 minutes, 30 minutes and one-hour duration (Table 1: of observations is included in Ethnographic Observations below). The initial and subsequent observations were done with researcher and two mentors observing and the researcher facilitated reflections after the observations. Final sets of observations were done with the same configuration in observations with Mentors facilitating reflections (supported by the researcher).

Reflection on observations formed a critical component to understanding and making sense of what was observed. The information was systematically collected using the raw data sheet (see Appendix 5) and decisions/conclusions (instructional and otherwise) made during reflection session was based on this information and recorded in the reflection summary sheet (see Appendix 6). The discussions during these refection sessions were focused on what was observed, what trends or abilities were observed and what the experience was for the resident. The reflection sessions formed a critical part of the reflective learning and potentially informed the adaptation of the tool for use by practitioners

Mentors continued to be rostered on regular shifts whilst participating in the observations with the exception of 60-minute observations. It was a critical component of the trial to evaluate how the tool can be applied as part of practitioners every day activity. When mentors were scheduled for 60-minute observations, they were rostered for half a shift on that day.

As described in Chapter one (pages 20-24) PIECE-dem is a manualised tool (a tool with an accompanying manual to support application), PIECE-dem Observational Process, and is an acronym for: **P**eople, **I**nteraction, **E**nvironment, **C**are, **E**xperience in **Dem**entia (as included in 5.5.3).

Before any observations were undertaken, there was a pre-observation summary completed for each participating resident (see Appendix 8 for an example of a pre-observation summary). These were completed with the researcher, and the mentors who worked in the unit with the person who was going to be observed. This summary considers the physical, psychological, social, spiritual, and communication needs along with the participants history, diagnosis medication and usual self –presentation. In addition, there was discussion and documentation on how the person usually demonstrates consent within their daily life. The pre-observation summary assisted in understanding how to approach the resident given their usual presentation, assess for signs of wellbeing or illbeing whilst engaged with them, and later during observations.

5.6.4 Completing the raw data sheet

During observations, the raw data sheet (see Appendix 9 for a completed raw data sheet) of PIECE-dem with coding focusing on three different engagement types was completed by each observer. The raw data sheet is accompanied by detailed notes. Each 15-minute time frame data was collected on:

1. Recording one of either **interaction**, **engagement** or **disengagement** during each minute of observation;
2. Qualitative notes concerning the minute-by-minute experience for the resident of the world around them; the narrative
3. Qualitative notes concerning the immediate psycho-social and physical environment surrounding the person.

Completion of the raw data sheet involved observing each resident for a total of 12 minutes in any 15-minute time frame. The additional minutes was to ensure completion of observational notes, before commencing the next 15-minute period.

Observation sessions took place for 15 minutes, 30 minutes or 60-minute blocks. One person was observed continuously with information being recorded at one-minute intervals. The raw data sheet collected data specifically on *interaction, engagement, disengagement* and the *immediate environment*. Along with recording the ‘state’ of the participant, such as disengaged, a narrative was written recording what was occurring, with whom, possible intention and observed wellbeing at the time of observation.

There were 510 minutes of participant observations recorded, involving five residents (see Table 2).

Table 2: Timeframes for observations with resident participants

Timeframes of observations				
Resident	**One hour**	**30 minutes**	**15 minutes**	**Total time**
RD01	1	3	1	165
RD02	-	-	1	15
RD03	-	2	-	60
RD04	1	3	-	150
RD05	1	2	-	120
Total number of minutes resident participants were observed				510 minutes

The maximum number of minutes spent by any individual mentor in active observations was 225 minutes and 120 was the minimum number of minutes (table 2). The researcher was actively involved in all of these observation sessions. After each of the observation period, whether it was 15, 30 or 60 minutes a debriefing reflection session occurred. The researcher led the reflection sessions, giving guidance into exploring intentions, patterns and abilities observed.

In all observation sessions there were two Mentors, one from each wing and the researcher (See table 3) total of three people per observation. These observation sessions and subsequent reflection sessions were led by the researcher.

Table 3: Time frames of observations with researcher and mentors

Timeframes of observations with researcher and Mentor (used in data analysis)				
Mentor	One hour	30 minutes	15 minutes	Total time (min)
MEN01	2	3	-	210
MEN02	1	2	-	120
MEN03	2	3	1	225
MEN04	1	2	1	135
MEN05	2	3	1	225
Total number of minutes spent observing				915 minutes

Subsequent observation sessions were undertaken with the intention of each mentor taking the lead. In taking the lead, they indicated when to commence observations and facilitated the discussion in the reflections after observations. Table 4 shows the mentor facilitated (or attempted) observation sessions.

Table 4: Timeframes of Mentor observations with other Mentors

Timeframes of Mentor observations with other Mentors (not used in formal data analysis)				
Mentor	One hour	30 minutes	15 minutes	Total time (min)
MEN01	1	2	2	150
MEN02	1	2	2	150
MEN03	1	2	2	150
MEN04	1	1	1	105
MEN05	1	2	2	150

Additional paper was taken during observation sessions to enable extensive notes to be taken beyond space afforded by the raw data sheets. This also made it possible to offer residents paper to join in if they approached observers/mentors during observations and showed an interest.

5.6.5. Reflection sessions

Reflection sessions were held immediately after each observation period. Each person involved in the observations attended. The session commenced with each observer identifying the number of descriptors (interaction', 'engaged', or 'disengaged') recorded. Then the activity observed was discussed and summarised into the reflection summary sheet (see Appendix 10 for an example of a completed summary sheet).

At the commencement of the reflection sessions after each observation, it was clearly articulated that it is the qualitative notes that tell the story of the experiences. As such the numbers of ticks or minutes spent were not considered without their accompanying qualitative notes. This is because the descriptor 'interaction', 'engaged', or 'disengaged' does not, by itself, communicate the impact of that experience on an individual's wellbeing and there should be no value judgements inherent in the use of the terms. Someone who is peacefully disengaged and showing no signs of discomfort may in fact be experiencing high levels of wellbeing. Conversely, a person who encounters an interaction that results in distress or anxiety may be experiencing illbeing. It is the qualitative notes that tell the real story.

The notes below were provided and referred to during each debriefing session, as it seemed to support mentors to understand the difference.

> **When to code interaction, engagement or disengagement**
>
> **Interaction**
>
> Interaction can be verbal such as words or sounds, or non-verbal such as eye contact, gestures and facial expression. In order for an interaction to be possible, the person

does need to be open to social opportunities thus they do need to be engaged with their environment. Any interaction with another person or an object that the person appears to be responding to as a person is recorded as an interaction for that minute. It is important to note that not all interactions are positive experience. The dominant features of an ‘interaction’ are its **apparent intent** on behalf of the person and an **expectation of response** from another person or object that the person is interacting with.

Engagement

When coding engagement, look for signs of the person being open to activity or receptiveness with other people or with the general environment surrounding them. Instances of engagement might include: walking, caressing, grooming, humming, drinking, speaking, shouting, moaning, holding, watching, or handling an object. Engagement can also be quietly passive such as simply viewing what is happening. Engagement may not necessarily be a ‘positive’ experience for the person

Disengagement

Disengaged is only recorded if the person is not involved in any sort of interaction, movement or any other engagement throughout the one-minute time frame. Disengagement can include being sedentary with eyes shut but not seemingly asleep, sedentary with open eyes but not seeming to be focused on any particular activity or place, maybe staring into the middle distance or possibly sleeping. Only record disengaged if the person is disengaged for the whole of the time frame. Write down descriptive notes of what you observed that led to the coding of disengagement. Disengagement does not necessarily need to be a negative experience for it to be coded as disengagement. A person can be peacefully disengaged.

5.6.6 Pre-post interviews with mentors

One on one interviews were conducted with each mentor pre and post the trial of PIECE-dem. Appointments were made with each of the mentors, and interviews were conducted in private within the RAC home. The interview pre-trial was done before the survey was disseminated, and the post-trial interview was done on the last day of the study. A debriefing session was held with staff and one on one interviews were held with each of the mentors. The interviews were recorded and transcribed by the researcher. Copies of the transcript were sent to each mentor to review the transcript as a correct representation of their responses. The questions in the interviews were across a range of areas related to working and communicating with people living with dementia.

Mentors were asked the same set of semi structured questions pre- and post-trial (see Appendix 6). The questions were framed around person-centred practice such as:

> **If I was a new staff member starting work with you, what is important to know when communicating with a person with dementia?**

At the interview post-trial, mentors were asked an additional five questions regarding their thoughts on PIECE-dem and its usefulness to them as practitioners (See Appendix 8).

5.7 How PIECE-dem is placed within the theoretical framework and key concepts

PIECE-dem provides the opportunity for practitioners to have a framework for making systematic observations of the person with advanced dementia experiencing their environment. In turn, the interpretation of those observations of the person with dementia engaging with others and with their environment can be guided by person-centred principles through reflective practice. Reflective practice discussing what was observed in relation to the individuals ‘known’ practices and responses and reflecting on what their activity might actually be telling about their capacity and agency.

The method used in this study was underpinned by the theory of symbolic interactionism and person-centred principles to investigate the research question ‘can PIECE-dem increase understanding and observational skills of practitioners to inform quality care to residents with dementia’.

Given this study is piloting an observational tool, and the goal is to explore how a person with dementia is experiencing their world, having an awareness to how they are influencing their social world, and what meaning might be behind their responses to situations is particularly relevant.

In Chapter Six, we will look at the results from the study, and see if there is the potential for PIECE-dem to be useful as a practice tool and can increase understanding and observational skills of practitioners.

CHAPTER SIX

6. Results

6.1 Introduction

A mixed method research design was used in this study. The quantitative component was the staff survey based on the 'Individualised Care Inventory' (ICI) (Chappell, Reid and Gish, 2007). The ICI is a staff-based measure of individualised care for persons with dementia in residential care settings. The selection of this measure has been discussed earlier in Chapter five, methodology. The qualitative component comprised the inquiry process using interviews, observations and field notes. The results of each of these methods will be discussed in turn.

6.2 Staff-based practices support person-centred living

6.2.1 The staff survey

The ICI was embedded into a staff survey that also included some basic characteristics to provide a picture of the sample. 103 surveys were distributed and 50 were returned of which 47 were included for analysis for a good adjusted return rate of 47%.

The staff responding to the survey were all female (100%), ranging from 20 to 78 years of age, with 60% over age 50. The majority (85%) work part time, with 8.5% being full time and only 3 respondents were in casual employment. Personal carers comprised 44% of the study sample, 17% were registered nurses, and 17% were enrolled nurses and 22% of the sample was ancillary support staff (not direct care staff). Of the large group of part time staff, 31% were clinical, 44% were personal carers and 25% were support services. In this study sample, only one personal carer was full time.

The ICI provides data that is an indicator of staff subjective perceptions and not actual care provided. As discussed in Chapter five, the ICI comprises three domains measured by four sub-scale scores out of 52 (IC-KNOW), 75 (IC-AUTO), 28 (IC-COMSR) and 44 (IC-COMSS) with overall ICI possible scores of 46 - 199. The actual scores in this study ranged from 125 – 187. The following provides a review of the ICI domain sub-scales and the raw scores in this study for each sub-scale:

Knowing the person (resident); [IC-KNOW]:

The higher the score the more knowledge staff perceive they have about the residents they care for as persons. This sub-scale of thirteen items has possible scores of 13-52. Actual scores for this study between 33-52 (mean = 43.17; Std Dev = 5.13).

An opportunity for autonomy and choice for the resident; [IC-AUTO]:

A higher score indicates that staff believe the facility where they work encourages and supports autonomy for residents living with dementia. This sub-scale has possible scores of 15 – 75 with actual scores in this study between 49-67 (mean = 57.70; Std Dev = 4.18).

Communication between staff and residents [IC-COMSR]:

The domain focuses on both verbal and non-verbal interactions necessary for staff to engage with residents with dementia. This sub scale consists of seven items which measure the extent to which staff members employ different forms of communication. Scores of 7–28 are possible, with actual scores in this study being 14-28 (mean = 20.11; Std Dev = 2.99).

Communication between staff members [IC-COMSS]:

This identifies interaction between staff and the aptitude of care staff to solve problems collectively. This sub scale consists of eleven items and reflects both communication with other staff and with supervisors in the institution (Chappell et al., 2007). Possible scores are 11 - 44; actual scores were 14 – 44 (mean = 33.47; SD = 6.59).

These four sub-scales represent domains that make up the ICI complete scale. Due to each sub-scale having a different number of items constituting the different scores noted, the data from the ICI and each of the domains has been standardised to make it easier to interpret the data overall. While raw scores have been identified at the domain level above, raw scores have been converted into ratio scores, where 1 is a perfect score, to enable easier understanding. The purpose of using this measure of individualised care was to determine the culture of care within the study site in which the trial was to occur. An examination of the ratio scores provides such insight and provides a context for the qualitative data obtained through the trial of PIECE-dem.

6.2.2 A culture supporting person-centred living: ICI and sub-scale domain scores

As a measure of individualised care, the ICI provides insight into staff perceptions of their experiences of practice within the organisation. Table 5 provides the scores across each domain and the ICI for all staff excluding mentors.

Table 5: Staff ICI and sub-scale domain scores baseline (n = 43)

ICI sub-scales	Mean Ratio Scores	St'd Deviation	St'd Error of Mean
IC-KNOW Knowing the resident	.8149	.01386	.02113
IC-AUTO Resident autonomy	.7884	.05757	.00879
IC-COMSR Communication with residents	.7074	.13034	.01988
IC-COMSS Communication between staff	.7547	.19755	.03013
ICI Individualised Care Inventory	.7779	.07942	.01211

As the mentors were selected as representative of leaders within the organisation, it is of particular interest to examine the ICI and sub-scale scores separately. The mean sub-scale domain scores for the four mentors comprised IC-KNOW at .8646, IC-AUTO at .8500, IC-COMSR at .6875 and IC-COMSS at .8625 combined to an overall ICI score of .8359. In acknowledging the lower mean score on the domain relating to 'communication between staff and residents' as there are only four mentors, two scores lower than the staff average (.5833 and .6667) have impacted on the overall domain score for the mentors which is likely reflecting mentors coming from the different levels of leadership existing within the organisation. Taken as a whole, the ICI and sub-scale domain scores illustrates a strong emphasis on person-centred practice within the leadership of the RAC home, which is important if staff are to support person-centred living amongst residents with dementia.

Within the general staff population, although there were no statistically significant differences in ICI and sub-scale scores across different positions or different levels of employment, there was some variation worth noting. The small group of staff in full time employment (all but one of whom were nursing staff) had the highest ICI mean ratio score of .8317, comprising .8750 for knowing the resident (IC-KNOW), .7867 for resident autonomy and choice (IC-AUTO), for communication between staff and residents.7500 (IC-COMSR) and .9091 for communication between staff and residents (IC-COMSS). Across the different staff positions, enrolled nurses has the highest ICI mean ratio score of .8078 as a result of the highest sub-scale scores for IC-KNOW (.8654), IC-AUTO (.7800) and IC-COMSR (.8295). Registered nurses had the highest mean sub-scale score for IC-COMSS of .7455.

A culture of care supporting person-centred living is reflected in high scores for each domain, a pattern that has not reflected in Australian RAC homes in which this same scale has been utilised (Davis and Campbell, 2012; Davis, Campbell and Capp, 2017). To put this into context, a national sample taken prior to the distribution of an educational package specific to person-centred dementia care, provides a benchmark for the study site scores. The overall ICI was .6595, with domain sub-scales of .7742 (IC-KNOW), .5037 (IC-AUTO), .7618 (IC-COMSR) and .7031 (IC-COMSS) (Davis, Campbell and Capp, 2017). Of those RAC homes from the national sample that used the eLearning contained in the educational package, post evaluation mean scores improved to an overall ICI of .7383 comprising sub-scale domain scores of .7891 (IC-KNOW), .6841 (IC-AUTO), .7031 (IC-COMSR) and .8151 (IC-COMSS) (Davis and Campbell, 2017). The lower IC-AUTO sub-scale score has been a general pattern found in Australian RAC homes and which has been associated with task-oriented, general institutional cultures that struggle with supporting person-centred living (Davis and Campbell, 2011; Davis, Shanahan, Campbell et al., 2011; Davis and Campbell, 2017). To fully appreciate the nature of the culture of care within the study site, an examination of the items from each domain is warranted.

Knowing the Resident (IC-KNOW)

The items on this sub-scale relate to staff perceptions of how well they know the residents to whom they provide care. As can be seen from Table 6, reading social histories is clearly emphasised in this RAC home with the majority of staff indicating that they have enough time to read social histories (70.2%) and 93.6% reporting that they do read the social histories in residents care plans, even though some do feel the quality of resident social histories are poor (21.3%). Nevertheless, almost all staff are confident that they have a good understanding of the residents that they care for and know what residents like (97.9%) Most importantly, the majority of staff indicate their awareness of residents remaining skills are acknowledged and included in care approaches (87.2%).

Table 6: Staff responses in valid percentages to IC-KNOW sub-scale items (n = 47)

Sub scale item	Agree	Disagree
I read the social histories of resident care plans	93.6	6.4
I do not have the time I need to read the social histories of the residents	29.8	70.2
The quality of the resident social histories is poor	21.3	78.7
I talk to family members and friends in order to learn what has been and may remain important to the residents	93.6	6.4
I have a good understanding of the residents that I am caring for	97.9	2.1
I do not know the behaviour patterns of individual residents	29.8	70.2
I know what the residents I care for like	97.9	2.1
I find it hard to talk to residents because I do not know enough about them	19.1	80.9
I do not think that care plans are based upon what residents' value in life	29.8	70.2
I plan a resident's personal care routine using the habits and routines they had at home.	87.2	12.8
I am aware of the skills that residents still have and include them into my care approaches.	97.9	2.1
Favourite beverages, meals, and activities are part of a resident's day	97.9	2.1
I do not feel like I know each resident as a unique individual	31.9	68.1

There are four items within this domain that do raise some concern. Around 30% of staff responding have indicated that they:

- Do not have the time needed to read social histories
- Do not know the behaviour patterns of individual residents
- Do not feel as if they know each resident as a unique individual, and

- Do not think that care plans are based on what resident's value in life.

Although the sample size limits the options for in-depth examination, descriptive analysis does provide insight into these four items. Of those who report not having time to read social histories 92% indicate they have done things for residents that they could do for themselves on a regular basis; 57% find it hard to talk to residents and do not know the behaviour patterns of residents and 46% report not knowing individuals as unique individuals. Even though an overwhelming majority of staff responding do report that they have a good understanding of the residents they care for, this does suggest that there are a small group of staff who struggle with knowing the residents well enough to support person-centred living. However, overall, the majority of staff appear to make a concerted effort to know the people residing in the RAC home by reading social histories and talking to family, and most importantly, are able to use their knowledge in everyday practice.

Resident Autonomy and Choice (IC-AUTO)

Given the comparative high score on this domain breaks the pattern found across a national sample of Australian RAC homes, an examination of the items on the sub-scale is important for understanding the culture of care at the study site. Table 7 provides an overview of responses for each of the 15 items making up this domain.

What is notable on this domain is the agreement of all staff that the RAC home supports resident independence, that they feel good about the quality of care provided and that residents get enough to eat. However, there is less certainty across staff in relation to certain items that are highly relevant for supporting resident autonomy and choice that seems to identify potential underlying issues.

Table 7: Staff responses in valid percent for IC-AUTO sub scale items (n=47)

Sub scale item	Frequently	Occasionally	Seldom/ never
Feel that you are not doing all you should in order to care for the residents that you look after	8.5	38.3	53.2
Feel rushed because of facility routines	23.4	51.1	25.5
Feel rushed because of the expectations of the other Care-Attendants you work with	6.4	31.9	61.7
Feel that the facility you work in supports the independence of residents	100.0	0	0
Feel that other staff you work with have different ideas about how dementia care should be provided	19.1	53.2	27.7
Feel that you are able to allow residents that you look after to make decisions for themselves	17.0	76.6	6.4
Feel that residents have enough to do during the day	66.0	27.7	6.4
Feel that residents get enough to eat	100.0	0	0
Feel that the facility you work in offers choice in activity programming	76.6	21.3	2.1
Feel that you have done things for residents when they could have done things for themselves	21.3	53.2	25.5
Feel that you have enough time to allow residents to do things for themselves	66.0	31.9	2.1
Feel that it is important that residents get to meals on time	76.6	17.0	6.4
Feel that the facility you work in makes an effort to include personal preferences into mealtimes	93.6	6.4	0
Feel good about the quality of care that you are able to provide at this facility	100.0	0	0
Feel that there are enough resources available for you to provide resident care	85.1	10.6	4.3

Issues such as, only 66% of all staff felt that they frequently had enough time to allow residents to do things for themselves. This, in conjunction with larger percentages of staff saying that they only occasionally felt able to allow residents to make decisions for themselves (76.6%), and that they have done things for residents when they could have done things for themselves frequently (21.3%) or occasionally (53.2%), it is important to recognise that as such, there are potential consequences for person-centred living.

The small sample size does limit any extensive, meaningful statistical analysis to explore further but some descriptive analysis does provide some insight. It does appear that feeling rushed by facility routines is a factor. Of those reporting not always being able to let residents make their own decisions and have done things for residents that they could do themselves, more than three quarters indicated that they felt rushed by facility routines (78% and 76% respectively). Given that nearly one quarter of staff responding indicated that they frequently feel rushed by facility routines and another 51.1% said they felt this way occasionally, it is noteworthy that a higher percentage of staff are not succumbing to such pressures but rather continue to provide residents opportunities for autonomy and choice, albeit occasionally rather than all the time.

6.2.3 Communication between staff and residents (ICCOM –SR)

Communication plays a critical role in person-centred living as it supports human needs such as identity, attachment, occupation and inclusion. The items on this sub-scale were designed to ‘measure the extent to which staff members employ different forms of communication… that are not task-focused’ (Chappell et al., 2007: 532).

One of the most salient points to highlight from the staff responses on this sub-scale presented in Table 8 is that *all* staff engage with residents using humour, physical touch and talking to residents about internal social events and what is happening outside the RAC home, and all but one part-time support service staff member engage in conversation about residents’ personal lives with them. Talking to residents about their personal lives provides an opportunity to gather information about the person, prompt self-disclosure and provide empathetic acknowledgement.

Table 8: Staff responses in valid percentages for ICCOM-SR sub-scale items (n=47)

Sub scale item	Often	Sometimes	Never
Use humour when talking to residents	93.6	6.4	0
Physically touch residents with their permission	74.5	25.5	0
Talk to residents about social events that are going on within the facility	89.4	10.6	0
Talk to residents about what is happening outside the facility	78.7	21.3	0
Talk to residents about their personal lives	65.9	31.9	2.1
Talk about my personal life with residents.	23.4	63.8	12.8
Talk to residents about the care they are receiving	63.8	31.9	4.3

Most importantly, it is an approach to engagement that provides opportunities to recognise the resident as ‘a person’ and to validate and respond to the persons’ feelings, both of which are crucial to person-centred living (Williams, Perkhounkova, Jao, et al., 2017).

There is a higher percentage of staff that are less likely to talk about their own personal lives with residents (63.8%) and some that never engage at this level (12.8%). The latter are all part-time, support services staff. Of significance in terms of staff/resident communication within this RAC home, is that the overwhelming majority of staff indicate that they do talk to residents about the care they are receiving.

Effective communication comprises both verbal and non-verbal, with the latter being particularly important for people with dementia. Chappell et al. point out that:

> ‘Communicating with the resident requires staff to be interpreters of the language of dementia, observing and listening to discover what is pleasing and comfortable and what is not, including not only care-related areas, but also personal and social areas of the resident’s life’ (Chappell et at, 2007: 530-531).

Overall, the data clearly indicates that all staff, including support service staff, are regularly engaging in verbal and non-verbal communication with residents as part of everyday life in the RAC home, using humour and physical touch and talking to residents about social and personal aspects of life and connecting them to the community by talking about what is happening outside the RAC home. To what extent staff are appropriately ‘interpreting, observing and listening’ in ways that enables them to determine positive outcomes for residents is outside of the scope of this measurement tool. However, the data does clearly indicate that the communication between staff and residents has all the necessary components to underpin opportunities for quality communication and engagement to support for person-centred living and enhance quality of life.

6.2.4 Communication between staff (IC-COMSS)

Open communication between all staff is also an essential part of developing and sustaining a culture within an organisation that supports high quality person-centred living. This second communication sub-scale focuses on how actively staff communicate with one another and the ways in which this occurs.

Table 9: Staff responses in valid percentages for ICCOM-SS sub-scale items (n=47)

Sub scale item	Often	Sometimes	Never
Share personal information that I learn about residents that may help other staff members	74.5	21.3	4.3
Staff members tell me about physical changes in residents	83.0	17.0	2.1
Ask other staff what I should know before caring for a particular resident	78.7	19.1	2.1
Share care approaches that can help residents to do things for themselves.	85.1	10.6	4.3
Share care approaches that can help manage the difficult behaviours of residents	83.0	12.8	4.3
Talk with other staff members in order to find out the meaning behind difficult resident behaviours	83.0	17.0	0
Tell my supervisors about the need to change a procedure/practice that is no longer working for resident care	68.1	17.0	14.9
Offer ideas for making changes within the care plans of residents	61.7	27.7	10.6
Play a part in the making of facility procedures and practices	44.1	40.0	25.5
Exchange information about residents at shift change	89.4	8.5	2.1
Supervisors consider the preferences of staff members when making decisions about resident care.	74.5	19.1	6.4

Table 9 displays the staff perceptions of various aspects of communication between care staff and between care staff and supervisors within the study site RAC home. On the whole, for each item, almost all staff engage in sharing information about resident personal information (included the exchange of information at shift change), physical changes, resident independence, strategies to support residents in distress and the meaning behind that distress.

The one or two staff members that report a lack of participation in staff communication in these areas are part time, support services staff.

Three items show some variation from this pattern. There is a small group of staff, largely in support services that report never telling supervisors about the need to change practice that is no longer effective for resident care, never offer ideas for making changes within care plans and, never play a role in making facility practices. It is the latter that is of particular concern with 25% of nursing staff and 15% of personal care staff reporting this lack of engagement (along with support services staff), albeit all part-time employees.

Care organisations that can facilitate a free flow of information to everyone, providing opportunities for all levels of staff to engage and share ideas, are likely to provide quality, innovative care (Colón-Emeric, Ammarell, Bailey et al., 2006). The IC- COMSS sub-scale indicates that the study site RAC home has staff that have high levels of communication engagement with other staff across all levels of the organisation.

6.2.5 A person-centred culture of care to trial PIECE-dem

Having provided an overview of the descriptive data from the survey, this final section explores the data with some further analysis of the features of the culture of care within the study site RAC home. Chappell and her colleagues found that the two communication sub-scales (IC-COMSR and IC-COMSS) were significantly correlated with one another and that correlations between IC-KNOW and IC-AUTO were stronger than those between the communication scales (Chappell et al., 2007, 534). In this study modest correlations were found as illustrated in Table 10 which paint a different picture to that found in the Canadian context. In this study, while IC-KNOW and IC-AUTO are correlated with one another, and the two communication sub-scales correlation is statistically significant, there is a stronger correlation between IC-KNOW and IC-COMSS than that of the two communication sub-scales.

Table 10: Correlation matrix for domain sub-scales

IC-KNOW	IC-AUTO	IC-COMSR	IC-COMSS
1			
r = .456**	1		
r = .405**	r = .145	1	
r = .526**	r = .219	r = .494**	1

** correlation is significant at the 0.01 level

What does this mean? First, staff who score higher on knowing the residents they care for also score higher on providing care that reflects greater autonomy for the resident. The descriptive analysis of the IC-KNOW and IC-AUTO sub-scale items illustrate that the staff clearly make the effort to get to know the residents they care for, and they believe in supporting autonomy for the residents as well. Secondly, the staff who communicated more frequently with one another about the residents they care for are also more likely to communicate with the residents in their care.

As previously discussed, there is a group of staff that report not having time to read social histories, do not know the behaviour patterns of residents and do not feel they know residents as unique individuals. This appears to be a very small group of staff who are struggling with aspects of knowing the residents which is impacting on their capacity to support person-centred living regularly. Nevertheless, the overall story that the ICI survey data provides, clearly indicates that there is no doubt that this RAC home provides an approach to providing care that supports person-centred living: in closing, it has a person-centred culture. This RAC home provided the appropriate care context in which to pilot the use of the PIECE-dem as a tool for practitioners.

6.3 Trial of PIECE–dem

6.3.1 Ethnographic Observations

6.3.1.1 Resident participant characteristics

The sample of residents had a mix of male (20%) and female (80%), with a range of abilities including verbal and nonverbal, highly mobile, agitated, verbal aggression and withdrawn states as identified by clinical leaders.

6.3.1.2 Mentor characteristics

The staff comprising the Mentor sample were all female (100%), with an age range from 24 to 64 years of age. The majority (4) were part time and one full time. The study sample was 3 personal care workers, 1 enrolled nurse and 1 registered nurse. A total of 510 minutes of observations were undertaken, over a five-month period.

6.3.1.3 Probationary trials in observation

The first observation trial was done for 30 minutes as part of the initial training day on PIECE-dem with mentors. This observation was conducted as a group; so that all mentors were aware of the observations being discussed and could actively participate. The pre-observation summary was completed on all participating residents before the training day in preparation. These summary sheets shed light on how to approach the resident and assess for signs of illbeing or wellbeing while talking with them, and during observations.

6.3.2 Observations

All of the observations done with the researcher were included in the inter-rater reliability scores; looking at what mentors recorded and what the researcher recorded at each observation. Concordance or agreement on observations was anticipated at 50%; given the novice level of observational experience of the mentors. It was surprisingly high given this none of the mentors had participated in formal observations previously.

Table 11: Inter-rater reliability concordance on 'Interaction',' engagement' or 'disengagement'

Resident	Total minutes observed	Percentage concordance	Areas of discordance
RD01	165	62%	Interpretation of interaction/ engaged and movements
RD02	15	100%	Nil
RD03	60	25%	Disengaged/engaged
RD04	150	58%	Interpretation of interaction/engaged
RD05	120	52%	Interpretation of interaction with environment

The discordance or discrepancies were mainly the interpretation of interaction versus engagement. The higher than expected concordance was more due to luck than clear and definitive decisions based on knowledge. This is due the lack of knowledge and thus understanding regarding the difference between the terms demonstrated by all Mentors. There was very low percentage concordance from observations with RD03, which was due to a difference between the researcher and mentors recording engaged versus disengaged. The mentors recoded disengaged because they observed closed eyes, whilst the researcher recorded engaged for a majority of the observation time as each time there was noise, movement or activity within the environment, the person would position their face toward the activity. Even though their eyes were closed seemingly most of the time, and they didn't actively participate in the activity, they responded to what was happening within their environment, an indication they were engaged with their environment.

It was anticipated that each of the residents would be involved in a range of observation time periods across 15, 30 and 60-minute block sessions of observation. This was applied flexibly as the situation deemed appropriate; availability and consent of residents to participate. The range of observations undertaken varied from the planned number due to personal situations of the residents and alterations to staff work commitments. However, the variation in number of observations completed provided a workable sample to enable the identification of useful information for the research question and to inform recommendations for adaptation of the tool. Table 12 below shows the total number of 510 minutes of observations that were completed with each resident participant. These observations sessions were made up of four 60-minute sessions, ten 30-minute sessions and two 15-minute sessions. All of the 60 and 30-minute sessions were completed with two mentors, one from each wing and the researcher (total of three people in the observation).

Table 12: Timeframes for observation with each resident participant

Timeframes of observations				
Resident	**One hour**	**30 minutes**	**15 minutes**	**Total time**
RD01	2	3	1	165
RD02	-	-	1	15
RD03	-	2	-	60
RD04	1	3	-	150
RD05	1	2	-	120
Total	4	10	2	**510 minutes**

As Table 12 shows, there was quite a variation in the time periods in which different residents participated in the study. This was due to personal situations, such as family visits during scheduled observations (RD03) and death two months into the study (RD02,) hence observations were limited. Family visits and illness made it inappropriate to observe certain participants at certain points in the study, thus including them to a lesser degree than other residents.

There was also some variation in the time periods each mentor spent doing observations as shown in Table 13.

Table 13: Timeframes of observations for each Mentor

Timeframes of observations with researcher and Mentor				
Mentor	**One hour**	**30 minutes**	**15 minutes**	**Total time (min)**
MEN01	2	3	-	210
MEN02	1	2	-	120
MEN03	2	3	1	225
MEN04	1	2	1	135
MEN05	2	3	1	225

Again, this variation was due to personal issues for MEN02 and MEN04 resulting in each doing slightly less than the original scheduled number of observations. However, this did not compromise the integrity of data regarding the opportunity to explore the utility of PIECE-dem and the research objectives.

It is the notes recorded during observations that tell the story of how the person is experiencing their world. Because of this, the numbers of ticks or minutes spent in interaction, engagement or disengagement are not considered without their accompanying notes. The descriptor ‘interaction’, ‘engaged’, or ‘disengaged’ does not, by itself, tell you about the impact of that experience on an individual’s wellbeing and there are no value judgements inherent in the use of the terms. Therefore, there is nothing to be added to the results by tabulating the ticks as it has no meaning without the accompanying narrative. Examples of narratives and field notes are utilised in the discussion in Chapter Seven as that provides more opportunity to explore the meaning behind the activity.

We will not be looking at the narrative here, as it is more effectively positioned in the discussion, but we will look at the results from the reflections on observations. The reflection on observations provided opportunities for thinking about what was observed, reflecting on what the actions might mean to the residents and discussion on trends with reference to the observation summary completed for each resident before any observations took place. As the narrative tells the story of what was occurring, the reflection sessions provided valuable insight into how the resident was experiencing their world, exercising capacity and agency.

6.3.3 Reflection on observations

6.3.3.1 Mentors response

There was uncertainty regarding the difference between the descriptors of interaction, engagement and disengagement. This was demonstrated through the inconsistencies in the data recorded throughout the observations with mentors and the researcher; there was often discrepancy between the recorded descriptor; interaction, engagement and disengagement.

At the beginning of each reflection session would be conferring on what descriptors were recorded; looking at similarities and discrepancies. This occurred before any other discussion occurred as it established a baseline of the possible intention of the person being observed. Reflecting on what was observed and considering the intent behind the action was critical and proved quite a challenge for the mentors. During the reflection sessions there was considerable discussion regarding intent, as this was the significant point of difference between *interaction, (*where a response is expected*),* and *engagement (*where there appears to be no intent of a response). It was through reflecting on the qualitative notes taken during the observations that provided context and a personalised perspective on what was happening at the time for or with the resident; was there social interaction being initiated and did they expect a response?

The mentors generally struggled with seeing beyond what they knew of the resident. However, consistent with the original UK PANICOA (Preventing Abuse and Neglect in Institutional Care of Older Adults) study, it was what surrounded the action that told the story of the resident's experience.

To facilitate an appreciation of the reflection session, below is an example of a 60-minute observation, including summary and reflections.

One-hour observation.

1. Observation narrative summary:

   Interacting or engaged for the entire observation period of one hour. Staff bought RD01 a cup of tea and a plate of bread and butter cut into triangles. They placed both on the small hospital table between RD01 in the chair and the larger dining table. RD01 places a cloth serviette over the bread and butter. For the next 20 minutes, RD01 sips her tea and eats small bites of the bread, and covers and uncovers the plate. The cup is moved from the small table to the larger table, with a slow stretch of the arm. The plate and cup get moved between the small and large table for the next 15 minutes. She sits back in the chair and looks around the room before leaning forward and moving the cup and plate again back onto her small table. She drains her cup and turns it upside down shaking it. Then slowly stretches and places it on the large table. Staff take the cup and plate away, and bring her a newspaper and large magnifying glass and place it on the small table. She picks up the magnifying glass, looks at the paper through it, and then places the magnifying glass, with a slow stretch onto the larger table, followed by the newspaper. Then sits back and smiles to herself, looks around and reaches for the paper. This movement of objects between the small and larger table continues throughout the entire observation period.

6.3.4 Summary of observation

During observations it became apparent how well RD01 used her immediate environment to support her self-initiated engagement. At the first observation, there was a small ‘hospital’ adjustable table placed between RD01 in her seat and the larger dining table. When RD01was engaged with objects, she kept them on the small table in front of her. When she had finished she placed them on the larger table, at a stretch, but outside her immediate environment. She moved objects between these spaces, and sat back intermittently and looked around the room. Her coffee cup, newspaper and magnifying glass kept her attention for the entire 60 minutes of observation. All self-initiated.

6.3.4.1 Reflection discussion following this observation

R: We have just been observing RD01 for 60 minutes. How do you think they were experiencing their world during observation?

M: She seemed very calm and relaxed.

R: Would you say they were in a positive or negative state during observation?

M: Quite positive actually. She often smiled to herself, and when she sat back in the chair there was often a little sigh, like one of being satisfied with yourself.

R: Yes, she often looked content and quite pleased with herself, I agree. Did you discover anything new about the resident during this observation?

M: Yes, I did. She was able to occupy herself really well, and for a whole hour. What I was really surprised by was that there were no cross words or any signs of verbal outburst, not even an inkling of any. That was amazing.

R: You sound surprised by the absence of any cross words. Is that what you expected to see and hear from RD01?

M: Well yes, as she does have a reputation for being pretty out there with her verbal aggression.

R: OK, so maybe you saw another view of RD01. So, would you say that she was able to exert control within her world?

M: Yes, I certainly did see another side I'd never seen before. Umm, I'm not sure what you mean by exerting control. Can you explain a little please?

R: Yes sure. In this observation there was a good example of how she exerted control over her environment. There were two tables, one smaller one up close to her and the larger dining table at an arm's length away. Did you see how she used the two tables? When she was wanting her cup of tea close by, it was on her small table. When she wanted it outside her direct environment, she moved it to the larger table. This she did with the bread and butter, newspaper and magnifying glass. She was able to control what was within her direct and immediate environment by having somewhere to move unwanted objects away. When the small table close by her was empty, she brushed it clean, sat back and sighed, just like a 'job well done' sigh. Then she bought different objects back into her immediate environment, all of her choosing. She was acting independently and exerting control of her immediate physical space. It appeared that her social needs were being well met by her activity.

M: Yes, I see, and it was quite amazing to see how engrossed she was with moving things around. I'd never noticed that before. I certainly hadn't thought of that kind of doing stuff as having control. I guess we see that we need to be the ones in control, and I didn't think about control and residents.

R: It's probably worth considering for a moment the notion of not being in control. How do you feel when you experience not being in control of a situation you are in?

M: Depends on the situation and how important it is to be in control. But it can be a little scary as you don't know what happening. It feels a bit like you are at someone else's will.

R: Yes, it probably does depend on the situation, but for people living with dementia, there would be many times during a day when they would feel not in control of their situation. So, when there is an opportunity for them to influence their environment, and exert some control it is important to support it. This example of how the two tables were used is a good example. So maybe it's not so surprising that there were no cross words as she was positively engrossed in her own world and all self-initiated.

M: That's amazing. I never thought about that little table in that way. Also, I never thought of RD01 as someone who could be so quietly engrossed. I hadn't seen her that way ever before.

R: That's what these reflection sessions are for, to tease out what we saw and attempt to make sense of how the resident is experiencing their environment. So, what do you think is key information from this observation session?

M: Well a couple of things. The little table seems to be important for RD01, but also that she is close enough to the dining table for stretching out to if she wants. Also, that she can become quite focused, and isn't always cranky and abusive. People tend to steer clear of her unless they need to interact because she is usually quite cross. I really am amazed by what I've seen this last hour. All this needs to go into the case notes, but also in the diary so everyone is aware of it straight away.

This example of one observation session and subsequent reflection demonstrates how preconceived ideas of a resident may influence how they are perceived, as well intended and caring staff such as the mentors generally struggled with seeing beyond what they knew of the resident. It was during guided reflection after each observation, looking at what surrounded the action that focused attention on the person, their perceived intent and efforts made within their immediate world; what was the resident's experience?

6.4 Reflection sessions

The reflection sessions were the key to try and make sense of what was observed from the resident's perspective. They provided a means of using base line information about the persons 'normal' response to situations (pre-summary sheets), looking at trends or patterns and considering actions or responses from the resident's perspective.

In 90% of the observation sessions, it was recorded that something new or surprising was observed about the resident. Often what was reported as a new or surprising ability seen during observations included activities relating to Activities of Daily Living (ADLs) such as removal of jacket, eating unassisted. This is not surprising as ADLs are within the context of care staff and provided an obvious and straightforward idea for the mentors to understand and comment on. Concepts such as intent that involved seeing the person as having capacity and agency, appeared to be more difficult for them to grasp. This I believe added to the difficulty of seeing the difference between interaction and engagement. Concepts such as intent and agency may be outside the situational context of a busy care staff member. In addition, there was a tendency for mentors to record a coding of disengaged when a person had their eyes shut even if they were responding to stimuli within the environment. If a person is disengaged from their environment they do not tend to respond to noises and ambient activity? One possible explanation for this may be that a person with their eyes shut, is sending a message of not looking for anything to be done; nothing being asked of the care staff. Thus, it does appear that mentor's perspective of what they observed was strongly influenced by their context.

6.5 Interviews with mentors

There were two separate sets of interview questions asked of the mentors. The first set were 10 semi-structured interview questions which the mentors were asked before any training or interventions occurred and again post interventions. These questions were to capture thoughts about working with people living with dementia; care practices; communication; reflecting on care; personhood and relationships. On completion of the interventions, mentors were also asked five questions about PIECE-dem. The results from the pre and post interviews will be looked at first then the responses to PIECE-dem. A summary of one respondent's pre and post responses is included (see Appendix 12).

6.5.1 Interview questions: working with people with dementia.

The responses to the questions about working with people with dementia had a change in orientation and emphasis from pre and post interventions. A selection of these questions will be outlined to show the changes in orientation. For example, when the question was asked, '*Keeping a person clean, comfortable and well-nourished are the most important aspects of care for a resident with dementia?*' pre-interventions, there was a proclivity of agreement;

> '*I think they are a priority as everyone should have the opportunity to be well looked after'* (M03)

> *'I think it's important. You need to continue to keep them safe and happy. Sometimes their behaviour makes it difficult to get things done, so you need to work with that first'* (M04).

These examples are representative of the responses which had an orientation toward ADLs. The post intervention responses shifted to have wellbeing more central in the responses, as shown in the following:

> *'the most important aspect of care is being able to have the resident in a place of wellbeing; where they feel valued and able to express their identity.'* (M03)

> '*a person's wellbeing is the most important aspect. Being clean, comfortable and well-nourished are components but not essential. Respect and validation of the individual's personal values and beliefs play a more important role.'* (M04*)*

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This demonstrates a significant shift in orientation of thinking as there was no mention of wellbeing in any of the first interviews. Meeting the physical needs of residents is important, but the thinking had broadened to include additional, more personal aspects including the general wellbeing of the person.

There were some interesting and noteworthy responses in both pre- and post-intervention interviews to the question; *"If I was a new staff member starting work with you, what is important to know when communicating with a person with dementia*?"

The responses pre-interventions show regard and compassion and a good understanding of communication strategies when working with people with dementia such as:

> *"They may need extra time to speak or to gather their thoughts, allow them to finish speaking, acknowledge what they are saying." (M01)*
>
> *"When you're speaking ask simple questions that are easily understood and be patient waiting for a reply as they often need time to process their answer."* (M02)
>
> *"Eye contact is critically important. Don't argue or challenge the person. Listen carefully." (M03)*

The responses pre-interventions were positive, but there was a shift in language and emphasis post interventions. Pre-interventions, there were suggestions of eye contact and tone of voice, however in the post-intervention interview these aspects were strongly emphasised. It is interesting to note that in the post-intervention interview each mentor mentioned the importance of body language. Here are two examples to illustrate the emphasis on observing and paying attention to body language:

> "*It's important to know 'How that person communicates'. If they can't tell you, watch what they do, their gestures will give you a good indication.*' (M01)

> *"Pay attention to their body language and how they react to other stimuli around them. Watch and learn."* (M03)

This is a highly significant shift in thinking. Not only did the mentors demonstrate an increased awareness of body language but mentioning it as a form of communication is an illustration of their broadened view of the care relationship. This was one of the most significant achievements in the development of the mentors' awareness of observing how the residents communicated their experience of their world.

Another question which showed significant development in thought was regarding personhood: "*How might you support the maintenance of personhood for a person with dementia*"? The pre-intervention responses were all quite simplistic with an orientation again toward supporting personhood during ADL's:

> *"Facilitate their preferences in care."* (M03)
>
> *"Keeping staff up to date and informed with any change in a resident's care/behaviour."* (M02)
>
> *"I don't know what personhood is."* (M04)

The responses post-intervention showed an improvement to more expansive view of personhood:

> *"Making sure that all staff understands and works towards the same goals of making the person feel valued and treated as any other person of the community is treated."* (M03)
>
> *"Understand their Life Story and identify what matters most to them; show respect*

> *and validation for their life experience. Also ascertain what they are able to do and provide opportunities to enable them to do those tasks independently such as special cutlery so they can eat unassisted."* (M02)
>
> *"You need to know what makes that person feel good about themselves, and support them to be as independent as possible."* (M04)

There was a much greater appreciation of the breadth of what constituted an approach which supported personhood; with the focus on the person rather than ADLs. This is an important change in orientation and attitude. The responses also demonstrated a greater appreciation of their role in supporting and maintaining others personhood.

From this sample of responses from the mentor's pre and post intervention questions, a change in perception and orientation is evident; body language is a form of communication; people with dementia are able to enjoy states of wellbeing; appreciation of the value of individually meaningful activities; seeing that care staff influence the world of a person with dementia both positively and negatively.

6.5.2 Interviews with mentors on the utility of PIECE-dem as a practice tool.

After the completion of the active phase of the study, all mentors were interviewed individually on their thoughts about the utility of PIECE-dem as a practitioner's tool. The interview was structured broadly around five questions. The responses to each question will be examined individually.

The first question explored the potential use to them as practitioners.

Question 1: "*Do you think it is of any use to you as a person who works in aged care? If so,* *why?*"

The responses fell into two main themes: observing wellbeing/illbeing; and communication practices. Examples of responses to each theme included:

Wellbeing/illbeing comments:

> *"The PIECE-dem framework captured information and after reflection we were able to distinguish what kind of activity or interaction is positive or enjoyable to the resident. We may also find the source of distress to them."* (M03)
>
> *"When you are actually looking, you can see if they are in a state of wellbeing or illbeing, and you see what places them in that state. That's really valuable."* (M01)

Communication comments:

> *"As many residents are unable to verbally inform staff what their needs are, to observe uninterrupted gives an opportunity to see how residents communicate; their patterns of gestures and responses become quite obvious."* (M01)
>
> *"It has made me more aware of what a resident might be feeling; how they respond to certain situations and the way they interact with staff."* (M02)

There was 100% agreement that the opportunity for observations was of value in seeing different perspectives of the care interactions and care environment.

Question 2. *"As a person who works in aged care, what did you find most useful or* *different about using the tool?"*

There was unanimous agreement that the raw data sheets were easy to use and simple to understand. The mentors appeared to feel comfortable with the framework and coding as all but one claimed that it was easy to 'work with'. There was also undivided agreement on the value of the reflection sessions;

> *"The reflection sessions were very important and resulted in amazing outcomes. More experience needed to lead the reflection time."* (M03)

> *"I particularly liked the reflection time. Amazing discussions about what we saw. Very insightful."* (M01)

Other responses to this question included aspects more to do with care practices rather than the tool, such as:

> *"Being able to gauge how a person is responding to staff, their environment and what might trigger someone becoming agitated or upset."* (M02)

> *"Doing this has shown me that it is the little things that can speak volumes e.g. identifying changes in a resident's ability to do things and what can I do to enable them to keep their independence."* (M05)

If PIECE-dem is to be of value to practitioners, it needs to be of practical use. If information is to be collected and discussed, then it needs to be able to inform care practices. Thus, the question was asked of the mentors; "*How might the information collected using PIECE-dem be put to use in your facility?"* The responses focussed on including the information in care plans and communication books and three included the possibility of small groups and discussing with staff the findings from the observations to increase their involvement in developing care plans.

All of the mentors claimed that they would use PIECE-dem after the project. How they would use it had slightly different orientations:

> *"Since there is so much more information we need to know and understand than verbal expression, I think I would introduce it to other staff members too."* (M04)
>
> *"If there is any particular issues with a resident, I think I would initiate this as a beginning of assessment to obtain information."* (M03)
>
> *"I think you would need maybe 3 sessions of 30 mins at different times of the day to have a good overview of the resident. I feel the discussions after the observations will be of great use and it would make the staff more aware of how each individual resident is experiencing their world."* (M01)
>
> *"I would hope that I can continue to use this to the full extent as I believe it is a great tool to learn/understand our residents' personal needs and values. However, this could not be done if I am on a shift."* (M05)
>
> *"I would be prepared to put in extra hours as this tool has the potential to improve the quality of life for the residents and that's of the most important thing."* (M02)

All of the mentors saw benefits in introducing the tool to their workplace, however there was significant hesitation regarding themselves as training other staff in PIECE-dem and taking on the role of guiding the reflection after the observation.

> *"The time restraints of observing and working in the unit at the same time is a matter*

> *that does need to be worked out but I would love the staff to learn the tool as I think it does provide very detailed information of a resident. It would give staff the opportunity to be more involved once they learn how the tool works and have a bigger input into trying to achieve the best care for a particular resident."* (M01)
>
> *"I do not feel confident in running reflection sessions; I don't know how to get beyond what I see. This is a skill I would like to develop more before I teach others."* (M05)
>
> *"I would hope to be able to teach other staff. The raw data sheet is straightforward but it's the reflection sessions, and they are the key. Firstly, I need to be able to think like you and tease out what it is we are actually seeing. I feel I don't have the words to do this well."* (M04)

The results of PIECE-dem interviews with mentors were encouraging. There was general agreement that the tool provided a framework that was believed of value to practitioners. This framework (after training in person-centred practice and principles, and the PIECE-dem process) included pre-observation information sheet for base line information about residents, an easy to use raw data sheet and a summary sheet to synthesise observations and narrative on.

There were three areas of particular challenge for the mentors; understanding the difference between interaction and engagement; the depth of knowledge around the theory of person-centred approaches and words and depth of conceptual knowledge to facilitate the guided reflection sessions. These challenges will be further discussed in the following chapter as they do inform the development of recommendations in the adaptation of the tool.

It was claimed that staff would need to be supernumerary to use the tool to allow the observer to focus their attention. Also, that two or three people observe concurrently in order to have a group discussion and to maximise objectivity. If PIECE-dem was to be used as a tool for gathering information about how a certain resident was experiencing their world, the optimal time suggested by mentors was three 30-minute sessions.

Generally, the responses from the qualitative data demonstrated a great deal of care and passion for working with people living with dementia. There was a strong person-centred foundation demonstrated across the organisation. This benevolent culture, was demonstrated by responses which cared for the wellbeing and supported the person but struggled to see them or think of them as people with capacity for agency. There were indications however that as staff became more familiar with observing and analysing what was seen, greater critical analysis developed when looking for what meaning the actions might have had for the person. This will be discussed further in the following chapter where discussion of the findings will explore further the results of this study.

CHAPTER SEVEN

7. Discussion

7.1 Introduction

In Chapter Three (page 53) when discussing the theoretical framework of symbolic interactionism, there was discourse on the prominence of interactions and the importance of context within this theoretical framework. What is of particular interest in relation to the findings of this study is that there appears to be a balancing dilemma between agency and structure as ultimately social order is dependent on how individuals interact, negotiate, manipulate and create their ‘place’, especially within an institutional setting, which often ‘set the conditions for actions’. Even in a RAC home with a strong person-centred approach to care across the organisation, the appreciation of agency in people with dementia is not readily recognised. In addition, there was a challenge to understand that ‘meaning’ for an individual is a social product which is formed from and created through the defining activities of people as they interact within a social context. However, there was an increase in awareness of both of these ideas after reflection on what actions might mean for the person involved.

Staff participating in this pilot study showed changes in their perception and orientation in several areas: understanding body language as a form of communication; identifying patterns leading to states of wellbeing; appreciation of the value of individually meaningful activities; seeing that care staff interactions influence the world of a person with dementia both positively and negatively. These are all significant developments in awareness of participating staff to inform enhanced quality of care. However, of greater importance from a social perspective is the development, after several reflection sessions and discussion on how a person might be experiencing their environment and possible meaning behind the actions, in staff gaining appreciation of people with dementia as people with agency, who exert influence over their care environment, and are thus co-creators of the care environment.

Before any further discussion of the finding of the study, it is necessary to reiterate the aim of this exploratory research. To examine the utility of the PIECE-dem as a tool for practitioners in a RAC home setting, with the subsequent research question 'can PIECE-dem increase understanding and observational skills of practitioners to inform quality care to residents with dementia?'

Objectives:

1. To examine the value of PIECE-dem as a tool for use by practitioners
2. Develop a set of recommendations to inform the adaptation of the original PIECE-dem manual for use by practitioners.

The research question will be discussed in the light of the findings from the study. However, before that occurs there is a contextual discussion on the theoretical foundations and key concepts of this study in the light of the results.

7.2 Symbolic Interactionism and Context

Social relations, interactions and relationships are at the most rudimentary level essential for an organism to develop as a human (Phillips et al., 2010). We are all social beings, and as Carl Rogers claims 'I speak (or communicate) as a person, from a context of personal experience and personal learning' (Rogers, 1961: 18). Language, as our vehicle for communication, is understood as the primary form of symbolic interaction (Stevens et al., 2013). Non-verbal interactions such as eye contact, or avoidance, being more subtle and easily overlooked can be open to interpretations of meaning (Bakker, 2011).

This is relevant to the research question as context did appear to influence not only how meaning arose for people in given situations, but also how meaning was modified through interpretive process, facilitated by guided reflection (Johns, 2013). In addition, understanding the messages given through communication are open to interpretation, which may be understood, or misunderstood as influenced by accommodation of other alternative contexts involved in the interaction.

The three basic assumptions underpinning social interactionism (Blumer, 1969) were evident in this study; people, independently and jointly acted on the basis of the meaning that situations had for them; meaning arises in the process of interaction among individuals; and meanings are given and modified through an interpretive process that is ever changing, as adaptation occurs within their context of their environment. The individual responding to situations in a way that has meaning for them is inherently appealing and appears a straightforward concept. However, when there is the intersection of different perspectives of multiple people with different meaning that situations have for them, the adaptations within their context may not mesh; and one context may dominate in the interaction.

Given that symbolic interactionism is the theoretical framework of this study, it is important to consider the complexity of contexts which exist within the composite environment of a RAC home, the research site for this study, as mentioned in Chapter 3 (page 54). A simplified overview of two different micro contexts at play within RAC facilities, there are people who live and sleep there 24 hours a day, seven days a week, who all have care needs which have resulted in them requiring sufficient assistance with ADLs to move into a RAC home. These people in addition to their physical needs also have other human needs such as the need for meaningful social interaction and engagement, relaxation, exercising choice and autonomy.

Overlayed on these more human and social needs is the dynamic of what is happening in their world at the time, how they slept, their general mood and so on, all quite individual and fluid. The care staff come on shift with their own personal feelings of the day, are provided with an overview at handover and commence their responsibilities and fulfilling their duty of care with knowledge of what they need to do this shift and for whom. Fulfilling their duty of care with residents and recording interactions and interventions in documentation are the primary expectations on staff in their professional roles.

The research site was approached due to their previous demonstration of person-centred approach across the organisation. This was further confirmed by the results from the staff survey done before any observations began in this study. One aspect that has been revealed through this study is that caring and compassion for a person with dementia is a solid foundation for entering into a care relationship but there are more complex concepts to be understood if people with dementia are to be accepted as co-creators of the social world which exists as a creation of human interactions (Sabat, 2001), rather than passive recipients of care. The care offered by practitioners who are kind and thoughtful, but not recognising residents as co-creators of the care environment, and thus people of agency, may actually be disempowering (Kitwood, 1997; Dupris et al., 2012) and negatively positioning (Harre and van Langenhove, 2008) the resident socially. Such a situation was revealed in this study in the following situations.

7.2.1. Context influencing understanding of co-creators of the social world

Notes taken during the observation session formed the basis of the discussion in reflection session. The subsequent notes made in the reflection session after one observation session indicates the influence of context on seeing residents as co-creators of the social environment.

During one 30-minute observation session with RD01 there was considerable self-talk over an eight-minute period:

> *"What did you do with my hanky? "Should have stayed at home, didn't know there was anything on. Glasses all smudged up and can't see a thing. When do we get home, I've got a cat to feed and kittens".*

When her self-talk was actually listened to it made sense, it told a story:

> *"they didn't tell me there was something special today. Who are these important people? Why didn't they tell me there was something on today? I'm not dressed right, I bet there will be food and everything and I have nothing to bring"* …

All of these questions and statements were said in a sharp tone. However, in the quietly spoken self-talk she was telling us why she was uneasy; it sounded like she felt socially compromised. By just hearing the sharp tones and annoyance in her voice, she could be thought of as 'her usual cranky self', but by listening to the words, insight is gained into why she might be feeling 'cranky'. Knowing the persons personal life story sheds light on how they respond to certain situations (McKeown, 2010). One of the purposes of the pre-observation summary sheet was to gather together such information. RD01 was accustomed to being in control of social settings, knowing what was going on socially and the social protocols in her local community. When mentors listened to the words which they did during observations, they heard the story. During the reflection session they connected RD01's past life roles, as the wife of the Shire Secretary and involvement in many local committees, with how she was responding to her present situation (Thompson, 2011). She had been documented as being verbally aggressive and resistive, when possibly most of the time she was actually telling them what was upsetting her when time was taken to listen. One key piece of information gained from these observations was to pass onto other staff to actually take the time to listen to what she was saying. This RAC home has comprehensive life stories for each resident and yet the connection had not been made for this resident and her need to be informed of ‘social events’ happening in her environment (we, the observers were the social event this time).

RD01 was a co-creator of the care environment as staff had developed a very cautious approach with her as they expected there to be cross or aggressive interchange. The sharp tone observed in the above situation appeared to be expressing her feeling socially compromised (Sabat and Gladstone, 2010).

This observation is also an example of how residents can be negatively positioned socially (Harré and van Langenhove, 2008; Sabat and Harre, 1992) without any malice intended (Kitwood, 1997; Sabat and Harre, 1992). Knowledge of this person’s life story, and the prominence social events had in her life, along with the importance of her physical appearance, contribute to how she responded to her context; how she makes meaning out of the situation she finds herself in (Blumer, 1969). There was an intersection of different contexts, this resident trying to make sense of what was happening, and staff who want to do their duty of care whilst needing to get on with their work, hear someone being ‘cranky’ and resistive. The adaptations within their context didn’t mesh, which appeared to place one person, the resident, in a weakened social position.

Even within this research site, where there was an organisational commitment to person-centred approaches, there was an emphasis in thinking and discussion during this study on what they could do, as a care provider for the resident rather than what can they do to support independence of the resident. Consistent with such an orientation there were indications that people with dementia who were observed in this study were considered from the perspective of care recipients, as indeed they are. However, they are also social beings with additional needs to simply that of a passive recipient of care. The perspective of citizenship (O'Connor et al., 2007) is one suggested means of considering a person's expression of agency. In addition, the potential for independence, agency and autonomy (Kitwood, 1997; Hugonut-Diener and Husson, 2007; Clare et al., 2008) need to be provided with opportunities. Clare et al. (2008) found that the context of institutional care, placed limitations on residents' potential expression of personal agency. There is a suggestion in this study that it was staff perception of agency rather than expression of agency that was limited, as there were examples of agency occurring during observations, but they weren't perceived as such by staff. As evidenced by the following situation.

7.2.2 Context influencing perception of agency

Once again it was the notes taken during the observation session which formed the basis of the discussion in reflection session. The subsequent notes made in the reflection session after one observation session which indicates the influence of context on seeing residents as individuals of agency:

> 'RD05 sees another resident enter the unit. He stands from the chair he has been sitting in and moves to another lower chair beside it. He pats the palm of his hand on the chair he has just vacated whilst looking at the resident. She does not enter lounge area but walks down the hallway. RD05 scans the kitchen and lounge areas, stands and goes to the dining room door. Opens the door, checks the latch and closes the door. He then walks over to the opposite door, opens the door, checks the latch and closes the door. As he walks past one of the observers, he stops, and picks up a woollen scarf that had

been tucked under a chair. He turns it over in his hands, smells it then replaces it on the floor near the chair. Once again he scans the room before returning to the lounge area where he sits down.'

Scenario reflection:

The reflection session began with the question, *"So how do you think this resident was experiencing their world? What did we see?"* The first comment from a mentor was, *"well that's just what he always does, 'wander around'".* It was during discussion of what the actions observed might have meant to the person that the mentors articulated two new insights. Firstly, the checking of doors was reflected on as to what it may have meant to RD05 rather than dismiss meaning; "*that's what he always does*". When observing the activity, it was more than opening and closing of doors, as it involved checking the latches, pushing them in and releasing, and the handles, turning and releasing. It looked like checking for functionality. As he crossed the room to the opposite door, he stopped, picked up a woollen scarf, turned it over in his hands, smelt it and replaced it on the floor before progressing to the door on the opposite side of the room. In discussing what these activities might have meant to the person, knowledge of his history as a truck mechanic provided some suggestions to meaning; checking the mechanics of the door latches, maybe doing a security check, doors OK, scarf a new object but no threat.

Secondly, they recognised that RD05 looks out for a particular resident. They knew they liked to sit together, but hadn't seen an example of him recognising the need to move from the higher chair which his friend needed to sit in and which RD05 vacated when he saw her enter, and patted the chair for her to sit in. This seemingly simple

> activity would have required a complex series of thought processing from RD05, something the mentors were surprised by when discussed. This resident who is considered to wander quite aimlessly around the unit appeared to have quite clear intentions behind many of his actions, several of which required complex processing of stimuli, and clear indications of capacity and agency.
>
> This resident demonstrated personal agency in several different activities, however it wasn’t recognised as such initially. There were examples of influence and control over the direct environment, checking doors and the potential threat of the new object (scarf) in the environment. There was surprising insight shown in recognising the need to move chairs in order for the friend to sit in the higher chair. There was considerable agency demonstrated by this person within a 30-minute observation.

These examples above are also presented as examples of showing different perspectives as they relate to the individual contexts of resident and staff; residents are responding to their situation as provides meaning to them, supporting their identity and autonomy, and staff are likewise looking at how the situation has meaning for them, by looking at what they need to do from a care provider context with safety first priority, and responding to the person they think they know. This knowledge of the person may however be on a superficial level and not necessarily consistent with a broader picture of the individual (McKeown, 2010).

What the data from this study shows is that even though we can measure the aspects of knowing the resident and resident autonomy, and the staff in this RAC home are supporting person-centred living as defined in earlier Chapters, they are in fact overlooking significant non-verbal and verbal communication from residents that clearly indicate agency.

This is supported by the findings as discussed in the results Chapter 6 (pages 131-133) in IC AUTO items. What is notable on this domain is the agreement of all staff that the facility supports resident independence, that they feel good about the quality of care provided and that residents get enough to eat. However, there is less certainty across staff in relation to certain items that are highly relevant for supporting resident autonomy and choice that seems to identify potential underlying issues. For example, only 66% of all staff felt that they frequently had enough time to allow residents to do things for themselves. This, in conjunction with larger percentages of staff saying that they only occasionally felt able to allow residents to make decisions for themselves (76.6%), and that they have done things for residents when they could have done things for themselves frequently (21.3%) or occasionally (53.2%), it is important to recognise that as such, there are potential consequences for supporting or undermining agency.

This could be a reflection of the lack of recognition of agency in residents. Therefore, not interpreting what they observe in the appropriate context is leading some staff to deny residents the opportunity to do things for themselves, to let them make their own decision and therefore they end up doing things for residents they could have done themselves.

When reflecting on the findings and considering the reflection session discussions there did appear to be a significant influence of meaning as it arises in the process of interaction for individuals, and the meanings were modified through an interpretive process. In addition, it appeared that meaning could be further modified through reflection on the process of interaction in an attempt to understand the perspective of another. This will be further discussed below in the discussion on the reflection sessions (7.3.2.1).

7.3 Key concepts:

7.3.1 Person-centred care

Person-centred practices which are grounded in relationships are more than the personalisation of care. To allow for the perspective of another, and the social dynamism of interactions, the two-way interplay which occurs and the influence of perspective and context has on how each environment or situation is interpreted and given meaning by individuals involved, does need to be recognised (Blumer, 1969; Sabat, Johnson, Swarbrick and Keady, 2011). This dynamic occurs for each party involved in the interaction, and moreover, each interaction is interplay between people within a given context, and success of any interaction is influenced by both parties (Sabat, 2001). When considering the research question, *can PIECE-dem increase understanding and observational skills of practitioners to inform quality care to residents with dementia,* one consideration is whether the use of PIECE-dem might facilitate practitioners to translate theory into practice. The answer to this question may be influenced by the context within in which it is asked and what theoretical information is involved.

There is a degree of sophistication in thinking expected of care staff if they are to practice person-centred care;

> ‘At the heart of any successful person-centred intervention are caregivers’ relationship skills: communication skills to elicit personal information from residents, cognitive skills to see how this information can be applied in caregiving tasks, and behavioural skills to enact these insights’ (Medvene, 2006: 220).

During reflection sessions, the mentors became more open to observing and not simply seeing what they expected (Sabat, Napolitano and Fath, 2004) There was a move away from language such as ‘aimless wandering’ which minimised the agency of the person to ‘exploring the environment', a more positive recognition of self-identity and intent (Sabat et al., 2004). It does appear that using PIECE-dem did enable care staff to translate theory into practice as their understanding or appreciation of residents' activity as having personal meaning. Through these observations and subsequent guided reflection on what was observed, participating staff looked more critically and attempted to interpret the meaning behind the actions. These guided reflections required facilitation, and inquiry to look beyond what was seen and into the possible meaning behind what was observed. This is consistent with what Walker (2012) found regarding opportunities for reflection on daily schedules and practice so as staff could construct their own learning from reflecting on practice.

7.3.2 Person-centred care verses benevolent care

It has been suggested (Davies and Harre, 2007) that it is common for people not to recognise the ways in which their taking up of paternalistic positions negates the agency of the people they are interacting with. So, within the institutional context, unintentional disempowerment can occur with good intentions and benevolence. Such a benevolent culture was revealed in this study through thoughtful supporting the person but generally not seeing them as people with capacity or agency. Such perceptions were evident in discussions during reflection sessions and the lack of which may underpin some of the inconsistencies found in the ICI data.

Some indications of such paternalistic positions which contravenes the agency of the people they are interacting with were evident in the survey data. On the one hand, almost all respondents (97%) indicated that they knew what people liked and were aware of residents' skills and yet, 76.6% report only occasionally feeling that they are able to let residents make decisions for themselves and nearly as many who indicate that they do things for residents they could have done for themselves (21.3% frequently; 53.2% occasionally). These inconsistencies do highlight one of the potential issues with the quality of knowledge that staff in rural areas may have based on pre-existing personal knowledge from their experience of the person rather than information from the individual resident. There are indications that an overwhelming proportion of staff (97%) are so confident that they understand the residents having read their social histories, talked to family/friend about what is important to the resident (93.6%) and using said knowledge of preferences, habits and routines to support care that they are not attuned to being observant to the actual person rather than the perceived person.

For example, with the observation of the removal of a jacket, the discussion from mentors was focused on ‘they hadn’t noticed that before’ rather than considering the complex process of thought that would have had to occur in order for the connection between feeling hot and the removal of the jacket by the resident. The focus was on the ADL rather than demonstration of intent, and capacity. What they saw was influenced by what meaning the situation had for them; the context they had was ‘what does this mean for me as a care provider’. There is value in tools or processes that raise awareness within care staff, and that did appear to occur within this study, particularly regarding signs of wellbeing, and embodied communication, and considering people with dementia can exercise agency.

It has been suggested that the idea of person-centredness is well understood at a basic level; however, the challenge is often recognising it or translating it into practice (McCormack et al., 2002; Nolan et al., 2004). The findings of this study are consistent with McCormack et al. who found that ‘no magic bullets’ exist regarding implementation of person-centred practice as the complexity of interactions between practitioners and their practice settings frame their context which is understandably different from residents’ (McCormack et al., 2002). Reflective practice has been suggested as one possible vehicle for assisting the translation of knowledge into practice across a number of academic disciplines (Clarke, 2014; Fook et al., 2006). The findings of this study do support the notion that guided reflections (Johns, 2013) support translating theory into practice, as the practitioners did develop greater understanding of residents' activities and involvement within their environment, especially an enhanced appreciation of embodied communication (Kontos, 2012) , signs of wellbeing (Kitwood, 1997) and acknowledging expressions of agency. This raised awareness was evident in responses of post-trial interviews with mentors such as;

> *"The most important aspect of care is being able to have the resident in a place of wellbeing; where they feel valued and able to express their identity."* (M01)
>
> and
>
> *"It's important to know how that person communicates. If they can't tell you, watch what they do, their gestures and responses will give you a good indication."* (M01)

7.3.3 Reflection informing practice

The findings regarding reflection in this study do seem to support John Dewy's (1933) statement 'We do not learn from experience … we learn from reflecting on experience'.

This study used guided reflections (Johns, 2013), where the intention of the reflections was to open a learning space so practitioners can learn from themselves. The guide, who in this study was the researcher, originally scheduled leading from the front initially then handing over the lead to mentors to build the groups' performance and learning outcomes (Johns, 2013).

When considering the possible meaning of actions for residents, this needs to be considered within the context of their environment. Given the importance of interactions and the prominence of context within this theoretical framework, there appears to be a potential dichotomy between agency and structure as ultimately social order is dependent on how individuals interact, negotiate, manipulate and create their ‘place’ in the space.

It is during reflection sessions that different aspects of the narrative collected during observations can be explored against the individuals’ contextual understanding, based on life story and usual presentations and the broader environmental factors - engaging in a dialogue of the particular with the universal (Rolfe, 2014). This process of reflection offers the potential for greater understanding of environmental and social context surrounding the person with dementia and resultant behavioural responses (Quinn et al., 2014). Johns (2013) suggests that where there is this interplay between ideas about practice and practice as experienced, the practice-theory gap is diminished. This was supported by the findings of this study through the reflection sessions.

7.3.3.1 Reflection sessions is crucial in understanding what was observed.

Post- trial, mentors did claim that the reflection sessions assisted them in seeing beyond what was observed to consider more critically what the activity or action might actually mean for the resident. Staff stated that they had never thought about people with dementia as being able to exert control over their environment. ‘Exerting control’ was not a term that was consistent with how they thought about or documented residents’ activity before using PIECE-dem. This is a salient finding given this study was done in a care home with a strong foundation of a person centred approach. This finding suggests that any education in person-centred practice is potentially incomplete if there is not a corresponding understanding and awareness of recognising and supporting agency and autonomy.

The findings of this study are consistent with other studies (Quinn et al., 2014; Walker, 2012;

Johns, 2013) in regards to increasing awareness of certain features of person-centred practice such as wellbeing and embodied communication. Within such a paradigm, reflection on experiences can result in ongoing professional learning (Walker, 2012; Johns, 2013).

During the reflection sessions, there was the emergence of a picture that was constructed during discussion about what all of the information might mean to the person being observed; what does it tell us about the agency exercised by the person; what were any patterns or trends; action that indicated capacity; influence exerted on their environment. It is only through reflection that the picture began to have a story, and the action a social context.

7.3.3.2 Equipped to facilitate the reflections.

It does appear that when reflection sessions are guided reflection (Johns, 2013) where the discussion is facilitated by a guide, there is a greater depth in the discussion. A guide who illuminates issues, sometimes leading from the front other times being quiet but ever mindful of the groups' performance and learning outcomes. In addition, guides need also to have an understanding of the community of inquiry within which the guided reflection is taking place - organisational and situational context are significant factors (Johns, 2013) to be aware of during reflections. Walker et al. (2012) found that the role of the Nurse Unit Manager (NUM) was critical in supporting and encouraging staff to participate in learning discussion and an augmented contribution by the NUMs would have accelerated the adoption of the reflective practice. One of the barriers identified as working against the adoption of practices such as reflective practices is the existing ontology of the workplace (Fay, 1987). Thus, the goal for establishing practitioners as guides would be to set them up with a wide range of knowledge but not the expectation of being the in-house expert. This will be further discussed in the conclusion and recommendations.

This dialogue has situated the findings of the study within the theoretical framework and key concepts, and leads into discussing the research question: Does PIECE-dem have utility as a practice tool *to increase understanding and observational skills of practitioners which inform quality care to residents with dementia*?

This is a small pilot study, however there are indications that PIECE-dem does have utility as a practice tool. The research question and research objectives will be considered in the light of the study findings.

7.4 Does PIECE-dem have utility as a practice tool?

With 100% agreement on the utility of PIECE-dem as a practice tool, the Mentors clearly saw PIECE-dem as being useful to practitioners in RAC homes. The basis for these claims fell into two main themes of use, firstly in identifying wellbeing/illbeing (Kitwood, 1997) and secondly as a means of observing nonverbal communication from residents (Kontos, 2004; Clare et al., 2008). Both are valuable uses for informing care practices and relationships between residents and care staff (Fossey et al., 2006; Clare, 2008; Kontos, 2012).

There was unanimous agreement that the raw data sheets were easy to use and understand. In addition, the mentors appeared to feel comfortable with the framework and coding as 80% claimed that it was easy to ‘work with’. If the tool is going to be used in the RAC context where time and resources are constant issues, and there is significant variation in the levels of education across staff, it must be clear and easy to use.

If PIECE-dem was to be useful as a practice tool, then the information collected needed to be of practical use. There was complete (100%) agreement that the information would be of value in informing care practices. It was clearly stated by the mentors however, that it would not be possible to complete PIECE-dem observations whilst rostered on shift. It was generally agreed by the mentors that 30-minute observations appeared to be the most preferred time for observations as it was time enough to observe activities but not overly long to get backfill on the shift. From the practitioners' perspective represented by the mentors, there was unanimous agreement in PIECE-dem being of use and value to practitioners in RAC homes to inform quality care. There was also unanimous agreement in the value of the reflection sessions to assist in making sense of what was observed, and discussion observations from the perspective of the resident. This is consistent with much of the research (Johns, 2013; Walker, 2012; Rolfe, 2014) regarding reflection informing care practices.

7.4.1 The research question considered.

Can PIECE-dem increase understanding and observational skills of practitioners to inform quality care to residents with dementia?

7.4.1.1 Changes in understanding

There was evidence of a broadening of mentors understanding of what they observed during reflection session held over the 5-month period of the active phase of the study.

There was an expansion of what mentors observed in latter observations and reflection sessions as compared with the earlier sessions. The reflection session usually began with the question, *"So how do you think this resident was experiencing their world*? *What did we see*?" The first comment from a mentor in several of the earlier reflection sessions was, "*Well that's just what … always does, wander around, sound cranky, unresponsive*". The perception conveyed in that language is an example of where negative positioning based on preconceived identity and queried the capacity of the person with dementia (Sabat, 2005). It was not intended to be negative necessarily; however, it placed the residents in a negative social position, and refuted their capacity of agency.

It does appear that the framework of PIECE-dem did facilitate a broadening of what the mentors saw in residents' activity and engagement. Applying the framework and going through an interpretive process during the reflection sessions facilitated mentors to think more critically. This is consistent with what Walker (2012), found regarding opportunities for reflection on daily schedules and practices so as staff could construct their own learning from reflecting on practices.

7.4.1.2 Changes in observational skills

It was during discussion of what the actions observed might have meant to the person that the mentors articulated new insights. For example the resident who was considered to 'wander quite aimlessly' around the unit appeared to have quite clear intentions behind many of his actions, several of which required complex processing of stimuli. It was during latter reflections sessions when the mentors became more open to observing and able to articulate what they observed, and they became aware of thinking about how the person might be responding to their situation. There was a move away from terms such as 'aimless wandering' to seeing that he was exploring, and moved around the unit and surrounds with more purpose.

In addition to the broadening of perception, were two main areas of positive development in mentors understanding during their time using the PIECE-dem framework. These areas were an enhanced awareness of and articulation on states of wellbeing and illbeing, and body language as a form of communication. It is noteworthy that during the initial interviews with mentors there was no mention of wellbeing, however in the interviews post-trial, each mentor stated they were more aware of looking for signs and gestures as indications of wellbeing or illbeing. In addition, in the pre-trial interviews with mentors, there was mention of the importance of body language, in particular eye contact, but the appreciation of the body expressing messages as communication was articulated in post interviews by the mentors.

There was a heightened sensitivity to individuals' patterns of movements, or gestures indicating like or dislike of certain situations. This is a highly significant shift in thinking, not only an increased awareness of body language but mentioning it as a form of communication (Kontos, 2004 and 2008; Ward, 2008). This was one of the most significant achievements in the development of the mentors' awareness of observing how the residents communicated their experience of their world (Clare et al., 2008). In addition, the increased cognisance of wellbeing and illbeing signs when observing residents (Kitwood, 1997) was a major development. Again, there was no mention of such in the pre-interviews, but there was an emphasis on these terms when talking about the value of PIECE-dem as a practice tool. There was a general claim by mentors that observing using the framework and reflecting on observations heightened their awareness to thinking in terms of wellbeing and illbeing as a part of how residents experience their world.

Not only did the mentors become more aware of these phenomena, but they also became more able to find the words and language to articulate what they observed; seeing patterns or trends in gestures and responses.

What is of interest, is that there was also a development in mentor awareness of agency in people with dementia, which became evident in later discussions in the study, and yet none of them articulated this in their interview about the value of PIECE-dem. However from a researcher's perspective, this was of major significance; a framework such as PIECE-dem could increase staff awareness of the existence and expression of person agency.

7.4.2 Research Objectives

7.4.2.1 Objective 1. Value of PIECE-dem for use by practitioners

Objective one was to examine the value of PIECE-dem as a tool for use by practitioners.

With 100% agreement on the utility of PIECE-dem as a practice tool, the mentors clearly saw PIECE-dem as being useful to practitioners in RAC homes. The basis for these claims fell into two main themes of use, firstly in identifying wellbeing/illbeing (Kitwood, 1997) and secondly as a means of observing nonverbal communication from residents

7.4.2.2 Objective 2. Recommendations

Objective two was to develop a set of recommendations to inform the adaptation of the original PIECE-dem manual for use by practitioners.

Recommendation one: Based on the findings of the study, it is recommended that there is adoption of the modifications made to the templates (see Appendix 16) used in this study. The modifications reflect inclusionary consent, how the data from observations can be used to inform practice and has language which is clearer and less open to interpretation from a practitioner's context.

Recommendation two: For PIECE-dem to be practice tool, it needed to be easy to use, inform quality improvement in practice and be resource efficient in both time and cost. Ideally this would mean that RAC homes can provide training ‘in house’. This could be achieved through a development of a ‘train the trainer’ educational package for practitioners. The goal would be to train selected practitioners to become trainers within their RAC home. The package would include training on person-centred principles and practices, experiential learning exercises and how to use PIECE-dem. Feedback from mentors involved in this study, suggests there is benefit in having a two-day training package similar to the one used in this study.

Recommendation three: To support the train the trainer package there needs to be an additional training resource of ‘how to guide reflective sessions’; conceptual language and words (understanding the language of person-centred theory) to facilitate reflection sessions. Guides need to have an understanding of the community of inquiry within which the guided reflection is taking place - organisational and situational context are significant factors (Johns, 2013) to be aware of during reflections. It is suggested that a team of guides be trained in each RAC wishing to use PIECE-dem. A rotation of personnel facilitating the reflection sessions, would be beneficial for building capacity in practitioners. There needs to be attention given to preparation of a team of practitioners as ‘guides’ for the guided reflections.

CHAPTER EIGHT

8. Conclusion

There is evidence that PIECE-dem has utility as a practice tool and that it does develop greater understanding and observation skills for practitioners which would inform quality care to residents with dementia. However, when considering the use of PIECE-dem by practitioners, there were three areas of particular challenge identified for the mentors:

1. Understanding the coding difference between interaction and engagement;
2. The depth of knowledge around the theory of person-centred principles, expressions of agency and citizenship; and
3. Conceptual language and words (understanding the language of person-centred theory) to facilitate reflection sessions.

These three areas that particularly challenged our practitioners in this study may be a major point of difference between the observers in the original study (researchers and academics) and the observers in this study (RAC staff). There was a difference in knowledge and experience, but also a contextual difference. All participants in the original research study developing PIECE-dem had a sound theoretical knowledge and understanding of person-centred principles and the complexities of co-creating a care environment. They were also coming from a researcher's perspective, within a developmental context, quite different from a care staff perspective with a practice context. This difference could be seen as a knowledge deficit with the practitioners in this study, or it could be an appreciation of the contextual difference.

8.1 Influence of contextual difference between practitioner and researcher.

It may be that the different contexts of researcher and practitioner find meaning in different aspects of the care environment. It is important to recognise the difference in context, as this could be considered as impacting on the potential to adapt PIECE-dem as a practice tool. If this difference in contexts is not acknowledged there is the potential to expect practitioners to shift their context, reframe, and realign the context they are coming to the observations with. It is unrealistic to expect practitioners to leave behind their practice context. However, that is not necessary as there is room for different contexts for the observers as demonstrated in this study.

Even though the original PANICOA study was undertaken in RAC homes, the purpose was different from the purpose of this exploratory study, thus altering another level of contextual boundaries. The original UK research team, headed by Professor Dawn Brooker developed PIECE-dem as a result of a research study funded by PANICOA with a focus on the potential for observing abuse, neglect and loss of dignity in people with advanced dementia in care homes. Abuse, neglect and loss of dignity in people with advanced dementia have at their core the notion of power, a concept not the focus of this study and thus not explicitly explored. The exercise of power was observed in some interactions. However, it was how the resident was experiencing and influencing their immediate environment that was the focus in discussions in reflection sessions.

It could be suggested that it is ideal for practitioners to have the depth of theoretical knowledge to garner full value from the use of PIECE-dem. That might be ideal, but is it necessary? The expectation of all care practitioners to develop and articulate theoretical concepts may be overly complicated and unrealistic. It would be more realistic to consider there being a team of practitioners who have this knowledge who can support other care staff in guided reflections. Each practitioner in this study stated they could see PIECE-dem as being of value to practitioners, and they gained insight from using it and they demonstrated a relatively superficial understanding of the person-centred principles. However there was an evolution of their appreciation of expressions of agency which developed through guided reflection.

8.2 Education to support PIECE-dem

The findings from the study do suggest that education on person-centred practice does need to include raising awareness of, recognising, and supporting agency and autonomy; otherwise the benefits of person-centred practice are largely lost as people become socially disempowered through benevolent care. In addition, it became evident that there needs to be an investment in developing practitioners' skills in guiding reflection session, and having confidence in looking beyond what they see, to uncover the meaning behind the action.

8.3 Concluding thoughts

What was a surprising outcome from this study was that you can have a care culture which is firmly founded on person-centred care practices, but without recognition of personal agency, the care is likely to be benevolent care rather than authentically person-centred.

This study indicates that a RAC home can have a strong base of person-centred care across the organisation, such as the research site, but be potentially disempowering in interactions as in the benevolent care culture where personal agency of people with dementia is invisible. It is not the lack of agency, but rather the lack of recognition that appears to be a limiting factor. This highlights the fact that education on person-centred care is of incomplete value unless expressions of agency are expounded, and understood. There needs to be the recognition of people living with dementia as people of agency.

These findings suggest that PIECE-dem has the potential building blocks to provide a foundation for constructing an awareness of autonomy and expressions of agency as it enables an exploration of how the person with dementia is experiencing and influencing their immediate environment; advancing the understanding of person-centred practice. The findings from this small trial are quite exciting as there are indicators that PIECE-dem has potential in moving dementia care forward within the RAC sector.

8.4 Future research

There are several opportunities for future research stemming from this exploratory study. The one-day training on the fundamentals of person-centred principles and approaches together with the one-day training on PIECE-dem application was adequate in developing an awareness and appreciation of the nuances of behaviour and responses regarding demonstrations of wellbeing and embodiment of communication. However, it does appear that the training was insufficient in supporting participants to cognise the demonstration of capacity, and certainly inadequate in providing participants with sufficient or adequate language to facilitate the guided reflection sessions beyond a relatively superficial level.

Additional future research would be to support practitioners mentoring other practitioners in the application of PIECE-dem in their workplace. If PIECE-dem is to become an observation tool for practitioners, then it really does need to be able to be taught and mentored ‘in house’. Research developing a support toolkit for RAC facilities is more likely to enable this development. A framework and timelines could be available at the commencement of the research with care staff involved in the development of ‘in house’ support kit as they learn from their experience. Involving care staff in the evolution of the support tool kit has the potential to identify what is of most use to practitioners.

8.5 Limitations

There was a small sample size in this study. Such a small sample does question the generalisability of the findings. However, it was an exploratory study and there are positive indications of the application of PIECE-dem as a practice tool.

In addition, the variance in contexts between the original research designers of the tool, and care practitioners is significant. To ask residential care staff to develop the sophistication of conceptual thinking of the original researchers is unrealistic, however consideration needs to be given to what level of conceptual thinking is required to use and understand what is observed. Rather than all care staff having to have a sophisticated level of conceptual understanding, this may be more the domain for practitioners who will be facilitating the guided reflection sessions; to effectively support care staff to explore expressions of agency capacity and influence over their environment.

Appendix 1

Individualised Care Inventory - staff based measures survey (Chappell et al., 2007)

1. **The following statements refer to different ways that you can obtain information about residents, and to your perceptions of how well you know the residents that you are caring for. Read each statement carefully and *tick the box* under the response which best represents your level of agreement.**

	Strongly Disagree	**Somewhat Disagree**	**Somewhat Agree**	**Strongly Agree**
I read the social histories of resident care plans	☐	☐	☐	☐
I do not have the time I need to read the social histories of the residents	☐	☐	☐	☐
The quality of the resident social histories is poor	☐	☐	☐	☐
I talk to family members and friends in order to learn what has been and may remain important to the residents	☐	☐	☐	☐
I have a good understanding of the residents that I am caring for	☐	☐	☐	☐
I do not know the behaviour patterns of individual residents	☐	☐	☐	☐
I know what the residents I care for like	☐	☐	☐	☐
I find it hard to talk to residents because I do not know enough about them	☐	☐	☐	☐
I do not think that care plans are based upon what residents' value in life	☐	☐	☐	☐
I plan a resident's personal care routine using the habits and routines they had at home.	☐	☐	☐	☐
I am aware of the skills that residents still have and include them into my care approaches.	☐	☐	☐	☐
Favourite beverages, meals, and activities are part of a resident's day	☐	☐	☐	☐
I do not feel like I know each resident as a unique individual	☐	☐	☐	☐

2. Here are some thoughts and feelings that people sometimes have about themselves as care providers in residential care facilities. How much does each statement describe your thoughts and feelings about your ability to provide care at the facility you work in? Please *rate each item* below based on *how you generally feel about each one* and *tick the box* under the response that best represents how you feel.

	Very Frequently	**Frequently**	**Occasionally**	**Seldom**	**Never**
Feel that you are not doing all you should in order to care for the residents that you look after	☐	☐	☐	☐	☐
Feel rushed because of facility routines	☐	☐	☐	☐	☐
Feel rushed because of the expectations of the other Care-Attendants you work with	☐	☐	☐	☐	☐
Feel that the facility you work in supports the independence of residents	☐	☐	☐	☐	☐
Feel that other staff you work with have different ideas about how dementia care should be provided	☐	☐	☐	☐	☐
Feel that you are able to allow residents that you look after to make decisions for themselves	☐	☐	☐	☐	☐
Feel that residents have enough to do during the day	☐	☐	☐	☐	☐
Feel that residents get enough to eat	☐	☐	☐	☐	☐
Feel that the facility you work in offers choice in activity programming	☐	☐	☐	☐	☐
Feel that you have done things for residents when they could have done things for themselves	☐	☐	☐	☐	☐
Feel that you have enough time to allow residents to do things for themselves	☐	☐	☐	☐	☐
Feel that it is important that residents get to meals on time	☐	☐	☐	☐	☐
Feel that the facility you work in makes an effort to include personal preferences into mealtimes	☐	☐	☐	☐	☐
Feel good about the quality of care that you are able to provide at this facility	☐	☐	☐	☐	☐
Feel that there are enough resources available for you to provide resident care	☐	☐	☐	☐	☐

3. The following statements refer to different forms of communication between staff members and residents. Read *<u>each statement</u>* carefully and think about the extent to which *<u>you have used</u>* this care approach *<u>in your last working week</u>*. Please tick the box under the response that *best represents your experience*.

	Never	Sometimes	Often	Always
Use humour when talking to residents	☐	☐	☐	☐
Physically touch residents with their permission	☐	☐	☐	☐
Talk to residents about social events that are going on within the facility	☐	☐	☐	☐
Talk to residents about what is happening outside the facility	☐	☐	☐	☐
Talk to residents about their personal lives	☐	☐	☐	☐
Talk about my personal life with residents.	☐	☐	☐	☐
Talk to residents about the care they are receiving	☐	☐	☐	☐

4. The following statements refer to different forms of communication between staff members. Read *<u>each statement</u>* carefully and think about the extent to which you have used it *<u>in your last working week</u>*. Please tick the box under the response that *best represents your experience*.

	Never	Sometimes	Often	Always
Share personal information that I learn about residents that may help other staff members	☐	☐	☐	☐
Staff members tell me about physical changes in residents	☐	☐	☐	☐
Ask other staff what I should know before caring for a particular resident	☐	☐	☐	☐
Share care approaches that can help residents to do things for themselves.	☐	☐	☐	☐
Share care approaches that can help manage the difficult behaviours of residents	☐	☐	☐	☐
Talk with other staff members in order to find out the meaning behind difficult resident behaviours	☐	☐	☐	☐
Tell my supervisors about the need to change a procedure/practice that is no longer working for resident care	☐	☐	☐	☐
Offer ideas for making changes within the care plans of residents	☐	☐	☐	☐
Play a part in the making of facility procedures and practices	☐	☐	☐	☐
Exchange information about residents at shift change	☐	☐	☐	☐
Supervisors consider the preferences of staff members when making decisions about resident care.	☐	☐	☐	☐

Appendix 2

Staff Information sheet

Application of a framework to enhance support for people living with advanced dementia

NOTE: This information sheet is yours to keep

My name is Alison Campbell and I am doing my Masters by research with the School of Palliative and Support Services, Flinders University.

I am undertaking research at Tongala and District Memorial Aged Care Service on the application of a framework to enhance support for people living with advanced dementia

You may be interested in what this includes.

What do we mean by 'application of a framework?

The aim of this research is to trial an observational framework that focuses on the experience of people with significant cognitive impairment living in RAC facilities. The reason for doing this is to gain a better understanding of their perspective and how they experience their care environment. People with advanced dementia face particular challenges when they are not able to tell anyone directly about their experiences. They are also vulnerable to being misunderstood or not having social needs met as they are unable to communicate easily. Whilst it is recognised that much can be gained by interviews and focus groups with residents, the perspective of those with significant communication problems is likely to be different and the risk is that it will continue to be under-represented unless tools are developed to capture it.

What does this framework consist of?

It is referred to as a framework, because there is a structure for recording information about that the actions of the resident, the interactions the residents has and how the resident is experiencing the environment. The framework is part of a tool called, 'PIECE-dem'; an acronym for: **P**erson **I**nteraction **E**nvironment **C**are **E**xperience in **Dem**entia.. The basis for the tool is to focus on residents living in RAC facilities, who are most vulnerable due to immobility or cognitive deterioration, and who are reliant on positive care for quality of life. The observation framework focuses on interaction and engagement of residents. Data is recorded each minute, in 15-minute blocks of time. The tool provides a framework for structuring observations to capture residents' how residents are experiencing their environment

I am an experienced trained observer, and I will be working with Mentors in two wings of the facility, in using this tool. These observations will be completed at designated times through the duration of the study.

Resident involvement in the research will include:

Assessment of eligibility will be done via existing documentation on care dependency, and participants may have one of the following

- Are least able to verbally communicate
- May be withdrawn
- May be at end of life

- Are viewed to have high levels of responsive behaviour
- May be very mobile or agitated
- Have significant sight and/or hearing loss

Residents meeting the above criteria, but currently with acute physical or mental health difficulties, will not be included in the research.

Observations of residents and interactions between staff and residents using PIECE-dem

Will this cause any discomfort or inconvenience to residents involved?
The observations will take place in the residential care facility, thus residents can be in an environment they are familiar with and in which appropriate privacy can be provided. If any resident, or family member shows distress, tiredness or signs of discomfort or inconvenience associated with the observations, the observation will be stopped and resumed at a more appropriate time.

What will happen to the information collected?
The information collected in assessments and observations will be used to:

- Evaluate knowledge, understanding and skills of practitioners when working with very dependent people with dementia.
- Examine the use of the PIECE-dem observational framework as a tool for practitioners to improve person-centred dementia care delivery
- Develop a set of recommendations for the designers of the tool to inform adaptation of the tool from a researchers’ tool to a practitioners’ tool.

All information collected will be kept in the strictest confidence, within the limits of the law and used in reports and other forms of dissemination in a way that does not identify any individual. Should data collected from the resident assessment reveal information that may indicate any potential risk, the information will be provided to the Residential Care Facility within their responsibility for care planning.

Mandatory reporting:
The Aged Care Act 1997 requires that abuse occurring in a Commonwealth government funded RAC service must be reported to the RAC provider or their representative, police or the Department of Health. Given the requirements for mandatory reporting of elder abuse, such observations will be reported to the mandated reporter within the organisation; confidentiality does not include concealing overt abuse which is by law reportable.

What are the benefits of participation?
Your family member may directly benefit from participation as information collected will be used to inform care practices of staff working with people who have advanced dementia. This is aimed at improving their quality of life. Participating staff members will gain new awareness into how a person with advanced dementia may be experiencing their environment, through the guided observations and coding; adding a different dimension to how the participating staff perceive the care environment.
These changes may benefit other residents in the facility and in particular those with advanced dementia responsive behaviours.

Can I contact you?
Yes you can contact me, Alison Campbell, at any time to ask questions, to comment or discuss your concerns about your family members' participation in the observations or the research study generally.

Email: alison.campbell@flinders.edu.au Mobile: 0429 214 221
Address: School of Palliative and Support Services, Box 2100, Adelaide 5001

If you have any concerns about the research practice, you are invited to contact the Ethic committee, details below.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 6541). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

Appendix 3

Pre-Observation Summary Questions (revised)

Participant Name:

Daily life: What is this person able to do for themselves? What does this person need help and assistance with? What does this person enjoy doing? Who this person like spending time with? Does this person have spiritual beliefs that are known about?
Understanding the person’s needs: How do you know when this person is happy and content? How do you know when this person is unhappy or uncomfortable with what is happening to them? How do you know if this person is experiencing pain?
Health: Does this person have a diagnosis of dementia? Do you know what type and when this was made? Does this person have any physical illnesses or problems that affect their daily life? What medication is this person taking currently?
Life before coming to the home: What roles have been important to this person during their life? What influence do these roles and their history have on their behaviour now?
Consent How the person usually demonstrates consent within their daily life? What is known of the person’s usual self-presentation and usual level of wellbeing /illbeing

Appendix 4

Raw Data Sheet (revised)

Participant.
Time Start:
Time Finish:
Date

Activity	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	Total
Interaction																															
Engaged																															
Disengaged																															

Time Frame Notes	
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	
13	
14	
15	
16	
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25	
26	
27	
28	
29	
30	

Immediate Environment

Appendix 5

Reflection session summary (revised)

Participant:____Date:____________________

When did the observation take place?

Morning	Early afternoon	Middle of the day	Late afternoon

Record number of minutes spent in each category

Interaction		Engaged		Disengaged	
How do you think the individual was experiencing their world during observation? Where they in a positive or negative state during observation?					
Were they in a positive or negative state during observations? Wellbeing vs illbeing +5 extreme wellbeing,+3 considerable,+1 OK,-1 small signs of illbeing,-3 considerable,-5 extreme state illbeing. On what evidence do you say this?					
Did you discover anything new, or surprising about the resident?					

Was the resident able to exert control within their world and how was this achieved?
How were the person’s physical social and spiritual needs met?
Could anything have been done differently to achieve a different outcome?
What was the purpose of any interactions which occurred and what impact did they have on the person with dementia?
Key information to capture; messages to note

How could we improve quality of life for this person
How can we use this information?

Observer's name____

Appendix 6

Semi structured Individual questions

Please consider the questions below, which have been developed for Mentors

Name:……… …………………………………………………………………

Keeping a person clean, comfortable and well-nourished are the most important aspects of care for a resident with dementia?

How would you know if the resident you were working with was responding positively or negatively to your approach to care?

Do you think you work differently with residents who have a diagnosis of dementia?

If you do, what is different?

Reflecting on care situations at work is difficult and not a priority.

If individualised care is provided to a person with dementia, then it would appear that person-centred care was occurring .Is there anything else to person-centred care do you think?

How might you support the maintenance of personhood for a person with dementia?

If I was a new staff member starting work with you, what is important to know when communicating with a person with dementia?

If I was a new staff member starting work, can you tell me what I need to be mindful of regarding the environment?

When I mention the words interaction and engagement for a person with advanced dementia, what kind of things comes to mind for you?

People with advanced dementia don’t develop new relationships, they can’t! What you think?

Appendix 7

Mentors interview questions on the utility of PIECE-dem as a practitioner's tool.

1. Do you think it is of any use to you as a person who works in aged care? If so, why?

2. As a person who works in aged care, what did you find most useful or different about using the tool (inclusive of observation time, framework for collecting information and reflection time after)?

3. How might the information collected using PIECE-dem be put to use in your facility?

4. Can you see yourself using PIECE-dem after this research project is completed? If so, for what purpose and how would you use it?

5. Can you see yourself training other staff in PIECE-dem?

Appendix 8

Pre-Observation Summary Questions example

Daily life: What is this person able to do for themselves? What does this person need help and assistance with? What does this person enjoy doing? Who this person like spending time with? Does this person have spiritual beliefs that are known about?
Relatively independent with eating and drinking. Needs assistance with cutting up food, raising from and sitting in the chair, walking, dressing and personal hygiene. Enjoys quiet time and being left to enjoy her own company whilst watching activity within the unit; enjoys having her shawl close at hand; enjoys a hot cup of tea Has not formed any strong connection with any other resident, however gets particularly verbally aggressive with one resident when they sit at her table or come within an arm's length. Strong Christian beliefs, and loves Methodist hymns
Understanding the person's needs: How do you know when this person is happy and content? How do you know when this person is unhappy or uncomfortable with what is happening to them? How do you know if this person is experiencing pain?
Happy and content is identified by quiet demeanour, quietly watching, sitting back relaxed in her chair or slight smile. Unhappy or uncomfortable is identified through verbalisations such as "get me out of here", "where's my money, who stole my money", "get away from me". Pain is identified through her rubbing at a part of her body, such as hand, thigh, elbow and grimaces. Also shifting in her seat, continually unsettled.
Health: Does this person have a diagnosis of dementia? Do you know what type and when this was made? Does this person have any physical illnesses or problems that affect their daily life? What medication is this person taking currently?
Yes, diagnosis of Vascular Dementia. Rheumatoid arthritis is a source of significant pain or discomfort**.**
Life before coming to the home: What roles have been important to this person during their life? What influence do these roles and their history have on their behaviour now?
Mother of six children living in a rural community. Her husband was a shire secretary for some years before amalgamation saw him retired early. As wife of the Shire secretary, there were many social events which she participated in. She was secretary of the church for several years which seems to be a role she still thinks about; coordinating activities, ensuring people who need to know are informed. She is sometimes asking if the mail had been posted, or the letter sent to Mr Evans… Her appearance has always been important to her and dressing appropriately for the occasion.
How does the person usually demonstrate consent within their daily life: Knowledge of the person's usual self-presentation and usual level of wellbeing /illbeing
Consent within her daily life is provided via eye contact, a smile in acknowledgement of request or question, or a pat on your hand. Non-consent is often demonstrated by turning her head away from you, pushing at your arm or motioning pushing you away. At times she also says to go away, leave me alone. Her usual presentation of wellbeing is sitting back in her chair looking at all that is occurring around her, smiling and nodding acknowledgement. She often looks out for her crocheted shawl and walking frame which has many useful items in the basket.

Appendix 9
Completed raw data sheet example

Participant. RDO4 Time Start: 14:25
Time Finish: 14:55 Date 23/07/2015

Activity	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	Total
Interaction					x				x									x									x				4
Engaged	x	x	x	X		x	x	x		x	x	x	x	x	x	x	x		x	x	x	x	x	x	X	x		x	x	x	26
Disengaged																															

Time Frame Notes	
1	Holding cup of tea in one hand, looking at other hand whilst drinking.
2	Breathing easily, slowly sipping cup of tea.
3	Places cup on the walker in front, sits back slowly scans the room
4	Looking at her hands, looking at nails on her hands. Rubs hands together gently, then alternately rubs the back of each hand
5	Looking at thumb nail. Staff member approaches; “all finished with your cup, no ok, I’ll be back”. Resident smiles at staff
6	Gently and slowly rubbing left thumb with a finger.
7	Looking out the lounge room window, and then looking down into her lap.
8	Looking at hands and left thumb. Looking up and eyes follow another resident around the dining room
9	Smiling at another resident. Looking around the unit, makes eye contact with another resident (same as person as previous)
10	Looks down at the newspaper which is laid out on the walker in front of her. Moving rings on her left hand with her right hand. Slight cough
11	Looks at the newspaper, picks up cup and sips tea, then looks at her hand not holding the teacup.
12	Looking at the newspaper. Still on the front page. Holding cup
13	As 12. Readjusting collar of her shirt
14	As 12
15	As 12. Readjusts rings on her left hand
16	Coughing, hand to mouth. Looks at another resident who has their back turned to her. Holding cup
17	Takes a sip from the cup. Scans the dining and lounge room, then looks back to the newspaper in front of

	her
18	Staff approach and ask if she has finished her cup of tea. “No” and hold cup closer to her body
19	Sips cup of tea then places cup down on walker. Picks up the corner of the newspaper. Appears to be listening to a nearby conversation between two residents
20	Looking at the newspaper, Watching other residents over the top of her glasses.
21	As 20
22	Watching staff and resident interactions in the adjoining room. Turns several pages of the newspaper which appear to be stuck together
23	As 20
24	Looking at the newspaper, and looks up to talking in the kitchen
25	As 20. Looks at resident who is self-talking
26	Looking at resident self-talking, looks down then looks at resident again but does not make eye contact
27	As 20. Staff approach asking if she has finished her cup of tea, and she nods her head toward the cup, and smiles at the staff member
28	As 20
29	As 22
30	As 24

Immediate Environment
Television is on quietly. RD04 is sitting in a lounge chair by the fireplace with her walker in front of her, and the newspaper spread out across the walker. There are 5 other residents in the area; one continually walking; one self-talking for most of the observation time; one in a tub chair in front of the television and two other residents in the dining- room. It is quietly busy with ample natural light, pleasantly warm and a sense of domesticity.

Appendix 10

Completed reflection session summary example

Participant: RD04 Date23/07/2015

When did the observation take place? Lounge room

Morning	Early afternoon	Middle of the day	Late afternoon

Record number of minutes spent in each category

Interaction	4	Engaged	26	Disengaged	0

How do you think the individual was experiencing their world during observation? Where they in a positive or negative state during observation?
RD04 looked relaxed, comfortable and safe.
Were they in a positive or negative state during observations? Wellbeing vs illbeing +5 extreme wellbeing, +3 considerable,+1 OK,-1 small signs of illbeing,-3 considerable,-5 extreme state illbeing. On what evidence do you say this?
+3, considerable wellbeing. She looked quite relaxed in body posture and facial expressions, quietly scanning her environment; aware of activity, but interaction with others appeared to be on her terms.
Did you discover anything new, or surprising about the resident?
How effectively she constructed her immediate personal space; with the walker directly in front of the lounge chair, newspaper opened across the walker, and walking stick protruding out from one arm of the chair. This created a separate space that was hers.
Was the resident able to exert control within their world and how was this achieved?
Her constructed space resulted in no one being able to come within a metre of her without having to remove part of the construction. Her body language and physically constructed space could effectively socially block people she didn't want to interact with.
How were the person's physical social and spiritual needs met?
She was sitting in a large lounge chair which looked comfortable, and it was positioned so as there was line of vision to all the public areas including the entrance corridor into the unit.
Could anything have been done differently to achieve a different outcome?
The outcome for this observation period was positive. If the cup had been removed or the newspaper taken away there may have been a very different outcome. However, this resident was in a relatively positive state for the entire 30 minutes.

What was the purpose of any interactions which occurred and what impact did they have on the person with dementia?
Two interactions were enquiring after the cup, which the resident exerted control over the timing of the removal. The eye contact was with another resident who she enjoys interacting with at times when she feels inclined.
Key information to capture; messages to note
The ‘props’, such as the walker, newspaper and walking stick, for her to construct her personal space with appear to be key.
How could we improve quality of life for this person
Ensure all staff are aware of the importance of the newspaper. The cup also appeared to be important as she kept sipping from it even when it was empty.
How can we use this information?
In care plans, communication book and especially talk about it at handover

Observer’s name____

Appendix 11

Prompt questions to facilitate reflection session discussion

The additional questions to facilitate reflection session discussion were as follows:

How do you think the individual was experiencing their world during observation? (original question)

> How would you describe how Mrs/Mr looked; what words capture what you saw; for example relaxed, restless, uncertain, curious, safe, scared, excited, sad… (added question)

Where they in a positive or negative state during observation?

> +5 extreme wellbeing - absolutely bursting with happiness and totally absorbed & engaged
> + 3 considerable wellbeing, enjoying themselves but could be distracted
> +1 neutral No evident signs of wellbeing or ill being
> -1 illbeing Small signs of distress, anxiety or discomfort
> -3 considerable illbeing, clearly distressed
> -5 extreme ill being. Things can't get any worse for them at that time

On what evidence do you say this?

What did you observe that bought you to that decision? What did you see or hear that led you to that conclusion?

Could anything have been done differently to achieve a different outcome?

Could anything be done to the environment to facilitate a more positive outcome for the resident? What other ways could the resident be approached or interacted with.

Did you discover anything new or surprising about the resident?

> For example; did they show abilities to do something you had not seen before; more awareness of the noises and activity around them; or following movements of a certain staff or resident; ability to manipulate objects; response time; exercising choice; show initiative?

Was the resident able to exert control within their world? If yes, how was this demonstrated?

Did they do anything that indicated they were able to exercise some influence over what was happening to them or around them? Did they show any ability to make choices to do something or not? What did you see?

How were the person's physical, social and spiritual needs met?

- Physical needs relating to ADL's and bodily needs
- Social needs relate to opportunities for social engagement/interacting; being included by sitting in a position where you can see the comings and goings of the unit; acknowledged and spoken with as being passed by ; having objects to engage with that are meaningful for them such as newspapers,
- Spiritual needs may not necessarily be religious in nature, they may be fulfilled by sunshine on their face, as told by the carer (soul food for my Mum)

How could we improve Quality of Life for this person?

Can this information be used to improve what happens within the day of this resident? Are there things learnt about what is important to them that all staff needs to be aware of? What did you see that put this person in a state of wellbeing? (+1, +3 +5)

How can we use this information?

It could go in the care plan but are there other options for daily reminders of how this information can be used to improve the resident's life; Maybe a photo collection in a place mat, maybe a prompt sheet in the nurses' station, maybe…. ….

The final question of "*How can we use this information?*" was the step of taking the information observed and putting it into practice. If this tool and process are to have utility as a practice tool, then ultimately it needs to inform quality care.

Appendix 12

Questions from a semi structured interview with Mentors. Pre and post responses		
Question	**Pre-interventions**	**Post interventions**
Keeping a person clean, comfortable and well-nourished are the most important aspects of care for a resident with dementia?	I think they are a priority as everyone should have the opportunity to be well looked after.	This will promote their wellbeing and quality of life. If the basic needs are fulfilled, then the residents are well prepared for activity/purpose in their day, equally as important to them.
How would you know if the resident you were working with was responding positively or negatively to your approach to care?	If they are refusing medication or something, I do something, say something to make them smile and engage. Then they do as I wish. If they refuse medication I do something that makes them laugh and relax, that kind of builds the trust	Relaxed body posture, a smile, and personal engagement facilitate positive interactions upon your approach.
Do you think you work differently with residents who have a diagnosis of dementia?	With people with dementia I see that they have some sort of orientation to their view. For example, I have a male resident with dementia he likes to have appointments, having pens and stuff. I would talk in a fashion with him, like he is the manager. Not so much because of his dementia, it just works with him. I do talk differently with a female, resident, it is probably more like a child mother relationship	I try to put myself to their position and the person that they would like to see me as. Also, to be more attentive to observable messages and pay extra attention to their posture, gait, facial expression and their verbal expressions.

Question	**Pre-interventions**	**Post interventions**
Reflecting on care situations at work is difficult and not a priority.	UHH. I think it is difficult. In the morning it is really busy. I think better when it is quiet, so. During the day it is not quiet, so it is a bit hard.	It may be hard, however very important. In the workplace sometimes an unexpected event happens and instant reflection is not possible. Usually time would be available at the end of shift or at handover time. Each staff member involved hopefully thought of it and come to discussion with an insight of how to improve or possible cause and to form a plan.
If individualised care is provided to a person with dementia, then it would appear that person-centred care was occurring. Is there anything else to person-centred care do you think?	I think it is important for people to function as they want to, their hobbies and all that. Not just care but everything else. It is not just about the nursing care but what they want to do.	The care plan in person-centred care informs us of their lives and values that they uphold. There are preferences written in care plan (individualised). However, understanding their preferences and why they are important is a key to quality care. Understanding the perspective of the person.
How might you support the maintenance of personhood for a person with dementia?	Facilitate their preferences in care	It is a bit hard when we have residents with dementia who shut off their communication. I wouldn’t get any idea of what they like what they don’t like. You need to build up information from the family and their notes. You need to observe and see how they respond to their environment, situations and people
If I was a new staff member starting work with you, what is important to know when communicating with a person with dementia?	I think I would tell them to make good eye contact. Smile, because those two things, tells them that you are friendly. If you are smiling that tells them you are there to help them. Introduce yourself, tell them who you are, they will know you are someone familiar; just not remember your name.	To gain their attention first, maintain eye contact, to slow down and talk while matching their position (sitting or standing). Because the residents can feel if you are rushing and may be difficult to obtain information. Also, to pay attention to their body language and how they react to other stimuli around them.

Question	**Pre-interventions**	**Post interventions**
If I was a new staff member starting work, can you tell me what I need to be mindful of regarding the environment?	To make the area restful as possible, and clean, as they might have walking problems. Then try to make it as homely as possible you wouldn't have dirty shirts on the bedroom or something like that	Each resident's room is their own private space that staff need to respect (i.e. knock, ask permission etc). In public space, some residents find comfort in certain way, such as a certain seat or position. Staff need to observe if there is any pattern, so they can support their preferences, independence and abilities.
When I mention the words interaction and engagement for a person with advanced dementia, what kind of things comes to mind for you?	Probably the main thing I think of is eye contact. And then being relaxed,	These residents may not be able to respond in words or actual gesture that they are listening to you. I would observe facial expression and muscle relaxation. Stimuli that we provide to the resident by their senses (massage, music, tv, book reading etc) will trigger behavioural response. Carer might get impression whether they enjoy it or not
People with advanced dementia don't develop new relationships, they can't! What you think?	Even I think they still form some form of engagement; interaction not as long as before. Maintaining eye contact is. Building the relationship is important as they know who you are, you are familiar	I would strongly disagree. I think even it may be slower but they know familiarity to certain people. I personally think that I have built rapport with residents, mainly started with touch and introduction on every encounter. Now I find they often look around when I enter and begin talking with others, perhaps looking for the source of voice.

Appendix 13

Original raw data template

Table 1	1	2	3	4	5	6	7	8	9	10	11	12	Total
Interaction													
Engaged													
Disengaged													

Participant no. **Time Start:** **Time Finish:**

Time Frame Notes	
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	

Immediate Environment

Appendix 14

Original Pre-Observation Summary Questions

Participant Name:

Daily life: What is this person able to do for themselves? What does this person need help and assistance with? What does this person enjoy doing? Who this person like spending time with? Does this person have spiritual beliefs that are known about?
Understanding the person's needs: How do you know when this person is happy and content? How do you know when this person is unhappy or uncomfortable with what is happening to them? How do you know if this person is experiencing pain?
Health: Does this person have a diagnosis of dementia? Do you know what type and when this was made? Does this person have any physical illnesses or problems that affect their daily life? What medication is this person taking currently?
Life before coming to the home: What roles have been important to this person during their life? What influence do these roles and their history have on their behaviour now?

Appendix 15
Original summary of reflection session

Participant Number:

Tick which observation block you are summarising

Early afternoon	**Late afternoon**	**Morning**	**Middle of day**

Record number of minutes spent in each category					
Interaction		**Engaged**		**Disengaged**	
Summarise your perception of the person's predominant experience of their world during this time period.					
To what extent was the resident able to exert control within their world and how was this achieved?					
How were the person's physical needs met?					
How were the person's psycho-social and spiritual needs met?					
When do interactions occur, who is the interaction with, what appears to be the purpose of these					

interactions and what impact do they have upon the person with dementia? Was knowledge of the person used in the interaction?
Was an empathic connection made during interactions between staff and resident? (describe how this was achieved and if not, why it appeared not to occur)
What facilities were present within the environment to support the person’s identity, occupation and inclusion? Were these facilities made use of in interactions with the person?
What emotions did you experience during this period of observation and why?
How do you think the staff experience this person?

Appendix 16

PIECE-dem as a practice tool; with modifications and editions

In preparation for and evolving throughout this study, modifications were made to some of the original PIECE-dem data templates. These modifications included revision of:

I. the raw data sheet for recording observation from 15 minutes to 30 minutes;

II. the pre-observation sheet to include how the person usually demonstrated consent within their daily life: (Appendix 8)

III. the summary sheet reflecting areas of interest to care practitioners, such as "*Did you see anything new or surprising?*", *"How could we improve quality of life for this person?"* and *"What will you do with this information?"* and removal of several questions (see Appendix10)

IV. the inclusion of a set of prompt questions to facilitate discussion during the reflection sessions post observations (see Appendix 11).

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