They are Still People:

An Ethnographic Investigation into a Reconfiguration of Personhood Practice in Residential Dementia Care

by

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Thesis
Submitted to Flinders University
for the degree of
Doctor of Philosophy

College of Nursing and Health Sciences
Flinders University, Adelaide, South Australia

September 2019

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Abstract

This doctoral research develops a reconfiguration of personhood practice in residential dementia care settings. The specific focus of the study is the level of prioritisation assigned to personhood by the organisation, and the level to which personhood care is consistently supported in dementia care practices. My original contribution to knowledge is the recognition and demonstration that societal and organisational cultures frequently stigmatise and undervalue people with dementia, thus justifying strategic under-resourcing. In order to reverse this trend, this study argues for the positioning of personhood at the forefront of dementia care, thus appropriately valuing and prioritising the person with dementia. In the context of this study, the concept of personhood acknowledges the intrinsic value of a person and understands that person’s need to feel respected and included in their environment. The fulfilment of these needs is particularly important in the residential dementia care environment, given the stigmas associated with ageing and dementia, as well as the vulnerability of this group of people.

An integrative review of the literature was undertaken to ascertain current understandings of a personhood model of dementia care, and how these insights are considered and practiced within the contemporary culture of residential dementia care. This review revealed differing approaches towards personhood from the organisational, daily care practice and personal perspectives. The theories and concepts of Tom Kitwood form the theoretical framework for this study, in particular his identifications of psychological needs of people with dementia, and the types of interactions which either undermine or support personhood.

Ethnography was chosen as the methodology to investigate the culture of personhood in residential dementia care. Fieldwork was undertaken at two RACFs, and data was collected from interviews with staff members, observations of interactions between staff and residents, and field notes collected during the fieldwork period.

The research findings reveal that both personhood preservation and personhood violation occur in the psychosocial environment in which the person with dementia lives. Factors influencing these themes include: the level of organisational connectedness to the practicalities of dementia care; aspects linked to staffing and support of staff members; staff interactions which result in either respect or disrespect for the person with dementia; and the degree to which the living space feels safe and homelike. The influencing factor on whether personhood is predominantly preserved or violated is the dominating culture of the psychosocial environment which is, in the main, controlled by the organisational culture. Ultimately, it is the ideologies of dementia and ageing that frame organisational culture. This thesis makes the case for the suppression of societal and organisational stigma which negatively impacts on dementia care, and argues, instead, for the positioning of personhood at the forefront of residential dementia care practices.

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Abbreviations

ACFI	Aged Care Funding Instrument
AIHW	Australian Institute of Health and Welfare
ANMF	Australian Nursing and Midwifery Federation
CNM	Clinical Nurse Manager
DAI	Dementia Alliance International
DoH	Department of Health
EN	Enrolled Nurse
LS	Lifestyle
LTC	Long Term Care
MSU	Memory Support Unit
NHMRC	National Health and Medical Research Council
PCA	Personal Care Assistant
PCC	Person-Centred Care
QOL	Quality of Life
RAC	Residential Aged Care
RACF	Residential Aged Care Facility
RN	Registered Nurse
SM	Site Manager
UN	United Nations
WHO	World Health Organisation

Declaration

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

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Jennifer Slape

September 2019

Acknowledgements

I acknowledge and thank the aged care facilities involved in this study and, in particular, the staff members who participated and made the study possible. Although your identities must remain anonymous, I am so grateful for your willingness to share your experiences and knowledge of dementia care.

My deepest gratitude goes to Professor Tara Brabazon for your supervision, understanding and guidance which enabled the completion of this thesis. Your willingness to support and motivate will never be forgotten. Such inspirational mentorship. Thank you.

Thank you to Associate Professor Ann Harrington and Dr Anita De Bellis who began this PhD journey with me, and shared my belief in the importance of this topic. Your supervision, encouragement, and confidence in my ability are greatly appreciated.

A special thank you to Dr Judith Clare for your enormous support through listening, reading and guiding. You were there for me and I am so grateful. Your knowledge, understanding and encouragement have been invaluable.

Thank you also to Dr Pen Roe for opening doors to new insights. You understood the topic and the challenges, and I truly appreciate your generosity and willingness to share.

My children Lyndal, Chris and Kellie, and grandchildren Ashleigh, Thomas, Georgia and Josephine all inspire and teach me so much, and are the source of great pride and joy in my life. I thank each one of you for being who you are, and for your understanding and encouragement during this challenging rollercoaster ride.

Finally, my very special thanks goes to Ian, my husband, best friend and life-long supporter. Your unwavering support and belief in me have provided the strength and resolve for this PhD journey. Together we did this – thank you.

Introduction

This doctoral research investigates the reconfiguration of personhood practice in residential dementia care. Following discussions on the concept of personhood, the investigation focuses on the impact of organisational culture on the residents and care staff within that organisation, and ultimately, explores whether each individual is consistently granted acknowledgement and respect as a person. The research is concerned with the vulnerability and voicelessness of people with dementia in residential care, and in some measure, the people who care for them, and discusses the potential for silencing and marginalisation to occur. By highlighting these issues of vulnerability and silencing, this research reconfigures residential dementia care within a framework of personhood practices. The seeds of concern about these issues were planted many years ago, through both personal and professional experiences.

The Beginnings of this Thesis

In many ways, this thesis is a tribute to my parents. For the last few years of their lives, they lived in an aged care facility, eventually dying in that facility. They each had complex health issues and, towards the end of their lives, both developed cognitive-related complications which produced symptoms of dementia. Supporting and caring for my parents over a number of years was a commitment I shared with my siblings, and one which we were happy to undertake. Around this time, my parents-in-law each lived and, ultimately died, in two separate aged care facilities. During this period of providing care for my parents and parents-in-law, I worked as an aged care chaplain across several facilities. Consequently, my exposure to care practices within the residential aged care industry has been extensive, both personally and professionally.

For the most part, my parents received satisfactory care, for which I am grateful. But there were also instances of poor quality care, and these are memories I continue to carry. I can recall care practices which were characterised by disregard, intimidation, lack of communication, and inadequate pain management. Alarmingly, on two separate occasions, each of my parents experienced the same form of negligent care, which, in both cases, led to serious consequences. Both of these incidents were treated in a dismissive manner by the organisation. For one of my parents in particular, end-of-life care was poorly managed, and, once again, feedback from the organisation was dismissive. Similarly, my parents-in-law each endured end-of-life care practices that were not satisfactory. On a regular basis, questions were raised in my mind about the apparent devaluing of my parents and parents-in-law as persons by the organisations in charge of their care. Why did these organisations not respect these four people enough to ensure their safety, provide appropriate pain management, and offer effective psychosocial care? How is the term ‘care’ interpreted within the aged care industry? Lingering memories of many of these incidents continue to be disturbing and painful.

Not surprisingly, the experience of being a family member is very different to that of being a staff member. In spite of knowing a significant amount about disease trajectories and organisational systems and policies, as a family member I often struggled to find my place in caring for my own mother and father. At times, the control and intimidation exhibited by staff members was overwhelming and I felt powerless to act. After all, how did I really know how staff might react to my attempts at advocacy when I was no longer there? It is an uncomfortable position to occupy.

During this period of caring for my parents, I was often experiencing my own grief as their health deteriorated. Then, of course, following their respective deaths, there was an overwhelming deeper sense of grief. But the full extent of my grief was not appropriately resolved. Thankfully, the process of creating this thesis has contributed to healing and resolution, and deepened my resolve to advocate for the reconfiguration of dementia care practices.

The undertaking of this thesis is driven by more than a personal story. My experiences of working as an aged care chaplain were rewarding and inspirational. To be invited into the personal world of older people and their families is indeed an honour. There is much sadness, of course, and often many challenges, but the act of providing emotional and spiritual care is a privilege beyond words.

Social categorising around the role of chaplaincy generally involves concepts such as religion, faith, deity, fundamentalism and indoctrination. Having just stated that I performed the role of aged care chaplain, it is necessary to declare that these stated concepts are far removed from my personal frame of reference regarding chaplaincy and spirituality. Although my early years were heavily influenced by conservative religion, I no longer adhere to such strict beliefs, choosing instead to transcend the limitations of fundamentalism to now experience a new understanding of spirituality. This fresh framework of spirituality recognises that each person seeks meaningful connections and purpose in life, which may or may not be connected to religious activities, and which may or may not be recognised as spirituality.

While occupying the very traditional, and sometimes limiting, role of ‘chaplain’, I was aware that this title provoked thoughts of religion in most people, a fact which is not surprising given that most chaplains are, in fact, ordained clergy. This was not so in my case, because, fortunately, I was one of a minority of people accepted for the role based on my skills and qualifications, and not because of a requirement to be ordained. Perhaps controversially, this trend seems to be changing and the requirement for chaplains to be ordained is increasing, which could be viewed as a push for an increased focus on chaplains with a clear religious focus rather than a concentration on the qualifications, skills and knowledge required to provide spiritual and emotional care to people with dementia.

Nonetheless, my chaplaincy role was fulfilling and rewarding, and presented countless opportunities to help others find personal meaning, connections and purpose in their current situations, whether or not their spirituality contained religious components. Along with providing emotional care, chaplaincy enabled me to deliver individualised spiritual care which took ‘care of the spirit that transcends religious, ideological and philosophical boundaries’ (Hegarty 2007). There is no doubt that this concentrated focus on the individual needs of aged care residents has directed my path towards a strong interest in personhood. Within my understanding, personhood and spirituality are closely aligned, particularly for the person with dementia. Spirituality and spiritual care are further discussed in Chapter Two.

The personal rewards of aged care chaplaincy co-existed with numerous examples of witnessing the consequences of residents’ unmet psychosocial needs. Despite many aged care staff delivering appropriate levels of care, and, in some cases, exceptional levels of care, quality care was not consistent across the industry. Inadequate staffing and funding dominated the wider dementia care landscape and, while dialogue occurred between society, organisations and governments, the actual people being discussed were often denied appropriate levels of physical and psychosocial care. Similar to the circumstances experienced with my parents and parents-in-law, from a professional perspective I frequently questioned the interpretation of ‘care’ within the aged care system as well as some of the philosophies which underpinned the dementia care model. A prevailing personal thought queried the juncture at which someone with dementia is no longer a person worthy of respect and dignity, nor requires their psychosocial needs to be met. Of course, this was not the case with all people with dementia, but for those whose care environment did not fully support their physical and psychosocial needs, it was clearly an issue that needed to be confronted. These thoughts encouraged the nurturing of those personal seeds of concern over several years, eventually leading to the undertaking of this doctoral study as a means of investigating a reconfiguration of dementia care.

Aims and Objectives of this Thesis

The major aim of this doctoral study is to investigate the reconfiguration of personhood practice in residential dementia care. A secondary aim is to argue for the positioning of personhood at the forefront of dementia care. Thus, dementia care is reconfigured within a framework of personhood practices. As discussed in Chapters Two and Three, personhood is the foundation of person-centred care and, therefore, in the view of this thesis, needs to take precedence when considering dementia care practices.

These aims are investigated through the development of an integrative literature review, the conduct of ethnographic research at two residential aged care facilities, analysis of the data, and presentation of the analysed data set. The ethnographic nature of this research will reveal the culture around personhood in Australian residential dementia care settings.

Role and Importance of this Research

This doctoral research focuses on strategies to maintain the personhood of people living in residential dementia care, and by implication, those who care for them. A detailed discussion on the theoretical perspectives of personhood is presented in Chapter One, but a brief introduction is presented here to emphasise the importance of this research to the field of dementia care.

Moving beyond the definition of merely being human, personhood inhabits a social context based on trusting relationships in which one human being is recognised and respected by another (Kitwood 1997a). In most cases, however, the progression of dementia gradually leads to levels of detachment from others (Kverno & Velez 2018), and significantly reduces a person’s ability to initiate the meeting of their own personhood needs. Therefore, there is a need for residential dementia care to be appropriately staffed and resourced, so that the person with dementia is surrounded by familiar people who enable relationship building and positive social interactions. In this way, interactions grounded in personhood principles are consistently maintained.

Concentration on the issue of personhood in dementia care raises questions about the quality, individualisation and consistency of care given to people with dementia, as well as the level of support and resourcing provided for care staff. Therefore, the issue of maintaining personhood is of vital concern to current and future residents living in residential dementia care, their family members and the staff who provide their care. Recently, the care practices of Australian aged care providers have been the subject of considerable media attention, with much focus on negligent care and abuse of people with dementia. Not surprisingly, such media attention has resulted in significant public outcry. As a result, the Federal Government is currently conducting a Royal Commission into Aged Care, the terms of reference authorising enquiry into various issues around quality and delivery of care (Royal Commission 2018). With aged care practices currently experiencing such intense scrutiny and media attention, this research is appropriate and timely.

This research is relevant to all multi-disciplinary teams composing the workforce in residential aged care, including nurses, care staff, physiotherapists, and allied health staff responsible for providing mental health support and social, emotional and spiritual care to residents. The findings of this research are also relevant to policy makers and governmental regulators in the fields of dementia care, aged care and palliative care. Because of its focus on respecting and valuing each person, this research also has relevance to other healthcare providers and policy makers involved in providing services to vulnerable and marginalised people.

Although the terms ‘personhood’ and ‘person-centred care’ are strongly connected and are sometimes used interchangeably, this study draws distinctions between the two. The theory of personhood is the foundation on which person-centred care is built, in that each individual is a person of enduring value and is therefore worthy of care practices which are centred on the individual needs of that person. In other words, the willingness to deliver person-centred care emanates from the belief that each person is worthy of respect and dignity, and that care practices must be aimed at meeting physical and psychological needs in a timely manner. Therefore, personhood, as discussed throughout this thesis, refers to the levels of intrinsic value and respect consistently conveyed to each person, rather than the description and nature of a specific care program. Consequently, person-centred care is the natural consequence of a genuine value and respect for personhood.

Since Kitwood (1997a) introduced the concept of personhood and, subsequently, person-centred care to the field of dementia care, a large number of studies have concentrated specifically on person-centred care (see, for example, Brownie & Nancarrow 2013; Edvardsson, Fetherstonhaugh & Nay 2010; Fazio et al. 2018; Hunter, Keady et al. 2016; Lynch et al. 2018; Stein-Parbury et al. 2012). In comparison, considerably fewer studies focus on personhood in dementia care[1] (see, for example, Higgs & Gilleard 2016; McCormack et al. 2012; Passmore, Ho & Gallagher 2012; Sofronas, Wright & Carnevale 2018; Tolhurst, Weicht & Kingston 2017). The intrinsic value of person-centred care as a tool for improving dementia care is recognised, however, given the continuation of some care practices which disregard and disrespect, it is appropriate to now focus on personhood as the foundation of dementia care.

The Shape of this Thesis

This thesis consists of eight chapters, all contributing and aligning to enable an ethnographic investigation into personhood in residential dementia care. Chapter One provides the background for the remainder of this thesis. The key focus of this

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[1] For example, a search on the Proquest (nursing and allied health) database of full text, peer reviewed articles from 2013-2018 with the search terms ‘person-centred care’ + ‘dementia’ in abstracts produced 52 results. Identical parameters with the search terms ‘personhood’ + ‘dementia’ produced 13 results.

study is the person living in residential dementia care, and Chapter One introduces that person by presenting their contextual reality at the time they enter residential care. The topics of ageing and dementia are discussed, followed by an introduction to the concepts of person and personhood. The ageing process and living with dementia have each significantly impacted a person’s life by the time they enter residential dementia care, and this chapter outlines the characterisations of those impacts. The terminologies of ‘person’ and ‘personhood’ are examined through a discussion on theoretical perspectives of these topics.

Chapter Two offers an integrative review of the literature relevant to personhood practice in residential dementia care. Results of the literature review revealed current understandings of the components of a personhood approach to dementia care, and the levels to which these components are integrated into care practices.

Chapter Three introduces the theories and concepts of Tom Kitwood (1937-1998) which form the theoretical framework for this study. Influenced by the client-focused work of Carl Rogers (1902-1987), Kitwood is credited with the introduction of personhood and person-centred care to the field of dementia care. Through the introduction of theoretical frameworks of dementia and personhood and a model of care for people with dementia, Kitwood’s philosophies provide direction to this study, particularly with regard to data collection and analysis, and ultimately, frame the discussion on the results of the study.

Chapter Four is concerned with the methodological structures of this study, describing the research strategies and providing justification for their use. Theoretical perspectives of qualitative research and ethnography are followed by descriptions of collecting and analysing data. Themes identified during analysis are introduced.

Chapter Five connects the methodological issues in the previous chapter with the research outcomes in the following two chapters. Metaphorically, this chapter acts as a bridge linking the theoretical processes of research with the personalised experiences of the people in this study. Interpretation of the data is discussed and presented through thematic and conceptual frameworks, followed by a discussion on matters regarding ethics and rigour. Descriptions of the two field settings precede brief extracts from the data which act as an introduction to the personal nature of the study outcomes in the following two chapters.

Chapters Six and Seven present the outcomes of the study under the themes identified in the previous two chapters. Chapter Six introduces the theme of Personhood Violation and discusses how an organisation’s disconnectedness from vital elements of dementia care leads to insufficient staffing levels and marginalisation of people with dementia. In discussing the theme of Personhood Preservation, Chapter Seven demonstrates how an organisation’s preparedness to understand the needs of people with dementia and to sufficiently resource and support staff lead to care practices which value and respect people with dementia.

Chapter Eight reveals the interpretations arising from the research by drawing on the literature reviewed in Chapter Two, literature emerging since the review, and data from this study. These interpretations show how the cultural stigmas of society and organisations significantly impact the quality of personhood care in a dementia care environment. Undervaluing stems from stigmatisation, and, as a general rule, leads to under-resourcing.

The conclusion of this thesis presents an overview of the existing dementia care culture. Discussions then follow on the significance and contributions of this study, and recommendations for moving towards a reconfiguration of residential dementia care.

My original contribution to knowledge is to recognise that societal and organisational cultures are major barriers to personhood care, and to argue for a reversing trend which positions personhood at the forefront of dementia care. By drawing distinctions between ‘personhood’ and ‘person-centred care’, this research locates dementia care within a cultural framework of value, respect and dignity for people with dementia. Through investigation of cultural perceptions of personhood, this research recognises the unfeasibility of merging personhood culture with societal and organisational cultures that stigmatise and devalue. Currently, the realities of dementia care are interpreted through the societal gauze and discriminations of age and dementia, as captured and circulated through societal structures and media platforms and interfaces. This research shows that the under-valuing impacts of stigma lead to under-resourcing in the dementia care sector, and, therefore, calls for the reconfiguration of dementia care within a framework of personhood practices. In this way, value, respect, dignity and equitable resourcing form the standardised framework for residential dementia care.

Chapter One: The Context of the Person with Dementia

Cultural Environments of Ageing, Dementia and Aged Care

Only a person with dementia knows the true experience of living with such a condition. Furthermore, the experiences of ageing, dementia and living in aged care are unique to each person. It may seem somewhat presumptuous for someone who has not personally experienced any of these circumstances to write about such realities. Nevertheless, it is imperative for someone who has a deep passion for improving dementia care practices to understand the scope of these realities as accurately as possible. The purpose of this chapter is to create an awareness of challenges and experiences a person with dementia has already faced, and continues to face, thereby establishing a realistic representation of the life and needs of this person who is now entering residential dementia care.

This chapter discusses the cultural contexts of ageing, dementia and aged care, followed by theoretical reflections on ‘person’ and ‘personhood’, presented under the following topics: 1) Global Configurations of Ageing and Dementia; 2) Aged Care in Australia; 3) Contexts of Ageing; 4) Living with Dementia; and 5) Theoretical Perspectives of Person and Personhood. These topics are used to present the contextual reality of the person with dementia at the time they enter residential care. For most people, challenges and losses linked to ageing and dementia would have occurred prior to their need for residential care and have, in some way, shaped the person they are at that point. Within the framework of personhood care, an understanding of the effects of societal attitudes and personal experiences is essential in order to genuinely understand the person’s situation.

The subsequent examinations of the theoretical perspectives of person and personhood serve as a reminder that, regardless of prior social or personal experiences, this person is worthy of respect and dignity. This chapter therefore, creates the foundation for the remainder of this thesis by introducing the lived experiences of the person with dementia and, furthermore, places the need for respect of their personhood at the forefront of their dementia care needs.

1.1 Global Configurations of Ageing and Dementia

In recent years, the number of older persons in the world has increased substantially and projections indicate that growth will continue to accelerate in the coming years. Globally, in 2015 the number of people aged 60 or over had reached 901 million, and by 2030 this number is expected to grow by 56 per cent, to 1.4 billion. By 2050, the number of persons aged 60 or over is projected to be 2.1 billion, more than doubling the size of the 2015 figure. Growing even faster is the cohort of 'oldest-old' persons which describes those aged 80 years or over. According to the United Nations (UN 2015), globally in 2015 there were 125 million people in this age bracket, and by 2050 this figure is projected to increase to 434 million, more than tripling in number since 2015.

In their ongoing advocacy for older people, the UN reiterates the need to address exclusion, discrimination and ageism which affect many older people, and acknowledges that some countries are systematically addressing forms of age discrimination. Development and implementation of policies around 'equality, equity and non-discrimination, dignity, independence and personal safety, and economic security' (UN 2013, p.12) are recognised and encouraged.

Dementia affected 47 million people globally in 2015, which is around 5% of the world's population of older people. It is estimated that nearly 9.9 million people develop dementia each year, meaning that the number of people living with dementia is likely to increase to 75 million by 2030, and 132 million by 2050. In order to meet the needs of these increasing numbers, it is estimated that by 2030 there will be a need for 40 million new health and social care jobs and around 18 million additional health workers. The World Health Organisation (WHO 2017) believes that appropriate skill mixes within this workforce will be essential to address areas of prevention, diagnosis, treatment and care for people with dementia.

Dementia is now recognised as a major cause of disability and dependency among older adults worldwide (WHO 2017), therefore, the UN Convention on the Rights of Persons with Disabilities, which was adopted in 2006, is now being used by the dementia community to promote rights for people with dementia (DAI 2016). Article 1 of the UN Convention (n.d., p.4) states that:

> The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Internationally over the past decades, there has been a growing appreciation that the wellbeing of people with dementia is largely dependent on the quality of their physical and psychosocial environments. This line of thinking concurs with increasing recognition that people with dementia are, in fact, human beings, and not merely patients (Pot 2013). With the intensifying worldwide acknowledgement that dementia care needs to focus on humanity, all countries need a fully integrated system of long-term care which supports the human rights of older people and enhances their dignity. As specified by WHO (2015a), long-term care should be affordable and accessible, and be based on the needs of the older person rather than the needs and structure of the service.

As countries prepare for increasing demands for high quality dementia care, WHO has declared one of their goals to be that, by 2025, ‘75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia’ (WHO 2017, p.10). Policies and strategies for people with advanced dementia are of particular interest to this thesis, because they are the most likely people to need specialist dementia support in residential care facilities. The first WHO Ministerial Conference on Global Action Against Dementia (WHO 2015b), professed that all countries should provide access to high quality, safe and appropriate environments for people with advanced dementia. This international commentary shows that, at a global level, the cultural contexts of ageing and dementia are high on the agenda of public organisations, with individual countries being encouraged to provide good quality care for people with dementia. The context of aged care in Australia is discussed in the section that follows.

1.2 Aged Care in Australia

Australian aged care has its roots in the early European model, where caring for those with ‘senility’ was provided in benevolent asylums established by philanthropists and religious charities (Hunter 2005; Allen et al. 2008). In spite of a growing interest in modernisation of health care, Walmsley and McCormack (2016, p.1686) believe that aged care has, in some ways, remained entrenched in a mindset ‘where the stigma of senility and benevolent asylums has remained in the poor underbelly of aged care’.

Biomedical developments eventually attracted government funding and commercial possibilities (Hunter 2005), and significant changes to the Australian aged care system have occurred in the past 30 years. Prior to the 1980s, policies around aged care concentrated on nursing home subsidies and aged pensions. Since that time, however, the implications of an ageing population have been acknowledged and social policies have focused on community and residential care (Hughes 2011).

Residential Aged Care (RAC) provides 24-hour care and accommodation for older people when their care needs can no longer be met in the wider community. The Australian Government subsidises this care, having invested $12.2billion in residential care in the 2017-18 financial year. The Aged Care Act 1997 provides the regulatory framework for aged care providers, and offers protection for residents. The Department of Health (DoH 2018c) reports that, as at 30 June 2017, ownership of residential care homes was divided between not-for-profit providers (55.3%), for-profit providers (40.6%), and government providers (4.2%).

Aged care facilities must be accredited to receive government subsidies. The accreditation process is based on the performance of an aged care facility against expected outcomes which are embedded within accreditation standards (Aged Care Quality and Safety Commission 2019). As part of government reforms to the aged care system, transition to new accreditation standards, known as the Single Aged Care Quality Framework Standards (DoH 2018a), is currently in progress. This new set of standards, which incorporates a single set of standards for all aged care services, takes effect on 1 July 2019. As specified by the Aged Care Quality and Safety Commission (2019), the outcomes with which all aged care providers are expected to comply are contained in these new standards:

Standard 1: Consumer dignity and choice
Standard 2: Ongoing assessment and planning with consumers
Standard 3: Personal care and clinical care
Standard 4: Services and supports for daily living
Standard 5: Organisation’s service environment
Standard 6: Feedback and complaints
Standard 7: Human resources
Standard 8: Organisational governance

In addition to government subsidies, allocation of funding to Residential Aged Care Facilities (RACFs) is assessed by the Aged Care Funding Instrument (ACFI). While an ACFI assessment does capture a person’s care needs and medical conditions, its purpose is to focus on resource distribution from the government to the aged care provider for delivering that person’s care. The ACFI application process involves completion of twelve items across three domains of care: activities of daily living; behaviour; and complex health care. ACFI is initially used to assess care needs at the time a person enters permanent RAC, and is then used periodically as care needs change (DoH 2018b; Joenperä 2017).

In the twenty years since Kitwood (1997a) integrated person-centred care with dementia care, there have been improvements within the aged care industry (Downs 2013; Fazio et al. 2018; McCormack et al. 2012; Mitchell & Agnelli 2015; Scales et al. 2017). However, the industry continues to face challenging times, especially as an ageing population places increasing pressure on the health system (Harris & Sharma 2018). Staffing in RAC remains an area of concern, particularly because of demanding working conditions, low levels of remuneration and the overall low status of aged care (Walmsley & McCormack 2016). Given that there is currently no cure for dementia and that older people are now living longer, dementia is looming as one of the greatest challenges facing aged care over the next twenty years. According to Keast (2015), aged care service providers will need to reconsider their current care models, looking at employment of more qualified and skilled staff, improved provision of education and training for staff, and care practices which enhance wellbeing in people with dementia.

Alongside these challenges, the values and mission of aged care are somewhat confusing. On the one hand, of major importance to older people is their quality of life, which they rightly expect to be able to live at their own pace and in which their choices are incorporated. Yet on the other hand, this quality of life is required to fit a residential care model adapted from a medical model of care whose focus is tasks and routines rather than long-term quality of life. As suggested by Walmsley and McCormack (2016), even though aged care staff may empathise with the older person's needs for wellbeing and quality of life, they lack the authority to adapt this standardised model of care to accommodate many of the older person's individual needs.

This overview of the Australian aged care system highlights conflicts and tensions about what actually constitutes care. The paradox here is that aged *care* does not consistently deliver appropriate *care*, and, in fact, the inconsistencies highlight a degree of societal and organisational dissonance about the concept of aged care. However, as has been suggested by Waghid (2018), discomfort arising from dissonance presents opportunities to look at a situation in a new light, 'with the aim of cultivating alternative modes of human action' (p. 384). This doctoral study provides such opportunities.

Having outlined cultural characteristics around RAC in Australia, it is important to understand the life experiences of older people with dementia who become residents in RACFs. A discussion on the cultural context of ageing precedes a presentation on dementia.

1.3 Contexts of Ageing

In line with the global trend, Australia's population is ageing. In this country, both the number and proportion of older people are growing steadily. In 2016, 3.7 million Australians were aged 65 and over, which is 15% of the population, while almost 500,000 people were aged 85 and over. According to the Australian Institute of Health and Welfare (AIHW 2018a), average life expectancy has increased extensively in the last century, with men and women currently aged 65 years having expected ages at death of 84.2 years and 87.1 years respectively.

The literature distinguishes between different age groups to highlight common characteristics and to add specificity to the categorisation of ageing. 'Chronological' age is the number of years and months since the person's birth (Sayers & Cotton 2014), while 'functional' age is measured in terms of the person's functional ability compared to what is normally expected for his or her age (Kalache, Barreto & Keller 2005). The United Nations (UN 2015) categorises those over 60 as 'older people', and persons aged 80 years and over as the 'oldest-old', while in developed countries such as Australia, 'older people' are defined as those aged 65 years and over (AIHW 2018b). This mode of categorisation is important as it enables not only a specificity of care, but enhanced clarity for research such as this current doctoral project.

The ageing experience is generally viewed as being unique to each person and understood to encompass the ‘physical, psychosocial and spiritual changes people may encounter as they age’ (Sayers & Cotton 2014, p.29). Successful ageing has been associated with a satisfactory functional status; ongoing spiritual encounters which provide meaning, purpose and satisfaction; and the ongoing experience of gerotranscendence (Flood 2002). In connecting gerotranscendence with maturity and wisdom, Tornstam (1999/2000) saw gerotranscendence as a new way of viewing ageing and described the process as ‘the construction of a reality somewhat different from the view commonly held in midlife’ (p.11). Similarly, MacKinlay (2006) described gerotranscendence as the eventual recognition that it is acceptable to simply ‘be’, thus the older person is able to move beyond the consequences of any diminishments they may be experiencing. Gerotranscendence is seen as ‘a natural and important part of the process of ageing’ (2006, p.161) in the latter stages of life.

Ageism in Society

Any form of social inequality activates and actualises marginalisation and discrimination against specified groups. Ageism is the term used to describe discrimination based on age (Gendron et al. 2016), and, according to Allen (2016), is one of the more prevalent forms of prejudice in society, with older people being ‘systemically disempowered, devalued, and excluded’ (2016, p.611). Age discrimination is frequently viewed as acceptable and normal, with societal and institutional ageism often excused or disregarded (Allen 2016; Angus & Reeve 2006).

When proposing the term ‘ageism’, Butler (1969) wrote that ‘ageism might parallel racism as the great issue of the next 20 or 30 years’ (p.246). Many years later, Butler

(2005) acknowledged there may have been some softening in ageist attitudes since his earlier article, but believed that ageism was still ‘deeply embedded in society in many areas’ (p.86). Butler’s (1969, 2005) observations of ageism are helpful in raising awareness of attitudes towards older people (Malta & Doyle 2016). In fact, Gendron et al. (2016) suggest that language around ageism is so entrenched in contemporary society that it usually goes unnoticed. With negative age stereotypes increasing over a number of years (Ng et al. 2015), cultural acceptance of ageism would seem to place the health care of older people at risk. Ageism continues to exist among undergraduate nursing students (Frost, Ranse & Grealish 2016), social work students and practitioners (Allen, Cherry & Palmore 2009), and the wider community (Cherry & Palmore 2008).

The media plays a significant role in how older people are portrayed, with the Australian Human Rights Commission (2013) reporting that older people are often portrayed as ‘lonely, victims, unhealthy and as sources of amusement’ (p.9). The most common words used by the media to portray older people are ‘forgetful, slow, frail, vulnerable, burden, grumpy and useless’ (2013, p.10). Minichiello, Browne and Kendig (2000) also found negative depictions in a study examining the meaning and experiences of ageism for older people. Participants in the study described oldness as ‘not trying, withdrawn, isolated, irritating, self-oriented, living outside the mainstream, unattractive, uninteresting, frail, senile, silly, over the hill, narrow-minded, a burden, lonely, vulnerable, dowdy, and unproductive’ (2000, p.259). These categorisations present a generalised, and somewhat inaccurate, unconstructive and depressing image of older people. Such representations encourage elder abuse which, in line with ageing populations, is prevalent worldwide (Yan, Chan & Tiwari 2015).

Ageism negatively affects older people and must be recognised, managed and addressed (Chrisler, Barney & Palatino 2016). The aspects of ageism which pose a risk to older people include prejudice, negative stereotyping and disrespect. These characteristics of ageism have been challenged for a number of years, but they still exist within society, and potentially frame the approach of policymakers and, therefore, policy design. Ageism cannot be overcome unless the consequences of this stigma are acknowledged and constrained. Public education, inclusion of effects of ageism in health curricula, and further research on 'biases into healthcare decision making' (2016, p.96) will assist in reducing the occurrences of ageism. The negative effects of ageism are multiplied for older people living with dementia, as they also experience levels of stigma.

1.4 Dementia

Although not a normal part of the ageing process (Walmsley & McCormack 2016), dementia is increasingly common with age and primarily affects older people. Dementia is a progressive condition and is, therefore, one of the leading causes of disability and dependency in the elderly (Prince, Prina & Guerchet 2013; AIHW 2018c), and, as such, is closely linked with the dialogue around ageing. On a global scale, there are estimated to be 47 million people living with dementia, with numbers expected to reach 75 million by 2030 (WHO 2018a). Following this global trend, it is estimated there were 298,000 people with dementia in Australia in 2011, with this figure expected to rise to almost 400,000 by 2020 (AIHW 2012). According to AIHW (2012), dementia:

> is not a single specific disease. It is an umbrella term describing a syndrome associated with more than 100 different diseases that are characterised by the impairment of brain functions, including language, memory, perception,

> personality and cognitive skills. Although the type and severity of symptoms and their pattern of development varies with the type of dementia, it is usually of gradual onset, progressive in nature and irreversible.

Around 100 different dementia subtypes are incorporated in the word ‘dementia’, with some of the most common types being Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. There are a number of other causes of dementia including dementia in Huntington’s disease, alcohol related dementia, HIV/AIDS related dementia, and Creutzfeldt-Jacob disease (AIHW 2012). Characteristics of the most common types of dementia are listed in Table 1.1.

Table 1.1: Characteristics of Dementia Subtypes

Type of Dementia	Characteristics	Approximate Proportion of Dementia Cases
Alzheimer’s Disease	▪ Short term memory loss, apathy and depression in the early stages. ▪ Difficulties with language, orientation, judgement, behavioural dysfunction. ▪ Onset is gradual and decline is progressive	50-75%
Vascular Dementia	▪ Caused by cerebrovascular conditions such as multi-infarct disease and stroke. ▪ Symptoms in the early stages are similar to Alzheimer’s disease, but memory less affected and mood fluctuations are more prominent. ▪ Physical frailty	20-30%
Frontotemporal Dementia	▪ Personality changes ▪ Mood changes ▪ Disinhibition ▪ Language difficulties	5-10%
Dementia with Lewy Bodies	▪ Characterised by the presence of Lewy Bodies. ▪ Symptoms similar to Parkinson’s disease (tremor and rigidity). ▪ Noticeable fluctuation in cognitive ability. ▪ Visual hallucinations; tendency to fall	5%

Source: Adapted from Prince & Jackson (2009); AIHW (2012)

Effects of Dementia on the Person

Regardless of the type of dementia, the progressive nature of the condition has significant impacts on the person living with dementia and their family carers. Despite this effect, many people with dementia continue to successfully live in the community, usually supported by family. Caregiving by family members is generally considered a rewarding role to accept, however, as noted by Slape (2014), because care needs intensify, many families face the situation of needing to admit the person with dementia to residential care.

Although the experience of dementia is different for each person, it is helpful to broadly categorise the progression of dementia into stages. As dementia progresses, the person’s limitations become more apparent and restricting. Increasing limitations are evident in the middle stage, while the advanced stage is one of almost total dependence and minimal activity. Memory disturbance and physical frailty are quite significant in the advanced stage. By the time of admission to residential care, the person’s dementia has usually progressed to middle or advanced stage. Setting out these symptoms in stages highlights the multiplying impact on the person as dementia progresses, and gives an understanding of the challenges faced by that person at the time of entering residential care. A guide to these stages is set out in Table 1.2.

Biomedical Approach to Dementia

Before the mid-twentieth century, death occurred prior to people reaching an age where dementia might begin to develop. However, advances in medical interventions increased life expectancy, resulting in a considerable escalation in the number of people likely to develop dementia (Walmsley & McCormack 2016). When dementia

Table 1.2: Common Symptoms Experienced by People with Dementia

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EARLY STAGE

The early stage is often overlooked and seen as just a normal part of the ageing process. Because the onset of the disease is gradual, it is difficult to be sure exactly when it begins.
The person may:

- Have language problems
- Have significant short-term memory loss
- Not know the time of day or the day of the week
- Become lost in familiar places
- Have difficulty in making decisions
- Become inactive and unmotivated
- Show mood changes, depression or anxiety
- React unusually angrily or aggressively on occasion
- Show a loss of interest in hobbies and activities

MIDDLE STAGE

As the disease progresses, limitations become clearer and more restricting.
The person with dementia has difficulty with daily living and:

- May become very forgetful, especially of recent events and people’s names
- Can no longer manage to live alone without problems
- Is unable to cook, clean or shop
- May become extremely dependent on family members and caregivers
- Needs help with personal care
- Has increased difficulty with speech
- Shows problems with behavioural issues such as repeated questioning and calling out, clinging and disturbed sleep
- Becomes lost at home as well as outside
- May experience hallucinations

ADVANCED STAGE

The advanced stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious.
The person may:

- Have difficulty eating
- Be incapable of communicating
- Not recognise relatives, friends and familiar objects
- Have difficulty understanding what is going on around them
- Be unable to find his or her way around in the home
- Have difficulty walking
- Have difficulty swallowing
- Have bladder and bowel incontinence
- Display inappropriate behaviour in public
- Be confined to a wheelchair or bed

Source: Adapted from WHO (2006)

was constructed as a disease in the late 1960s and early 1970s (Herskovits 1995), what was once seen as a social issue was then redefined as a medical problem (Penrod et al. 2007), moving the focus from the person to the disease.

As suggested by Chaufan et al. (2012), the reassigning of dementia from a social issue to a medical and public health problem limited perceived dementia expertise to predominantly medical professionals, and, not surprisingly, placed emphasis on developing a cure and effective treatments. Clearly, a cure for dementia is a worthwhile goal, but questions have been raised about the effectiveness of dementia care in the interim, especially when provision of that care sits within the biomedical model. Within this framework, ‘care’ is reduced to ‘little more than treatment of behavioural disturbances’ (2012, p.794), which, in many cases, involves medication with the intent to sedate the person (Power 2010). Subsequent care plan documentation often reports that the medication had the desired calming effect, but, in these circumstances, it is reasonable to question whether this was the best outcome for the person with dementia. The case could be made that, while the person is now compliant and, therefore, not disruptive, they no longer have any means of expressing their needs (Power 2010). As explained by Gauthier et al. (2010, p.350), unmet psychological needs ‘such as those associated with thirst, hunger, pain, distress, feelings of abandonment, or fear of endangerment’, are likely to be manifested in so-called disruptive behaviours.

A biomedical focus has considerably advanced the understanding of pathology and diagnosis associated with dementia (Alladi & Hachinski 2018). However, several scholars have suggested that the domination of the biomedical approach to dementia is at the detriment of other approaches and largely ignores individual and social factors (Bartlett & O’Connor 2010; Brooker & Latham 2016; Kitwood 1997a; Power 2014; Sabat 2001; Swinton 2012). Almost 30 years ago, Lyman (1989) was critical of a model of dementia care which ‘explained and treated personal and social troubles as medical problems' (p.598). Fazio et al. (2008) believe the medical model focuses on staff and organisational needs, thus ignoring the strengths and remaining abilities of the person. While dementia continues to be constructed exclusively as a medical condition and, therefore, requiring a biomedical approach to manage symptoms, social elements are ignored, thus affecting decisions in research and policies, and, very likely, resulting in adverse effects for people with dementia (Cuijpers & van Lente 2015; Chaufan et al. 2012). With a focus on the difficulties of dementia, the biomedical approach advances stigmatisation towards people with dementia.

Stigmatisation and Dementia

The personal experience of living with dementia can only truly be known by a person with such a diagnosis. However, an insight into societal discriminations and stigmas around dementia leads to some understanding of the humiliation that may personally be experienced. In the context of this study, it is important to understand as much as possible about the subjectivity of a person with dementia, particularly at the time of their admission to an aged care facility. This experience requires both monitoring and understanding regularly after admission.

With an ability to reduce a person 'from normal to someone who is a person with whom something is wrong' (Innes 2009, p.73), stigma aimed at people with dementia is widespread with far-reaching consequences (Alzheimer's Australia 2017; Batsch & Mittelman 2013; Benbow & Jolley 2012). Ghosting is a form of stigma suggested by Davis and Pope (2010) to describe occurrences where dementia is 'superimposed upon the person' and, consequently, their identity is 'subsumed in stereotype' (2010, p.36). Institutionalised ghosting, therefore, describes situations where organisations and staff see only the effects of dementia rather than the person behind the dementia.

Personhood is threatened when powerfully disturbing metaphors and images are used in reference to those who are elderly and experiencing memory loss, and the person is vulnerable to being ‘mocked, humiliated, controlled, questioned and institutionalised’ (Behuniak 2011, p.84). While metaphors help to gain different perspectives, thereby finding new meaning, they can also lead to misrepresentation. Metaphoric thinking about dementia can be problematic, particularly when dementia is interpreted through unrealistic frameworks, such as a ‘persistent vegetative state’, a ‘living death’, or ‘no longer there’ (Johnstone 2013, p.40).

The imposition of stigma may occur through stereotyping, prejudice or discrimination. Stereotypes are shared judgements about people with dementia, prejudice describes unfavourable emotional reactions to someone with dementia, and discrimination refers to responses to prejudice, such as ‘avoidance, coercion and segregation’ (Benbow & Jolley 2012, p.166). Any form of stigma will have a negative impact on care practices, potentially leading to neglect and abuse of people with dementia (Fang & Yan 2018). Such situations affect not only those with dementia, but also family members, the quality of care provision and resourcing of the dementia care sector.

Stigmatisation cultivates negative opinions of dementia, to the point where dementia may be ‘feared, dreaded, hidden’ and surrounded by ‘shame and embarrassment’ (Hughes 2014a, p.28). Milne (2010) suggests that ‘receiving a dementia diagnosis allocates the older person to a new lower status social group’ (2010, p.228), and

Behuniak (2011) believes there is a public fear of people with dementia that both stigmatises and dehumanises. Sabat's (2001) observation that 'to be old and also to be afflicted with Alzheimer's disease can be seen … as being doubly damned' (p.22) reinforces the stigmas accompanying both ageing and dementia.

This discussion has shown that living with dementia and the effects of stigmatisation around dementia can undermine personhood. However, moving the focus from the effects of dementia to the value of the person will facilitate the maintenance of their personhood.

1.5 Theoretical Perspectives of Person and Personhood

The original intention of this doctoral thesis was clear. That intention was to explore the concept of personhood as it relates to each person with dementia living in a RACF, and to each person who delivers dementia care. In other words, are matters relating to individual *persons* given appropriate attention amongst the competing demands of *organisational* needs and *governmental* obligations? What is the actual level of care for each person who is a resident, and the actual level of support for each person who is a staff member?

During the early stages of the literature review on the concepts of 'person' and 'personhood', that were the foundational components of this thesis, the enormity of the task became apparent. Questions were raised rather than solutions reached as conflicting understandings of *person* emerged. What is a person? What, then, is personhood? How does someone living with dementia relate to the view that dementia diminishes their status as a person? Initial perceptions relating to the core ideas of this thesis were being challenged. Yet, as with the most important of research, the complexity and interdisciplinary dissonance and disagreements were potent and powerful. Through these challenges, the original intention of the thesis remained and, in fact, increased in its motivation and urgency, because these were questions that needed answers.

Ambiguity of Person and Personhood

When reflecting on what a person is, most scholars – indeed most people – conflate this noun with human being (Barresi 1999). However, there are various views on the actual definition of the word ‘person’, with its meaning often disputed (Ohlin 2005) and highly reliant on the context in which it is used (Spaemann 1996). Agreeing that a specific answer to the question ‘What is a person?’ is vague and undefined, Erde (2001) suggests that the question does prompt some interrelated concepts such *as individual, human, autonomy, self, identity, mind, personality, spirit, soul* and *consciousness.*

Similarly, reaching a consensus on the meaning of the word ‘personhood’ seems problematic. In spite of an abundance of literature on personhood, there is no morally acceptable agreement on its meaning (Erde 1999). The word appears to be challenging to define (Hirst, Lane & Reed 2013), controversial and often disputed (Kittay 2008), perplexing (Myser 2007) and complicated (Higgs & Gilleard 2016). The term ‘personhood’ usually focuses on characteristics related to being a person (Buron 2008); the ‘quality or condition of being a person’ (Edvardsson, Winblad & Sandman 2008, p.362); and the fact that personhood is dependent on ‘being recognised as a person’ (Coulson & Ronaldson 2000, p.120). Personhood, therefore, is a twofold concept denoting possession of characteristics pertaining to a person, and, concurrently, requiring recognition by others of the possession of these characteristics. Because of their obvious close connection, the words ‘person’ and ‘personhood’ are often used interchangeably.

Appearing to have arrived at a clear explanation of personhood, it would seem feasible to move on to a discussion on the next topic - personhood and dementia. Straightforward, that is, until evidence emerges of conflicting views amongst philosophers and ethicists as to what constitutes a person. This question is problematic given that *personhood* is dependent on a clear understanding of *person*. Consequently, because this thesis is directly concerned with personhood as it relates to dementia, clarification is needed regarding the concept of ‘person’. People with dementia are among those whose personhood is in doubt (Swinton 2012; Post 2000), but, if they do not warrant classification as persons, how are they to be classified? Perhaps nonpersons? If so, what are the guidelines for administering care and provision for nonpersons? We now explore the underlying question – what is a person?

Philosophies and Theories of Person

In the fifth century AD, Boethius (approximately 480-524) described a person as ‘an individual substance of a rational nature’ (Barresi 1999, p.80). At that time, the rational component was relatively spiritual in nature and pertained to human beings as well as ‘immaterial spirits, such as angels and God’ (1999, p.80). With increasing developmental approaches, however, the classification of person altered considerably to refer only to human persons.

A fundamental difference between the terms ‘human being’ and ‘person’ is that ‘human being’ is classified as biological, while ‘person’ is a psychological classification (Barresi 1999, p.80). It was John Locke (1632-1704), an influential English philosopher and physician, who ‘provided an empirical framework within which to develop a science of persons’ (Barresi 1999, p.80). Locke (1690/2001, p.195) defined a person as a:

> thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places; which it does only by that consciousness which is inseparable from thinking, and, as it seems to me, essential to it.

Locke’s work resulted in the more explicit definition of a person ‘as a unity that is a self-conscious agent, an intentional being’ (Barresi & Juckes 1997, p.694), with his consciousness benchmark of person assuming ‘a central role in postmodernist discussions’ (Torchia 2008, p.220).

With his emphasis on rationality and consciousness as necessary components of person, Locke’s philosophy has raised concerns about the exclusion of some human beings from classification as persons. His view that personhood is based on a ‘capacity for self-consciousness’, a ‘capacity to participate as moral agents’ (Rich 1997, p.209), and ‘reason and reflection’ (Warner 1997, p.91), strongly suggests that some people with mental impairment are not considered to be persons – a view that has ‘very profound ethical implications’ (Warner 1997, p.91).

Based on Locke’s definition, personhood ‘is defined in terms of a capacity for self-awareness, continuity of thinking, a sense of self over time, consciousness, and memory’ (Swinton 2012, p.123). In this scenario, the concern is that people diagnosed with dementia will progressively move from personhood into non-personhood. Disturbingly, this suggests that some human beings can be persons for several decades and then, following a diagnosis of dementia, find themselves living out the rest of their lives as non-persons, who ‘become less worthy of moral attention and protection' (2012, p.123) because 'non-persons count less, if at all' (Post 2000, p.79).

It is clear that philosophers and theorists have varying views on what constitutes a person, with some rigorously challenging the idea that every human being is a person. Many of them 'press the envelope of our anthropological presuppositions to the limit and beyond' (Torchia 2008, p.217) by generally subscribing to the suggestion that the ability to participate in conscious experiences is vital for categorisation of a person (Rich 1997). This issue is important because such theorists have strongly influenced those doubting the personhood of people with dementia (Mitchell, Dupuis & Kontos 2013). One such view was expressed in a 'shocking form' (Hughes 2014b, p.69) by the medical philosopher Dan Brock (1988, p.87):

> I believe that the severely demented, while of course remaining members of the human species, approach more closely the condition of animals than normal humans in their psychological capacities. In some respects the severely demented are even worse off than animals such as dogs and horses…. The dementia that destroys memory in the severely demented destroys their psychological capacities to forge links across time that establish a sense of personal identity across time and hence they lack personhood.

Reluctance to classify people with dementia (and other disabilities) as persons stems, at least in part, from the work of Immanuel Kant (1724-1804). Interpretations of Kant's work have resulted in some writers, such as Cooley (2007), believing that 'those with diagnosed dementia have a Kantian-based duty to end their lives' (Cholbi 2015, p.607). However, in spite of believing in a lack of personhood among 'the soon-to-be demented', Cooley (2007) does not explain precisely how or when the 'end, loss or destruction' of personhood actually occurs (Myser 2007, p.56). Following the same line of thought, Sharp (2012) comments that several writers supporting the Kantian approach believe that suicide is a moral requirement by those who are rational but who will soon be irrational, and adds that this line of reasoning is rather convincing.

Baroness Warnock, an ethicist and advisor to the British government, believes that people with dementia are ‘wasting people’s lives’ and ‘resources’, and, therefore, have a moral duty to die (Beckford 2008, p.53). Of particular interest to this thesis is her belief that, in the case of dementia, ‘the real person has gone already and all that’s left is just the body of the person’ (Malpas 2009, p.53). Warnock’s claim that dementia invalidates personhood raises questions about how individuals with dementia are classified, and the suggestions of ‘non-persons’ or ‘bodies’ seem reasonable under these circumstances (2009, p.58).

Although Warnock’s comments were largely condemned (Malpas 2009), disputes continue over the categorisation of personhood (Mitchell, Dupuis & Kontos 2013). In discussing the negative effects of frequent reference to people with dementia as ‘the living dead’, Behuniak (2011, p.70) says ‘it is disconcerting to find frequent and overt references to zombies’ within the literature and the arts when referring to people with dementia. Likewise, Mitchell, Dupuis & Kontos (2013, p.2) maintain that ‘popular literature and social media portray … disregard for persons with dementia’. Aquilina and Hughes (2006) agree, stating it is very likely that people with dementia will be perceived as ‘already dead and as walking corpses’ (p.143) if language such as ‘living dead’ continues to be used in the context of dementia.

The term ‘hypercognitive’ was created to argue against the reduction in moral status of people with dementia by those claiming to be ethicists (Post 2000; 2011). The ‘hypercognitive culture’ to which Post refers effectively removes the status of moral agents from those who are cognitively impaired, therefore rendering them devoid ‘of moral significance and concern’ (Post 2000, p.79), and reducing them to non-persons (Sabat 2001).

Opposing the Kantian perspective, some writers assert that an individual’s foundational personhood is not lost or destructed, but, on those occasions when the personal journey is interrupted, as is possible with dementia, a person may need assistance to recuperate their personhood (Myser 2007). Likewise, Cholbi (2015, p.607) declares that people diagnosed with dementia ‘do not have a duty to die’, but rather the responsibility of ‘indirect duties that shape the morally proper responses to demented persons who are no longer rational’ (2015, p.608) falls to other people. In spite of wide-ranging theoretical views on person and personhood, Post (2000, p.81) believes that most people ‘think that a task of ethics is to include rather than exclude the vulnerable’ (p.81), and therefore, the overall mark of the public is grounded in a moral sentiment which cares for the neediest, including people with dementia.

Towards a Principled Concept of Personhood for RACFs

Having established there are several schools of thought on the concepts of ‘person’ and ‘personhood’, an understanding is sought of personhood as it relates to residential dementia care. In recognising the wide range of views on the concept of person, it is reasonable to concede a specific definition of ‘person’ is unrealistic. However, ‘in an age of increased sensitivity to the social and political harms caused by stereotypes, stigma, and discrimination based on disease’ (Behuniak 2011, p.70), a balanced understanding of ‘person’ and ‘personhood’ within the dementia care environment is important.

The context of the person as part of community is important to Spaemann (1996). As a moral philosopher, he believes the significance of the person can be gained through the recognition of persons as members of the community of humankind. Each person occupies a unique position in the human community, and the only way to occupy this position is ‘by being born to membership of the human race’ (1996, p.247). According to Spaemann (1996), entry to this community of persons is a status that is not conferred to someone, but is naturally obtained by human beings, and personhood is situated in the *life* of each one of those human beings.

It seems reasonable to adopt this same principle of personhood status within humankind to any specific community within the human race. Therefore, any person within the context of a RACF is, by implication, to be granted the status of personhood. Furthermore, Erde (2001) suggests that, philosophically, characterisation of a person is already known, therefore, there is no need for a theory about the makeup of persons to better understand the meaning of the word. In order, then, to grasp any deeper meaning, it is more helpful to focus on the linguistic and social contexts of the specific scenario in which the term ‘person’ is used (2001, p.79), than to seek a specific definition. As stated by ter Doest, Semin and Sherman (2002), language plays a key role in social cognition, and it has been demonstrated that people alter the construction of their communication to maintain stereotypical language within their specific group.

Linguistic context pays attention to the use of language and plays a significant role in social judgement and memory (ter Doest, Semin & Sherman 2002.) Meanings of language use are established by the cultural practices in which members of a group communicate with each other, consequently users of a language know the connotations of the meanings even though they may not know the specific definition of terms they are using (Erde 2001). When an individual uses the word ‘person’ they can presume they will be understood because others in their group are familiar with the language (2001). The context of the sentence and manner of communication provide a legitimate framework to portray the intended meaning on that occasion.

Social context refers to the setting or environment in which communication is occurring. Within a RACF, for example, the sentence ‘Mrs Smith is a person, not a dementia’ would be a call to acknowledge Mrs Smith as a person, and not think of her merely in terms of her diagnosis of dementia. This sentence is not a description of Mrs Smith – rather, it implies that she is a person worthy of respect, who is not defined by her diagnosis (Erde 2001). On the other hand, if the meaning of the term ‘person’ in this scenario was intended or understood in a derogatory or disrespectful manner the problem may be of ‘moral inconsistency’ (2001, p.82), more than likely reflecting the social practice of that environment.

Therefore, linguistically and socially, anyone living or working in RAC is a person regardless of any diagnosis they may have or employment role they fulfil. Within this framework of understanding, every human being is a person, and is, therefore, worthy of personhood status, regardless of their mental or physical condition. As stated by Kitwood (1997a), personhood status acknowledges personal identity and individuality, and is maintained through relationships comprising respect, dignity and fairness.

Dementia by ‘Another Name’

Within a ‘hypercognitive culture’ (Swinton 2012, p.131), philosophers, such as Peter Singer (1995), continue to debate issues around personhood. Singer, an Australian ethicist and possibly ‘the most controversial philosopher alive’ (Specter 1999), is often ‘at the forefront of challenging suggestions that people with profound cognitive disabilities such as dementia are persons’ (Swinton 2012, p.126). As discussed by Swinton (2012), Singer highlights the capacities of consciousness and self-awareness as indicators of personhood, a fact which, of course, ‘excludes people with advanced dementia’ from being considered persons (2012, p.127).

Although not swaying from his ethical views on personhood, Singer’s (1995) perspective seemed to change somewhat when his own mother, Cora, was diagnosed with dementia, and became a ‘non-person’ when she was no longer able to recognise herself or her son. During a media interview around this time, Singer stated that he ‘would never kill his mother, even if he thought it was what she wanted’, and added ‘perhaps it is more difficult than I thought before, because it is different when it's your mother’ (Specter 1999). As Swinton (2012) points out, ‘dementia looks different when it has another name’ such as when the name changes from ‘dementia’ to ‘Cora’ (2012, p.131). Indeed, ‘coming close changes things’ (2012, p.133), and reinforces with alarming clarity the ethical and moral responsibility to acknowledge each human being as a person, and, by definition, to respect their personhood.

This chapter has presented the contextual background of ageing, dementia and aged care, and established frameworks of understanding around the concepts of ‘person’ and ‘personhood’. Thus, a contextual reality of the person at the time they enter residential dementia care has been presented. For some time, this person has been living with the effects of stigmatisation imposed by a society which deems them to be ‘other’ because of their advanced age and diagnosis of dementia. The experience of dementia has already inflicted several losses for this person, and now they are experiencing further losses by leaving the familiarity of, and sentimental attachment to their home. The extent to which they are able to adjust and settle in their new home will depend, to a large degree, on the willingness and ability of staff and family members to maintain their personhood. Chapter Two explores the literature regarding personhood in residential dementia care.

Chapter Two: Personhood - The Foundation of Care

A Review of the Current Literature

It is not possible to understand the feelings of a person as they transition into residential dementia care. As a researcher, this ontology can be overwhelming. However, the importance of the research means that alternative methods and theories are summoned to provide a strategy and frame for this research. The previous chapter discussed the already challenging life situation for this person, who is now facing further challenges in an unfamiliar living environment. The quality of dementia care receives much attention from the literature, yet, in the public space, the aged care environment continues to be characterised as unfriendly and unpleasant, and, to some extent, unsympathetic to personal needs. What, then, does the future hold for this person? The answer to this question very much depends on the support the person receives in this environment to maintain their personhood. Therefore, personhood practices for this person must be upheld.

As reinforced by the title of this doctoral research, and contrary to some societal opinions, individuals with dementia are still people, and, in order to investigate a reconfiguration of personhood practice, this research narrows the broad scope of the dementia care literature by focusing on those practices which directly involve personhood care. Through a review of the literature, this chapter explores the current practices which relate to the reconfiguration of personhood practice in residential dementia care. In the following discussion, personhood values are presented as a sound basis for respectful and comprehensive care for people with dementia.

Growing concerns about traditional dementia care practices have resulted in the development of new models of care which focus on the person with dementia as central to their care provision (Petriwskyj et al. 2016). These developments have seen a concerted effort to implement policies and strategies designed to improve the quality of accommodation and care within aged care facilities (Brodaty & Cumming 2010). In an attempt to distance dementia care from institutionalised practices, changes in culture designed around person-centred and relationship-centred practices have been encouraged (McCormack et al. 2012). The introduction of the term 'humanisation' to the dementia care literature (Borbasi et al. 2012) reinforces the notions of personhood and person-centred care developed by Kitwood (1997a). It seems, therefore, that the literature supports the concept of maintaining personhood in residential dementia care.

In spite of supporting evidence, maintaining the personhood of people with dementia does not seem to be an accurate depiction of the aged care system as manifested in many RACFs. The aged care system is complex and inequitable, and lacks sufficient resources to support high quality care (Henderson et al. 2017; Hughes 2011). Characterisations of living or working in dementia care include systemic stigmatisation (Walmsley & McCormack 2016), missed and neglected care (Henderson et al. 2017), and poor remuneration for demanding and highly skilled work (Chenoweth et al. 2010).

Under these circumstances, it is reasonable to explore the experience of the person living in dementia care and the various factors which influence that experience. Therefore, this thesis is centred on that person, with a specific interest in whether they are acknowledged and respected as an individual - in other words, the level of organisational prioritisation that is invested in their personhood.

An integrative review of the literature, based on Whittemore & Knafl’s (2005) revised framework for integrative reviews, was undertaken to explore the culture around personhood in residential dementia care. In particular, the aim of the review was to ascertain current understandings of the components of a personhood model of dementia care, and how these components are considered and practiced within the contemporary culture of residential dementia care. This chapter details strategies undertaken in the literature search, lists the articles identified in the literature search, and presents results of a thematic analysis on those articles. Topics identified in the thematic analysis form the framework for the discussion which concludes this chapter.

2.1 Literature Search Processes

Articles were sourced from these electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Google Scholar, ProQuest (Nursing & Allied Health), PubMed, ScienceDirect, Scopus, Taylor & Francis Online and Wiley Online Library. The criteria limited the search to peer-reviewed primary research articles published in the English language between 2008-2017. Key words used in the literature search included: Alzheimer’s, dementia, dignity, identity, interactions, nursing home, organisational culture, personhood, relationships, residential aged care, respect, and spirituality.

Database searches identified 240 articles and an additional 162 articles were handpicked from bibliographies, resulting in a total of 402 research studies. Following removal of duplicate articles and a screening process based on inclusion and exclusion criteria (see Table 2.1), sixteen articles were selected for the literature review.

Table 2.1: Inclusion and Exclusion Criteria

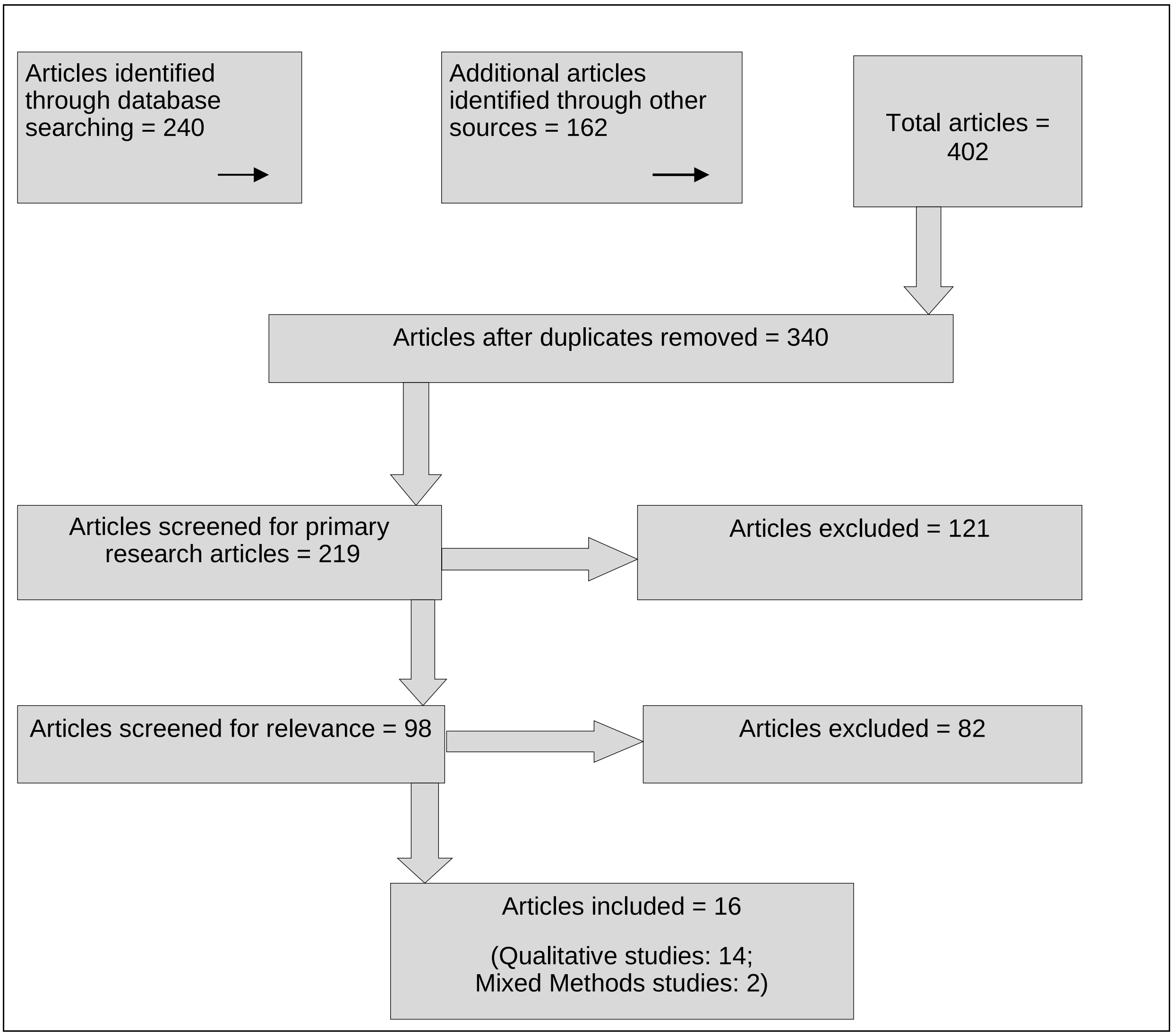
Inclusion criteria	Exclusion criteria
Published between 2008-2017	Published prior to 2008
Published in English language	Published in language other than English
Primary research article	Article other than primary research article
Full text available	Full text unavailable
Peer reviewed journal	Journal not peer reviewed
Contained search keywords	Did not contain search keywords
Specific to residential dementia care	Not specific to residential dementia care
Addressed components relevant to personhood, psychosocial environment or organisational culture	Did not address components relevant to personhood, psychosocial environment or organisational culture
Personhood related to person with dementia or staff member	Personhood related to someone other than person with dementia or staff member

Figure 2.1 represents the screening process which was adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2009).

Evaluation of Articles

Of the sixteen articles analysed for inclusion in this review, fourteen articles were qualitative research and two articles (Henderson et al. 2017; Powers & Watson 2011) were mixed methods. As suggested by Pluye and Hong (2014), the mixed methods approach ‘combines the power of stories and the power of numbers’ (p.30), thus the overall findings of the two mixed methods studies were strengthened (Broadhurst & Harrington 2016). Because the quantitative components of both mixed

Figure 2.1: Flow Chart of Literature Search



Adapted from PRISMA (2009)

methods studies were presented in narrative form, it was decided to evaluate all articles against a qualitative research checklist.

Questions were adapted from the CASP (2017) checklist, and each of the sixteen articles was evaluated for inclusion against this checklist. When evaluated alongside the quality appraisal questions, all sixteen of the studies were found to satisfactorily meet all requirements. Initially, it was felt that one article (Reed, Lane & Hirst 2016) may not be suitable for inclusion because it was a single case study, and, therefore, only one participant was recruited. However, it was decided to include this article in the review because the participant was a person with dementia and the article contained several references to personhood components. A summary of the articles included in the literature review is shown in Appendix 1.

Thematic Analysis

Thematic analysis was chosen as the tool of analysis for the review articles. As a means of identifying patterns and themes within data (Braun & Clarke 2006), thematic analysis enables detection of both differences and similarities in the text, and highlights unexpected insights (Nowell et al. 2017). The process for analysis included familiarisation of the review articles, coding, and identification of themes. This process is set out in Table 2.2 and was adapted from the six phases of analysis as suggested by Braun and Clarke (2006).

Table 2.2: Data Analysis Process

Phase	Task
Phase One	Sixteen articles read several times for familiarisation
Phase Two	Generation of initial codes
Phase Three	Collation of codes into potential themes
Phase Four	Reviewing of themes
Phase Five	Themes named and defined
Phase Six	Writing of literature review

Adapted from Braun & Clarke (2006)

Analysis of the literature revealed a range of issues relevant to personhood in dementia care. Of particular significance is the often-ignored fact that recognising the personhood of staff members is a major factor in maintaining the personhood of the individual with dementia.

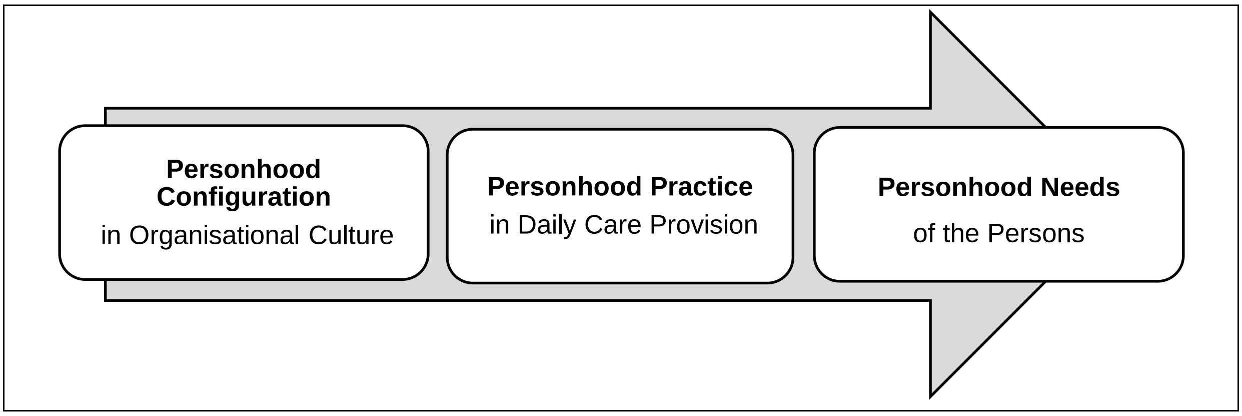
According to the literature, it is clearly unrealistic to expect staff to respect the personhood of residents if they themselves are not feeling respected and supported.

Therefore, this literature review discusses personhood in residential dementia care as a blended concept which embraces all the people directly concerned – each person with dementia as well as each staff member who cares for them.

As represented in Figure 2.2, three themes relating to personhood were identified during the thematic analysis:

1. Personhood Configuration in Organisational Culture
2. Personhood Practice in Daily Care Provision
3. Personhood Needs of the Persons

Figure 2.2: Thematic Map



The direction of the arrow in the thematic map (Figure 2.2) symbolises the traditional perception of personhood in residential dementia care. The organisational culture (Theme 1) dictates the level and quality of configuration given to personhood; the environment of daily care provision (Theme 2) is where personhood practices may or may not occur; and, ultimately, the accurate indication of respect for personhood is whether the resident or staff member is experiencing support and the meeting of their needs on a consistent basis (Theme 3). In this thematic map, the ‘personhood needs’ theme is placed at the arrowhead to symbolically indicate that a good starting point for configuration and practice of personhood in dementia care is by listening to the needs of people with dementia and the needs of staff members as conveyed by them personally.

The findings in some of the sixteen studies were represented in more than one theme, in particular the studies for themes 2 and 3. The main articles for each theme are shown in Table 2.3.

Table 2.3: Themes Identified from Analysis of Research Articles

Theme	**Articles**
1. Personhood Configuration in Organisational Culture	Henderson et al. (2017) Hirst, Lane & Reed (2013) Killett et al. (2016)
2. Personhood Practice in Daily Care Provision	Carr, Hicks-Moore & Montgomery (2011) Hunter, Keady et al. (2016) Milte et al. (2017) Perkins et al. (2015) Powers & Watson (2011) Reed, Lane & Hirst (2016)
3. Personhood Needs of the Persons	Edvardsson, Fetherstonhaugh & Nay (2010) Kaufmann & Engel (2016) Milte et al. (2016) Moyle et al. (2015) Nowell, Thornton & Simpson (2011) Talbot & Brewer (2016) Walmsley & McCormack (2016)

The findings from the literature review are presented in the following discussion under these three identified themes.

2.2 Personhood Configuration in Organisational Culture

From the time a person with dementia is admitted to an aged care facility, it seems obligatory that the organisation should take significant responsibility for supporting their personhood. It is well documented that personhood is acknowledged ‘in the context of relationship’ (Kitwood 1997a, p.8) and ‘through interactions with others’

(Edvardsson, Winblad & Sandman 2008, p.362). Respecting and supporting personhood in dementia care, therefore, is dependent on supporting social engagement, building relationships and an environment which facilitates friendships and quality interactions. As stated by Hirst, Lane and Reed (2013), ‘valuing personhood must be included in a nursing home’s policies’ (p.83). Clearly, the culture of an aged care organisation has a significant impact on whether the personhood of each resident and staff member is valued or devalued. The consideration given to personhood within organisational cultures will now be discussed.

Organisational Culture, Personhood and Care

The Australian RAC sector is perceived as being poorly resourced and struggling to maintain high quality care (Henderson et al. 2017), and it is this characteristic of constant struggle due to under-resourcing which seems to shape the culture of aged care organisations. The literature highlights that narratives about residential dementia care are frequently interspersed with accounts of unrealistic demands on staff (Talbot & Brewer 2016; Walmsley & McCormack 2016), resulting in reduced quality of life for residents (Milte et al. 2017; Nowell, Thornton & Simpson 2011). On the other hand, the literature also reveals evidence of care practices which enable quality care and quality of life (Carr, Hicks-Moore & Montgomery 2011; Milte et al. 2016; Moyle et al. 2015).

For the last twenty years, Australian aged care facilities have been required to achieve accreditation standards in order to receive government subsidies (Moyle et al. 2015). Alongside attainment of these standards, there has been a concerted effort to implement person-centred care that reflects ‘respect for dignity, worth and human rights' (2015, p.1), thereby aiming to improve quality of life for people with dementia. It is fair to say, therefore, that the standard of care in Australia has improved significantly in recent times, and the implementation of person-centred care has contributed to better care practices (Edvardsson, Fetherstonhaugh & Nay 2010). Consequently, aged care organisations are eager to promote an integration of personhood and person-centred care within their stated values to promote their quality of care (Milte et al. 2016).

The culture of an aged care organisation has been recognised as having a major influence on that organisation's provision of good dementia care (Killett et al. 2016). This view is supported by Kitwood (1997a). When enabled to move beyond promotional material and management level discussions, a genuine culture of personhood is portrayed through interactive relationships between staff members and people with dementia. Day-to-day interactions have the potential to either maintain or undermine personhood, and interactions which disrespect personhood have been identified as generally being 'related to the care culture rather than being intentional' (Killett et al. 2016, p.161).

The importance of quality interactions and relationships is supported by Carr, Hicks-Moore and Montgomery (2011) who believe that organisations have ethical obligations towards those in its care. Drawing on the work of Gilligan (1993), Carr, Hicks-Moore and Montgomery (2011) note that an 'ethic of caring' (2011, p.410) recognises that those involved in both providing and receiving care are entrenched in 'webs of relationships' with each other. Gilligan's (1993) framework for an 'ethics of justice and care' (1993, p.63) includes 'the vision that self and other[s] will be treated as of equal worth, that despite differences in power, things will be fair; the vision that everyone will be responded to and included, that no one will be left alone or hurt' (1993, p.63). Within this framework, relationships of care are based on equality, fairness, inclusion and 'the premise of nonviolence' (1993, p.174). Gilligan's (1993) inclusion of nonviolence as a characteristic of care is supported by Waghid (2019), whose interpretation of nonviolence in this context proposes that 'people cannot be silenced when they speak in their own voices', nor should they 'experience a violation and exclusion when they proffer a different point of view' (2019, p.4). In the spirit of personhood and equality, the characterisation of Waghid's (2019) insights into nonviolence are broadened in this thesis to incorporate nonverbal communications by people with dementia. For this reason, in order to maintain personhood, an organisation's culture must facilitate dementia care relationships which are fair and nonviolent (Gilligan 1993), and which are unsilencing and inclusive (Waghid 2019). Thus, this ethic of care framework provides a basis for caring relationships in dementia care settings, and stipulates that the basic moral and ethical responsibilities in dementia care settings include 'avoiding harm, responding to need or vulnerability and maintaining caring relationships' (Carr, Hicks-Moore & Montgomery 2011, p.410).

Maintaining personhood involves care of the whole person. Therefore, nonviolence, as discussed here, incorporates the absence of physical, emotional, spiritual and social harm or diminishment to a person with dementia. Findings in a study undertaken by Milte et al. (2016) endorsed an organisation's responsibility to consider 'social and emotional needs' (p.12) as part of care requirements in a dementia care setting. By enabling the social and emotional needs of a person with dementia to be met, the organisational culture would be embracing an ethics of care based on relationships and respect of personhood.

Killett et al. (2016) believe that aged care organisational culture is created in the unique context of each facility, and, therefore, cannot be successfully introduced through the importation of generic values, or appointment of the ‘right’ management or staff. Therefore, when issues need resolving, solutions should be created which are consistent with that facility’s unique context, values and culture. In order to create cultures of care which are positive and sustainable, organisational leadership needs to trust and support staff to resolve problems using methods which are consistent with stated person-centred values.

Organisational Culture and Staffing Issues

Research undertaken by Talbot and Brewer (2016) found aged care staff were overwhelming in their negativity about the organisational culture in their workplace, particularly in regard to understaffing. Staff despaired at the dismissive organisational response which seemed to not recognise the serious consequences for both residents and staff of insufficient staffing levels. Organisational adherence to the policy that ‘you only need so many staff per resident’ (Talbot & Brewer 2016, p.1746) led staff to believe that management had ‘a poor understanding of the caring role’ (2016, p.1746). Staff members in Talbot and Brewer’s study reported they frequently had insufficient time to spend with residents and expressed their concerns about the safety of residents when they were not being monitored. As a result, staff often needed to respond to challenging situations, and felt extremely frustrated when they knew the challenging situation could have been prevented through the availability of sufficient staff.

Management’s unwillingness to change staffing policies for the benefit of residents has been identified as a contributing factor to serious understaffing in aged care facilities (Killett et al. 2016), and the need for staff to focus on competing obligations significantly reduces the time available to provide important social interactions with residents (Moyle et al. 2015). Edvardsson, Fetherstonhaugh and Nay (2010) found in their study on the characteristics of person-centred care, that people with dementia and their family members needed to develop a trusting relationship with staff. The prerequisites for this to happen are for staff to be ‘available and present’ (p.2616), a consistency of rostered staff members and minimal staff turnover.

Tasks, Routines and Negligent Care

The persistent focus on maintaining tasks and routines in many aged care facilities is reminiscent of the medical model of dementia care. Walmsley and McCormack (2016) suggest it is a focus on ‘pace and regimen’ (p.1697) in residential care which renders person-centred care difficult to instigate and maintain. Likewise, Talbot and Brewer (2016) suggest that organisational directives to complete task-based performance targets result in quality care being evaluated on achievement of tasks rather than quality of interactions with residents. As pointed out by Hirst, Lane and Reed (2013), the structured and medicalised routines of institutional life gradually deprive people with dementia of their sense of self, independence and identity and can, therefore, be viewed as depersonalising.

Talbot and Brewer (2016) found that time constraints were a significant barrier to the provision of effective dementia care, in that, although staff were aware that people with dementia needed companionship and friendship, strict organisational routines did not allow the time necessary to meet this need. It would seem that organisational perceptions of care were not consistent with staff members’ characterisations of quality care in a dementia care environment. This inconsistency in perceptions of care is supported by staff reporting they felt they were ‘being judged negatively’ (2016, p.1747) by management when they did take the time to meet personhood needs. Another barrier to effective dementia care identified by Talbot and Brewer (2016) was the lack of dementia specific training, with some staff expressing frustration at needing to deal with situations for which they were not prepared, either through theoretical training or in a practical sense.

A focus on tasks and routines that aims to benefit the efficient operation of the organisation is likely to demean personhood. In their ethnographic study on personhood in aged care facilities, Hirst, Lane and Reed (2013) identified that 98% of observed interactions between staff and residents were ‘objective and rote’ (2013, p.77), with a focused intent on completing tasks as quickly as possible. Clearly these tasks were important, however, it could be argued that such a high percentage of task-focused interactions strongly suggests that interactions which focused on social engagement or meaningful connection are extremely rare. Hirst, Lane and Reed’s (2013) findings indicate that there was an expectation that residents would observe systematically organised routines, therefore activities such as eating meals, showering, timetabled activities and bedtime were strictly scheduled. However, enforcing such strictly regulated timetables had the potential to transform a person with dementia ‘from a person to an object’ (2013, p.77), thereby disrespecting personhood. The person’s independence and autonomy were significantly depleted, and, with staff focusing on completion of tasks, the ‘normative culture’ (2013, p.77) of the environment was dominated by the institutionalised characteristics of tasks and routines.

In a study by Henderson et al. (2017) to explore the frequency and causes of missed care in Australian RACFs, aged care nurses and care assistants participated in a survey on their perceptions of missed and rationed care. From a total of 22 nursing tasks included in the survey, it was found that all tasks were recognised as being ‘missed at least part of the time’ (2017, p.413). Tasks regularly identified as being missed were answering call bells, toileting residents within five minutes of the initial request, and walking with residents. Additional tasks repeatedly missed are associated with unplanned care and rehabilitative care. Various reasons connected with staffing were provided as reasons for missed care, with the most frequent reason being insufficient staff for the number of residents. Also regularly cited was the inappropriate skill mix of staff, specifically the recent trend within the aged care industry to replace nursing staff with care assistants who are often expected to undertake tasks for which they are not sufficiently trained. Discussions on the results of this study indicate ‘skeleton staffing’ (Henderson et al. 2017, p.415) may be a contributing factor to missed care, and concerns were raised about the apparent ‘rationing of health care to the elderly in residential aged care’ (2017, p.415).

Expectations, Contradictions and Assumptions

One of the greatest anomalies in residential dementia care is the expectation that quality person-centred care will be provided for each resident (Edvardsson, Fetherstonhaugh & Nay 2010). However, this expectation appears to be largely devalued given that the aged care industry continues to be underfinanced (Henderson et al. 2017), understaffed (Talbot & Brewer 2016), and stigmatised (Walmsley & McCormack 2016). The benefits of integrating personhood care into dementia care practices have been well documented (Hirst, Lane & Reed 2013;

Kaufmann & Engel 2016; Kitwood 1997a; Nowell, Thornton & Simpson 2011), and practices which maintain personhood are welcomed and expected by people with dementia and their families (Moyle et al. 2015; Perkins et al. 2015; Milte et al. 2016). Yet residential aged care appears to be entrenched in an environment of contradictions and competing values. On the one hand, society justifiably demands the highest standards of individualised care for people with dementia (Hunter, Keady et al. 2016; Moyle et al. 2015; Reed, Lane & Hirst 2016). On the other hand, Walmsley and McCormack (2016) found several barriers continue to exist which impede good practice in dementia care. These barriers include an ongoing standardised approach to aged care, a deep-rooted stigma linked to aged care, and 'medical model constraints' around care practices (2016, p.1694). Clearly, some of the cultural characteristics of dementia care are at odds with the principles of respecting the personhood of people with dementia.

Systems and processes akin to a medical model approach have been 'superimposed' on aged care 'without due regard for the pace and quality of ageing' (Walmsley & McCormack 2016, p.1686). Of equal importance, is the fact that the emotional and spiritual needs of people with dementia rarely feature within the scope of the medical model. It is very unlikely, therefore, that the identified needs of relationship (Perkins et al. 2015), acknowledgement of preferences in dietary care (Milte et al. 2017), spiritual connectedness (Powers & Watson 2011; Reed, Lane & Hirst 2016), and the primary personhood needs of comfort, inclusion, identity, occupation, attachment and agency (Kaufmann & Engel 2016; Kitwood 1997a) would be met in an environment based on the medical model of care. Doyle and Rubinstein (2013) suggest that, even in aged care facilities where person-centred care is recognised and sometimes practiced, the overall care culture is frequently dominated by traditional methods of dementia care, such as those based on the medical model of care. Despite awareness of improved care practices, Ericson-Lidman et al. (2012) believe that many staff in environments dominated by the medical model are not empowered to deviate from the traditional care model.

The best possible person-centred care is enabled in organisations where the culture supports a shared purpose at all staff levels. In their research on the impact of organisational culture on residents, Killett et al (2016) found that in facilities where quality care was regularly observed, care practices and interactions were consistent with stated personhood values. It was clear, therefore, that management and staff in those facilities shared the cultural values of person-centred care, and that staff were sufficiently resourced to provide this care. However, conflicting assumptions emerged when the organisational culture did not support a policy for engaging sufficient staff. In some facilities, staff found they were ‘compensating for organisational shortfalls’ (Killett et al. 2016, p.175) as they frequently encountered the expectation that they should provide quality care despite experiencing shortages of staff. At those times, staff members, as a group, needed to find solutions to understaffing and, when those solutions involved spending less time with residents and, therefore, reduced emotional engagement with residents, then progressively the values related to those solutions became enmeshed in the organisational culture. Consequently, while the organisation promoted person-centred values, groups within the organisation were, by necessity, pressured to undermine such values. The study by Killett et al. (2016) identified an ‘apparently contradictory assumption’ (p.183) that each staff member was individually responsible for providing quality care, however, the contradiction was evident in the realisation that staff members were not empowered to generate change or ‘overcome barriers to good care’ (2016, p.183).

Rather than avoiding responsibility for 'enacting solutions conducive to espoused values' (2016, p.183), organisations need to develop cultures of quality care which are sustainable and which support staff to find solutions compatible with their stated personhood values.

The power of the organisational culture to affect the personhood of people with dementia is clear. There is now the need to move beyond the corporate sphere into the day-to-day life of the person with dementia and the staff members who care for them. The quality of daily experiences and interactions, and the level of priority given to personhood care practices will now be discussed.

2.3 Personhood Practice in Daily Care Provision

The literature revealed several categories of care which support personhood in the daily experience of the person with dementia. These categories include personhood care (Hirst, Lane & Reed 2013; Kaufmann & Engel 2016; Milte et al. 2016; Milte et al. 2017); spiritual care (Carr, Hicks-Moore & Montgomery 2011; Perkins et al. 2015; Powers & Watson 2011; Reed, Lane & Hirst 2016); relationships and social interaction (Moyle et al. 2015; Perkins et al. 2015); psychosocial interventions (Hunter, Keady et al. 2016); and person-centred care (Edvardsson, Fetherstonhaugh & Nay 2010). Each of these categories of care will now be discussed in the context of daily personhood practice in residential dementia care. The literature revealed strong interconnections between personhood and spiritual care, therefore, these two categories have been integrated in the following discussion.

Integrating Personhood and Spiritual Care

The interconnections between personhood and spirituality were strongly presented in the literature. Hirst, Lane and Reed (2013) stated that personhood ‘involves spirituality’ (p.71), while Powers and Watson (2011) maintained that one of the basic principles of personhood was to view people with dementia as ‘human, spiritual beings’ (p.61). Carr, Hicks-Moore and Montgomery (2011) identified that ‘spiritual care involved the promotion of personhood’ (p.405) and that when a sense of personhood was reinforced, the spirit was nurtured (2011, p.411). A study on spirituality in people with dementia (Perkins et al. 2015) identified that the ‘retention of identity and personhood’ (p.276) was important, and Reed, Lane and Hirst (2016) found that spiritual care ‘communicates the value of personhood’ (p.347). There is, therefore, a strong argument for a discussion which links personhood with spiritual care.

Despite widespread unfamiliarity with personhood terminology, personhood has become a major focus point in dementia care (Nowell, Thornton & Simpson 2011), and is closely linked to preservation of identity and individuality, and to showing respect for the person with dementia (Hirst, Lane & Reed 2013). Spirituality is also a term which is often misunderstood and difficult to define, mainly because the expressions and experiences of spirituality are specific to each person (Perkins et al. 2015). In its broadest sense, however, spirituality incorporates the ‘essence of a person, a quest for meaning and purpose in life, and connectedness to self, other, nature, and/or a higher power’ (Carr, Hicks-Moore & Montgomery 2011, p.400). This broad understanding of spirituality presumes that each person has a spirituality or inner life that is an enabler to finding meaning and purpose in life (Speck 2016). Although not always recognised as spirituality, this form of inner life is ‘a deep, inner resource on which people can draw’ (Hegarty 2007, p.43), especially during times of challenge or crisis.

Although the terms spirituality and religion are sometimes connected, they are not the same concepts. While some people express their spirituality through religious activities, many others sustain their spirituality through meaningful activities and connections. Therefore, in the context of spiritual care, it is important to recognise the probability that a person’s needs may be met without adherence to organised religion (Carr, Hicks-Moore & Montgomery 2011). Spiritual growth has been recognised as a developmental task of ageing, whereby the older person finds internal strength to transcend disabilities and losses encountered in ageing, and to face an uncertain future which, ultimately, includes failing health and eventual death (MacKinlay 2017). As stated by Hudson (2012, p.110), ‘Personhood is nothing less than humanity in its fullness; a worthy aim for all persons concerned with spirituality in healthcare’. Therefore, spiritual support is an essential component of holistic personhood care in residential dementia care environments.

The benefits of providing effective spiritual care as a means of maintaining personhood in dementia care have been well documented (Brooker & Latham 2016; Carr, Hicks-Moore & Montgomery 2011; Edvardsson, Fetherstonhaugh & Nay 2010; Kitwood 1997a; Meaningful Ageing Australia 2016; Perkins et al. 2015; Powers & Watson 2011). Both personhood and spirituality are considered to be significant aspects of quality dementia care, each complementing the other (Carr, Hicks-Moore & Montgomery 2011; Hirst, Lane & Reed 2013). The task of spiritual care is to care for a person’s spirit by addressing their individual spiritual needs, a task which remains relevant when caring for a person with dementia (Carr, Hicks-Moore & Montgomery 2011). A person’s spiritual life continues to exist with advancing dementia (Powers & Watson 2011; Reed, Lane & Hirst 2016), and, quite often, increases in intensity as the dementia progresses. The task of personhood care is to respect ‘one’s total being in the physical, psychological, sociological, and spiritual dimensions’ (Gress & Bahr 1984, p.20). Reed, Lane and Hirst (2016) believe it is possible for personhood to be ‘nourished and, in fact, flourish’ (p.339) as dementia advances.

Reed, Lane and Hirst (2016) used a case study approach to document the impact of spiritual care over a two-year period for a person with dementia. Based on a personalised approach which prioritises the person’s needs, spiritual care was provided to the participant by a spiritual care provider using several interventions. The progress of dementia was causing some confusion, and his ‘sense of personhood’ (2016, p.342) was disappearing, however, attending to the person’s emotions and enabling him to tell his life story on several occasions helped to maintain meaningful connections. Several recent losses, along with the effects of institutionalisation, all contributed to a growing feeling of powerlessness for this person, yet appropriate spiritual care and advocacy helped to maintain a sense of dignity. Towards the end of this person’s life, spiritual care that ‘fit where he was in the disease process’ (2016, p.345) provided him with a regular comforting presence along with support for his family members.

Carr, Hicks-Moore and Montgomery’s (2011) study on the meaning of spiritual care in dementia identified that recognition of, and attendance to ‘the little things’ (2011, p.405) promoted connectedness and personhood for the person with dementia. As a single action, a little thing may be a simple intervention by a staff member. In actual fact, however, the effectiveness of that action as a spiritual care intervention involved a deep knowledge of the person’s needs and preferences, and was, therefore, an ‘intentional act’ (2011, p.405) which held significance for the person with dementia. Described as having an ‘element of planned spontaneity’ (2011, p.405), these intentional acts were opportunities for people with dementia to feel secure and connected in that moment, and to feel cared-for, loved and comforted.

The deep personal need for connectedness can also be fulfilled through acknowledgement of personhood. Hirst, Lane and Reed (2013) suggested the importance of respecting personhood was intensified in the person with dementia, particularly if they were experiencing physical illness, had endured multiple losses in life, and were living in an institutional environment. In their recent study, Hirst, Lane and Reed (2013) reported that staff acknowledged that the ‘personhood of an individual extends beyond the physicality of the body’ (p. 79). However, examples of depersonalisation were observed, and data revealed that the people with dementia who were depersonalised felt ‘a sense of humiliation and embarrassment’, and their ‘shoulders fell and faces saddened’ (2013, p. 79), indicating that depersonalisation produced negative emotional and physical reactions.

Perkins et al. (2015) studied the concept of spirituality in residential dementia care and identified that the spiritual needs of people with dementia included significant meaningful relationships, the need to retain identity, and support for coping with the effects of the progression of dementia. Staff intentionally nurtured meaningful relationships between the person with dementia and staff members, other residents and family members. Identity was maintained as staff and family members ‘repeatedly affirmed the retention of identity and personhood’ (2015, p.276) by enabling the person with dementia to maintain connections with significant interests and activities. Perkins et al. (2015) noted that, as the dementia progressed, staff supported residents in the changing nature of their needs, and, notwithstanding the ongoing process of dementia, many people continued to engage with their spirituality, and were able to indicate the value of participation.

Likewise, Powers and Watson (2011) researched the spiritual needs of people with dementia. They found that interactions with religious rituals and symbols were spiritually meaningful to some people with dementia, which they were able to express either verbally or emotionally. Other participants identified non-religious expressions of spirituality such as art, music, nature, and the bonds of social relationships as being meaningful and satisfying. In discussing their findings, Powers and Watson (2011) highlighted the value of communicating directly with people with dementia where possible when researching spiritual needs. Staff and families may have an opinion about a person’s spirituality, ‘but the persons themselves are the only ones who truly know’ (2011, p.75). In reinforcing the concept of person-centred care, Powers and Watson (2011) commented that the adoption of a personhood perspective would acknowledge a person with dementia as a human being with a spiritual component, able to participate in relationships and communicate their needs and feelings. From this perspective, Powers and Watson (2011) conclude that actions which are often referred to as problem behaviours can be reframed as indications of some need and, therefore, present opportunities for communication and interaction.

A person needs to retain a sense of personhood throughout their life and to experience ongoing meaning and quality in the way that personhood is valued and communicated by others (Hirst, Lane & Reed 2013). Likewise, the capacity and need for individualised spiritual care generally increases in importance with the progression of dementia, particularly as deeper meaning and life purpose are explored (Reed, Lane & Hirst 2016; Carr, Hicks-Moore & Montgomery 2011). Understanding and meeting the spiritual needs of a person with dementia are important aspects of holistic care (Perkins et al. 2015), and when given sufficient time for communication, it is believed people with dementia are able to experience spiritual wellbeing (Carr, Hicks-Moore & Montgomery 2011). The core of spiritual care in dementia is ingrained in a fundamental respect for personhood, therefore, the enablement of spiritual care which offers opportunities for a person with dementia to 'find and sustain meaning, purpose and personhood in life and living' (2011, p.400) is imperative. Hirst, Lane and Reed (2013) state that, regardless of a person's age or cognitive ability, respect for their personhood involved support for all areas of their life, including their spiritual dimension.

Person-Centred Care

The introduction of person-centred dementia care is credited to the work of Tom Kitwood (1997a), and, in recent times, person-centred care has been increasingly linked to quality dementia care (Edvardsson, Fetherstonhaugh & Nay 2010). Although personhood and person-centred care are different concepts, the theory of personhood is considered the foundation of person-centred care. A clear understanding of personhood 'is closely related to understanding and delivering person-centred dementia care' (Nowell, Thornton & Simpson 2011, p.396), therefore practices which maintain personhood are considered to be the focus of good dementia care.

Edvardsson, Fetherstonhaugh & Nay (2010) undertook research to determine how person-centred care was understood by people with dementia, family members and dementia care staff. A factor identified as important to person-centred care was to live in an environment which supported the person with dementia in their pursuit of normality and ‘continuation of self’ (2010, p.2614), with that individual being acknowledged as a valuable person and having control over day-to-day decisions. To support this type of environment, it was identified that staff needed a deep knowledge of the person’s history, preferences, needs and interests and then be willing and empowered to translate that knowledge into practice so that care is person-centred (Edvardsson, Fetherstonhaugh & Nay 2010). Other recognised aspects of person-centred care were the welcoming of family members as part of the care team, and the provision of individualised meaningful activities.

Despite the increasing popularity of person-centred care and its association with quality dementia care, the overall understanding and practice of person-centred are ‘still abstract and vague’ (Edvardsson, Fetherstonhaugh & Nay 2010, p.2611). There has been an extensive body of literature produced on the topic over the last few years, yet much of this literature is based on ‘personal opinion, anecdotal evidence and/or theoretical constructs only’ (p.2611). As a term, person-centred care has become accepted as common dialect in the dementia care arena and, although the principles behind it are widely accepted, its instigation and practice are ‘often ill-defined and difficult to evidence’ (Brooker & Latham 2016, p.24). However, the concept continues to grow, thereby providing increasing opportunities for people with dementia to maintain their personhood and quality of life. When enabled by organisational culture, person-centred care provides people with dementia with opportunities to enjoy wellbeing and quality of life (Brooker & Latham 2016). Although some adaptations to Kitwood’s (1997a) theories are recommended (Kaufmann & Engel 2016), the fundamental principles around maintaining personhood remain relevant. Nowell, Thornton and Simpson (2011) believe that personhood is maintained in a person-centred dementia care environment which is focused on the individual needs of each person living in that environment.

Psychosocial Interventions and Personhood

Although adherence to personhood care requires the inclusion of psychosocial interventions in everyday care practices, inadequate implementation of such interventions in some aged care facilities has been identified (Vernooij-Dassen et al. 2010). Hunter, Keady et al. (2016) note that, in organisations where the medical model continues to dominate care practices, staff have minimal opportunities to address psychosocial needs. Theurer et al. (2015) agree, noting that, when the care focus remains on ‘task completion and body care’ (p.207), very little time is available for psychosocial interventions.

Hunter, Keady et al. (2016) defined psychosocial interventions as ‘everyday therapeutic endeavours involving purposeful human interaction behaviour between staff and residents with dementia’ (p.2025). Hunter, Keady et al. (2016) maintained that such interventions should be incorporated in everyday care practices, and, consequently, undertook a study in psychosocial intervention use in long-stay dementia care. They found that, as staff struggled ‘to make the most of time’ (2016, p.2030), maintaining a positive attitude facilitated the ability of staff to look beyond the tasks and symptoms and see people with dementia as individuals. The identified theme of ‘individualising status’ (2016, p.2029) explained the capacity and preference of each person with dementia towards specific psychosocial interventions. The core theme of ‘becoming a person again’ (2016, p.2028) revealed the mutual benefits experienced by both residents and staff when psychosocial interventions were used, thereby endorsing the understanding that maintaining personhood is relational and psychosocial in nature.

A recent study by Milte et al. (2016) identified that psychosocial interventions in the form of meaningful activities significantly contributed to good quality care. People with dementia identified that accessibility to interests and activities was essential to avoiding boredom, underscoring the fact that quality care goes beyond physical care to also consider ‘social and emotional needs’ (2016, p.12). Participants believed that provision of meaningful activities supported their personhood, but emphasised that, rather than traditional activities which bore little relevance to them, they needed to participate in activities that reflected their preferences and interests. However, participants did express regret that, as their dementia progressed, their ability to participate in activities would decrease, and conveyed a sense of frustration and sadness at this outlook for their future. But, for the time being, the need to contribute to community life and to feel ‘useful and valued’ (2016, p.12) was met through access to meaningful activities.

Moyle et al. (2015) studied the influencers on quality of life as experienced by people with dementia and found that appropriate psychosocial interventions which provide meaningful occupation are important to quality of life. These interventions take the form of solitary activities such as reading, listening to music, word finds, knitting and gardening, or organised activities such as concerts, bingo, church services and visits from school students. The fact that ‘other people should not assume which activities residents will find meaningful’ (2015, p.6), was reinforced by the fact many residents stated a preference or dislike for specific activities, and could therefore choose interventions which were personally meaningful.

Theurer et al. (2015) agree with comments by people with dementia that psychosocial care must provide ‘opportunities for emotional and meaningful social engagement’ (2015, p.202). In advocating for a change from traditional psychosocial interventions which are often intended to ‘entertain and distract’ (2015, p.203), and, therefore, reinforce the stigma and marginalisation of people with dementia, Theurer et al. (2015) argue for flexible approaches to psychosocial care which ‘foster meaningful connections or engagement’ (2015, p.203). A task-oriented approach to psychosocial care usually means staff are under pressure to document residents’ participation in programmed activities, a requirement which may, in fact, conceal genuine psychosocial needs. Theurer et al. (2015) suggest that people with dementia actually need a space where they can ‘speak and be heard’ and ‘be sustained with hope and purpose’ (2015, p.203) rather than repeatedly face expectations of being involved in regular group entertainment and diversions.

Relationships and Social Interaction

Hirst, Lane and Reed (2013) believe that personhood is supported when staff choose to relationally engage with people with dementia. As Killett et al. (2016) noted in their research on organisational culture in aged care facilities, there are often links between the ‘sense of connectedness’ (2016, p.179) within a facility and the quality of care its staff offer to residents. In one particular facility Killett et al. (2016) noted ‘close, micro-level connections in caregiving and social interaction’ (p.179) indicating strong friendships and connectedness in many of the caregiving relationships.

A study by Moyle et al. (2015) identified the importance of social interaction for people with dementia. The data showed that companionship, relationships and conversations were important to many people with dementia and that talking to others reduced loneliness, increased happiness and made life more meaningful (Moyle 2015). Because ‘people with dementia do not and cannot exist in isolation’ (Nowell, Thornton & Simpson 2011, p.405), it is vital that psychosocial interventions are enabled to build positive relationships between staff and residents (Hunter, Keady et al. 2016).

However, as noted by Carr, Hicks-Moore and Montgomery (2011), some organisations continue to view time spent engaging with people with dementia as ‘not really working’ (2011, p.411), therefore, in those cases, time spent building relationships is not valued or rewarded. Yet, offering undivided attention on a regular basis is an important means of building relationships with people with dementia, thus reinforcing their own sense of personhood. In their study on life in residential dementia care, Perkins et al. (2015) found that resident-staff relationships were vital for addressing residents’ needs, and noted that, as staff focused on fulfilling such needs, meaningful relationships would form between specific staff members and people with dementia. Therefore, a working environment which prioritises relationships over routines will develop strong and meaningful connections between residents and staff, and, by so doing, enhance the sense of personhood for people with dementia (Hirst, Lane & Reed 2013).

Care practices which support personhood in the daily experience of a person with dementia have been discussed, however, the nature of the organisational culture may override the need for care practices to be individualised and meaningful. In the configuration and practice of personhood, therefore, it is important that individualised needs of people with dementia be well known by staff and incorporated into care practices. Equally important, is the personhood of staff members. It is reasonable to argue that, when staff feel respected, valued and supported by the organisation, they will incorporate these values in their daily work practices. The personhood needs of residents and staff will now be discussed.

2.4 Personhood Needs of the Persons

According to Hirst, Lane and Reed (2013), institutionalisation can significantly affect the personhood of those with dementia. The structured and medicalised routine of residential care can slowly erode the ‘autonomy, decision-making and identity’ (2013, p.71) of people with dementia, potentially setting up a continual struggle for that person to retain their identity and personhood (Hunter, Keady et al. 2016). Evidence shows that people with dementia and their family members need the aged care facility to know and respect the individual and their needs (Milte et al. 2017). It is important, therefore, to listen to the voice of the person with dementia.

The Voice of the Person with Dementia

The importance of ensuring the wellbeing and quality of life for the person living with dementia in residential dementia care is consistently discussed in the literature (see, for example, Kaufmann & Engel 2016; Killett et al. 2016; Milte et al. 2016; Moyle et al. 2015; Perkins et al. 2015; Reed, Lane & Hirst 2016), and these ideas are supported by Kitwood (1997a). However, wellbeing and quality of life are subjective concepts, and organisational and personal interpretations may differ. Although the literature indicates that the voice of the person with dementia is limited (Moyle et al. 2015), genuine personhood care would ensure issues around wellbeing are viewed from the perspective of the person with dementia.

A recent study (Milte et al. 2016) explored the meaning of quality residential dementia care from the perspective of people with dementia. The data consistently revealed that ‘good quality care supports personhood’ (2016, p.11), particularly through interactions which acknowledge identity, show respect, and value personal likes and needs. Residents reported that being labelled as a behaviour or diagnosis was ‘dehumanising and disrespectful’ (2016, p.11), while having choice and freedom, and feeling useful and valued gave them a sense of control which presented opportunities to contribute to their community. Milte et al’s (2016) study highlighted the voice of residents, thereby providing evidence that, from their perspective, personhood is a vital component of care for the person with dementia.

Also wanting to highlight the voice of those with dementia, Kaufmann and Engel (2016) studied personhood and wellbeing from the perspectives of people with dementia and compared their findings with Kitwood’s (1997a) model of psychological needs. Kaufmann and Engel’s (2016) categorisation of needs was similar to Kitwood’s model, but with the addition of another classification. As with Kitwood’s (1997a) work, Kaufmann and Engel’s (2016) study identified psychological needs were grouped under the domains of comfort, attachment, inclusion, identity and occupation, with the addition of agency as an extra domain.

People with dementia reported they found comfort in individualised ‘small pleasures of life’ (Kaufmann & Engel 2016, p.780), interactions, activity and spiritual rituals. The need for attachment related to people, animals, an appropriately challenging task or anchor items such as sentimental objects. Feeling included in the community was important, as was the need for occupation which may be fulfilled through exercise, conversation or observation. Identity could be achieved through role maintenance, recognition and lifestyle continuity (Kaufmann & Engel 2016). The additional domain heading of agency incorporated the need for self-determination which expressed ‘the wish to be informed in an understandable manner and to be asked’ (2016, p.784). Other needs under the domain of agency were the desire for freedom of action and independence, which related to moving freely, doing things of one’s own choosing, and being self-sufficient. The results of Kaufmann and Engel’s (2016) study not only supported Kitwood’s (1997a) theories but further contributed to the maintenance of personhood in people with dementia. Kaufmann and Engel’s (2016) study confirmed the importance of consulting with the person with dementia when assessing their needs and wellbeing ‘because everybody else is an outsider in the subjective experience’ (2016, p.785) of individuals with dementia. Kaufmann and Engel’s (2016) study is of particular interest, not only because it supports the view that people with dementia can be ‘important informants of their subjective wellbeing’ (2016, p.785), but also because it provides insights into the subjective needs of people with advanced dementia.

Moyle et al. (2015) also acknowledged the importance of the voices of people with dementia in a study exploring quality of life in aged care facilities. Most participants stated that maintaining independence was an important element of quality of life, while others found the structured routines and lack of power limited their choices and freedom. Social interactions with family members, staff and other residents were all identified as contributing to quality of life, although some residents expressed regret at limited opportunities to meaningfully engage with staff, and others experienced periods of loneliness when visits from family and friends were infrequent (Moyle et al. 2015).

Milte et al. (2017) enabled the voices of people with dementia and their families to be expressed in a study on dining experiences in aged care facilities. The findings from Milte et al's (2017) study could be described as following the journey of a person with dementia as they initially set out to have their dining preferences recognised, then became frustrated with increasing barriers to their preferences being met, and eventually experienced decline in the amount of control and choice over matters related to meals due to the progression of dementia. The identified theme of 'we know what we want, just ask us' (2017, p.54) described a need to be consulted on issues such as menu choice, meal sizes, location and timing of meals and involvement in meal preparation and routines. In spite of some of these preferences being expressed, the theme entitled 'our wants are not always heard' (p.54) described a number of instances where individualised needs did not appear to have been considered, let alone met. Family members spoke of their frustrations when the person with dementia was no longer able to communicate specific needs about dining preferences, leaving the person highly vulnerable to inappropriate support and insufficient nourishment at meal-times (Milte et al. 2017). When needs could no longer be communicated by the person with dementia, individuality and choice seemed almost non-existent as was evident in the institutionalised style of seating arrangements, abrupt transition to modified and vitamised foods, and, ultimately, quality of life (Milte et al. 2017). An organisational 'one size fits all' approach (p.56) often obstructed attempts of people with dementia and their families to maintain individuality and choice. Having discussed personhood practices relating to the person with dementia, the configuration and practice of respecting personhood in staff members will now be examined.

Personhood of Staff Members

The level of respect, value and support rendered by the organisation to staff members cannot be ignored in this conversation about personhood. As explained by Hirst, Lane and Reed (2013), when members of staff are not treated with value or shown respect, their sense of personhood will be affected. In the context of this thesis, it is reasonable to argue that, any aged care organisation which claims a commitment to the personhood of residents, must, by definition, also be committed to the personhood of all staff members. As stated by Kitwood (1997a), ‘there is a close connection between the personhood of clients and that of the staff’ (1997a, p.109). In line with the theories of personhood, when staff feel supported, respected and valued, their sense of wellbeing and empowerment is enhanced, and this will be the approach they take when providing care. On the other hand, if staff members feel abandoned, disrespected or mistreated, it is very likely these characteristics will infiltrate their care practices.

The culture of the workplace environment will influence whether staff value or devalue each other. Each aged care facility has its own distinctive behaviours and traditions (Killett et al. 2016), and it is these cultural characteristics which shape the ‘common sense, prejudices, values and knowledge’ (Hirst, Lane & Reed 2013, p.80) of staff members. Facility staff are also influenced by the corporate culture of the organisation, and it is in this broader context of the working environment where there is the need for staff members of ‘various professional groups’ (2013, p.80) to support, value and empower each other. When staff feel empowered, they have a stronger commitment to their employer, and residents will receive better quality care (Hunter, Hadjistavropoulos et al. 2016).

Talbot and Brewer’s (2016) study explored the experiences of staff members in residential dementia care environments in the United Kingdom and identified that the psychological wellbeing of care assistants was an overwhelming factor in their working experience. There is sufficient evidence in the literature to conclude that this topic is also relevant in Australian aged care facilities (Edvardsson et al. 2011; Karantzas et al. 2012; Petriwskyj, Gibson & Webby 2015). The research undertaken by Talbot and Brewer (2016) revealed that burnout was a regular factor impacting the wellbeing of care assistants in a role described as frequently ‘physically and emotionally demanding’ (2016, p.1741). Data indicated that these reasonably high levels of stress and exhaustion often affected personal lives of care assistants as well as their ability to perform the caring role. Participants reported that their relationships with people with dementia were mostly positive and rewarding, and, to a large extent, helped to overcome the negative aspects of their work. However, conflict within the role was more difficult to manage and added to ‘feelings of powerlessness and depersonalisation’ (2016, p.1743). As noted by Talbot and Brewer (2016, p.1743) when commenting on the organisation’s expectations of staff, a care assistant stated: ‘It’s about feeding people, keeping them clean, comfortable, dry, it’s not about fulfilling their needs of companionship and things like that’. This comment illustrates the conflicting expectations of the role that sometimes existed between care assistants and management. On those occasions, care assistants experienced inner conflict because the need to complete routine tasks frequently took priority over the need to spend time with residents.

Walmsley and McCormack (2016) conducted a study which sought to understand the experiences of interdisciplinary health professionals in Australian dementia care settings. Systemic stigma around dementia was identified as an issue which impacts health professionals in dementia care. Participants revealed that, not only did they personally struggle to make sense of this entrenched stigma, but reported they often felt ‘exhausted emotionally, physically and psychologically’ (2016, p.1691) as they supported people with dementia, family members and other staff through advancing stages of dementia. Walmsley and McCormack’s (2016) data exposes the traditional view within the medical profession that ‘aged care remains perceived as a dumping ground’ (2016, p.1692), thereby creating a sense of inadequacy in staff who struggled for a modern individualised approach to dementia care. However, the moral challenges, invalidations and sadness experienced by these professionals were outweighed by their desire and persistence to provide high quality dementia care (Walmsley & McCormack 2016). Indeed, strong determination and willpower were required to overcome such entrenched stigma in an industry which is characterised by poor remuneration, inaccessible training and high staff turnover. A willingness to reject views that dementia care was ‘a matter of just showering someone or feeding someone’ (2016, p.1693), enabled these professionals to diligently seek to offer appropriate and individualised dementia care.

Staff Undervalued

The literature confirms that, traditionally, the personhood of staff has not been well respected by aged care organisations (Hirst, Lane & Reed 2013; Talbot & Brewer 2016; Walmsley & McCormack 2016). Talbot and Brewer’s (2016) study on subjective experiences of care staff revealed an overall lack of value shown to staff by senior management and the organisation. Indications of staff being undervalued included a general unwillingness by management to appreciate the expertise of care assistants, and management’s relationships with staff were characterised by minimal recognition and negative feedback (Talbot & Brewer 2016). Walmsley and

McCormack (2016) note that dementia care staff have often been confronted with challenging and traumatic situations, yet Talbot and Brewer (2016) believe timely and appropriate organisational support for staff is frequently unavailable.

Further evidence of the traditional undervaluing of staff could be interpreted from the inaccessibility of appropriate dementia care training. Talbot and Brewer (2016) found that, in spite of the physical and emotional demands of their role, care staff were provided with only minimum training, resulting in them ‘feeling demoralised and undervalued’ (2016, p.1748). A study by Killett et al. (2016) revealed contradictory expectations around staff training. Although training was identified by management as necessary for delivering ‘the best care’ (2016, p.175), staff were only resourced to attend mandatory training, thus highlighting the organisation’s culture of dismissing specific dementia care training needs (Killett et al. 2016). Walmsley and McCormack (2016) maintain that care staff have the most contact with people with dementia, but, due to minimum training opportunities, have the ‘lowest dementia literacy’ (2016, p.1687). For this reason, care staff need training as much, if not more than other staff disciplines, yet, are the most unlikely to receive it. The widespread organisational practice that appropriate training is rendered inaccessible for care staff ‘subsequently justifies their poor remuneration’ (2016, p.1687), and significantly contributes to ‘little recognition from senior management and negative reactions from the general public’ (Talbot & Brewer 2016, p.1742).

This chapter presented a review of the literature relating to personhood practices in residential dementia care. The process and results of the literature search were explained, which resulted in the identification of three themes: Personhood Configuration in Organisational Culture; Personhood Practice in Daily Care

Provision; and Personhood Needs of the Persons. Discussions on these three areas of personhood care demonstrated a lack of consistency and cohesion between each area. For example, there were frequent disparities between the organisation’s configuration of personhood and the actual needs of the person. Where people with dementia needed social interaction and individualised psychosocial interventions, organisations focused on routines and completion of tasks. Maintaining dignity and respect were important to people with dementia, whereas the organisation imposed unrealistic demands on staff which restricted the amount of time spent with each resident. At the level of daily care provision, although staff were often able to meet physical needs, they frequently struggled to find time to address psychosocial needs such as spiritual care, or were not trained to provide such care. As a result of these disparities between configurations of personhood, organisational needs were frequently given priority over needs of the person, particularly psychosocial needs.

Personhood is the foundational concept of person-centred dementia care, however, in spite of the widespread implementation of programs under the person-centred care banner, personhood is not widely understood or considered in the literature. Many person-centred care interventions are discussed in the dementia care literature, but there is a scarcity of evidence on the benefits of stepping back from models of care to focus on personhood itself, and to ask specifically, how is this situation for this person right now? Rather than focusing on a specific program or intervention, this doctoral research focuses on personhood in the context of aged care organisational culture. The following chapter discusses the theoretical framework used to undertake this research.

Chapter Three: An Opportunity to do Better

Theories of Personhood

The prime task of dementia care … is to maintain personhood
(Kitwood 1997a, p. 84)

The theoretical framework of dementia care created by Kitwood (1997a) is discussed in this chapter. Driven by deep frustrations with dementia care practices at that time, it was Kitwood who concluded ‘that this is a time of opportunity to do something better’ (Kitwood 1995a, p.7). Consequently, improvements were made, but, as was found in the literature review in the previous chapter, much work is yet to be done to consistently maintain personhood in dementia care. So, twenty four years since Kitwood’s declaration of an opportune time, frustrations around dementia care continue. It is time, therefore, to once more declare that another opportunity to do something better is created through this doctoral research.

In a sense, current challenges were anticipated in 1997. At that time, Kitwood was frustrated that the acceptance of personhood in dementia care practices was facing several obstacles, hence progress was very slow. In light of this frustration, he predicted a possible state of affairs for the future of dementia care (Kitwood 1997a, p.133):

> It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 might be as bad as it was in 1970, except that it would be varnished by eloquent mission statements and masked by fine buildings and glossy brochures.

Some people today - in 2019 - might say that, in many cases, reality has exceeded Kitwood’s prediction. It seems that opportunities to do better continue to exist.

The focus of this research is to place the practice of personhood care at the frontline of residential dementia care. Although the benefits of personhood practice have been debated in the literature for over twenty years, the fundamental theories and principles of personhood are not yet standardised practice across the aged care industry, therefore, reconfiguration of personhood practice is required. Kitwood, whose theories provided direction for this study's examination of the culture around personhood, was greatly influenced by the client-centred therapy work of Carl Rogers. Following a discussion on Rogers' work, this chapter focuses on Kitwood's philosophies and theoretical framework for dementia care.

3.1 Rogers and Client-Focused Therapy

Carl Rogers (1902–1987) was an American psychologist who revolutionised psychotherapy through his introduction of client-centred therapy (Rogers 1961). His life's work was based on a deep-seated belief in the human potential for growth (Rogers 1980). Although Rogers initially developed his work for use within the counselling and education arenas, exploration of his philosophies reveal significant relevance and appropriate applications for the aged care environment.

Rogers spent time working as a scientific investigator in the field of psychology as well as acquiring extensive experience as a therapist, becoming 'increasingly conscious of the gap between these two roles' (Rogers 1955, p.267). He saw advantages in a therapist regarding the client as a person rather than a client (p.271), yet also knew that science focuses on objects, meaning that 'everything it touches is transformed into an object' (1955, p.273). Although deeply aware of the value of science as an important tool, he was concerned about the ability of science to 'lead toward manipulation' (1955, p.273). Therefore, after many years of engagement in therapy with people often experiencing deep needs, Rogers sought to formally articulate ‘a theory of psychotherapy, of personality, and of interpersonal relationships’ (Rogers 1957, p.95) which would embrace and incorporate his experiences.

Opposing the undercurrent of authoritarianism pervasive within the helping professions at that time, Rogers was concerned that psychotherapy was endorsing a form of social control (Zucconi 2011, p.4). He wrote: ‘I object to the process of depersonalisation and dehumanisation of the individual which I see in our culture. I regret that the behavioural sciences seem to me to be promoting and reinforcing this trend’ (Rogers 1968/1989, p.266). Consequently, he introduced a humanistic approach which recognised that, while the therapist acts in a supporting role, the client would always be the most powerful figure in this approach to psychotherapy (Rogers, 1961).

Rogers continued to challenge psychotherapists to use the term client rather than patient because ‘it seems to come closer to conveying the picture of the person as we see it … since it avoids the connotation that he is sick’ (Rogers 1951, p.7). In this manner, client-centred therapy focuses on the person rather than the problem, aiming to achieve ‘greater independence and integration’ for the person (Rogers 1978, p.6). This method facilitated empowerment for the client because, as Rogers stated: ‘It is not that this approach gives power to the person; it never takes it away’ (1978, p.xii).

According to Rogers, the ideal environment for client-centred therapy was one in which a ‘person felt free from threat, both physically and psychologically’. This type of environment could be achieved through relationships based on deep understanding, acceptance and authenticity (BAPCA 2015). He had a particular interest in helping relationships ‘in which at least one of the parties has the intent of promoting the growth, development, maturity, improved functioning and improved coping with life of the other’ (Rogers 1961, pp.39-40). Rogers viewed such relationships as vital to therapeutic development and transformation (Brooker & Latham 2016, p.130).

An association and occasional working relationship with Martin Buber (1878-1965) resulted in Rogers feeling validated and supported in his advocacy for the establishment of helping relationships (Rogers 1980). Like Rogers, Buber placed great emphasis on the importance of relationships, believing that ‘all real living is meeting’ (Buber 2010, p.11). He maintained there are two ways of being in a relationship, choosing the contrasting terms *I-Thou* and *I-It* to describe these relationships (Buber 2010). Buber’s writings assist in understanding the nature of relationships, but his language is somewhat complex to comprehend. Here we are assisted by Westerhof et al. (2014), who offer valuable insight into Buber’s philosophy, and then apply his approach to examine interactions within an aged care environment.

According to Westerhof et al. (2014), Buber maintained there is no such thing as a separate person because ‘human beings are always in relation to the world around them’ (p.356), either within an *I-Thou* or *I-It* relationship. *I-Thou* relationships are typified by ‘true interest in the uniqueness of the other person to whom one is relating’ (2014, p.356). Conversely, *I-It* relationships imply objectification tending, therefore, to treat the other person as an object. Although Buber felt that too much emphasis on *I-It* relationships has the potential to be dehumanising, he considered they do play a vital role in maintaining ‘order and consistency in life’ (2014, p.356).

In professional relationships, a complex mix between both types of interacting and interaction exists. *I-Thou* interactions focus ‘on the other as an individual person with his or her own specific wants and needs’ (Westerhof et al. 2014, p.357), while *I-It* interactions focus on ‘methodical delivery of therapy, care, or knowledge to a client, patient, or student’ (p.357). Buber’s insights into these two modes of relating deepen our understanding of person-centred (*I-Thou*) and task-centred (*I-It*) encounters within a RACF environment. This perspective does not benefit either the caregiver or the resident. Rather it highlights the ways in which they move together through unobtrusive shifts between task-centred and person-centred modes of communication (2014, p.357). Characteristics of a relationship are determined by the nature of ongoing interactions (2014, p.356). Significantly, however, ‘the world of relations’ (Buber 2010, p.6) is established through *I-Thou* encounters.

Although familiar with each other’s work, Rogers and Buber did not meet until their public debate in 1957. In his opening remarks of the debate, Rogers commented: ‘it was only an hour or two ago that I met Dr Buber, even though I met him a long time ago in his writing’ (Buber & Rogers 1990, p.45). Discussing several ‘resemblances in their thought’ (p.44), they concurred that Buber’s understanding of an *I-Thou* relationship was similar to what Rogers saw as the ‘effective moments in a therapeutic relationship’ (1990, p.47).

A number of similarities existed in their views on relationships, and both believed in the importance of establishing a ‘world of relation’ (Buber 2010, p.6). Rogers stated that ‘a finely tuned understanding by another individual gives the recipient a sense of personhood, of identity’ (Rogers 1980, p.155), and noted that ‘Buber has also spoken of the need to have our existence confirmed by another’ (p.155).

Rogers maintained that feelings of loneliness and isolation could be overcome through meaningful encounters in which ‘we relate as persons, when we risk ourselves as persons in the relationship, [and] when we experience the other as a person in his own right’ (Rogers 1980, p.179). He equated these encounters to ‘what Buber has called healing through meeting’ - relationships in which a person experiences genuine meeting and acceptance (p.175).

Rogers and Buber shared similarities in their respective views on the ability of acceptance and confirmation to contribute to the success of helping relationships. Buber used the phrase ‘confirming the other’ to describe the act of ‘accepting the whole potentiality of the other’ and to recognise and know ‘the person he has been … created to become’ (Buber & Rogers 1990, p.60). Concurring with this idea, Rogers (1961, p.55) wrote that the phrase ‘confirming the other’ had meaning for him in the context of accepting a person ‘as a process of becoming’. Rogers later confirmed this idea when writing on the importance of empathy in relationships. He states that Buber spoke of ‘the need to have our existence confirmed by another. Empathy gives that needed confirmation that one does exist as a separate, valued person with an identity’ (Rogers 1980, p.155). It is clear that, in his development of client-centred therapy, Rogers drew inspiration and endorsement from the work of Buber, whose thinking he found to be ‘congenial’ (Rogers 1961, p.199), and whose concept of the *I-Thou* relationship he ‘was able to embrace’ (Merrill, 2008, p.8). They each had a focus on the person *(I)* in the context of others *(Thou)* and, therefore, on the facilitation and promotion of meaningful and healthy relationships.

In the context of this thesis, the interest is in the potential for Roger's and Buber's philosophies to provide guidelines for healthy relationships between persons living and working in the RAC environment. As moderator of the 1957 dialogue between Rogers and Buber, Friedman's (1994) summary of their respective views presents helpful models of interaction. Buber's belief in the importance of confirmation as a characteristic of relationships is summarised in this way: 'Although I cannot impose on you what your direction should be, I can listen and respond to you and thus, walking that stretch of the way with you, I can help you in your struggle' (1994, p.63). Similarly, Rogers placed much importance on congruence in relationships, paraphrased by Friedman in this manner: 'I will come to you and I will be concerned for you; I'll have empathic understanding of you, but I can only do so if I do it authentically as the person I am' (1994, p.63). Thus, adhering to the guidelines suggested by Rogers and Buber, interactions in a dementia care environment are characterised by listening, support, empathy and authenticity.

In the later stages of his career, Rogers pondered the main focus of his professional life and reflected on the variety of descriptions he had given to this theme over the years, such as 'nondirective counselling' and 'client-centred therapy'. As the areas of application had expanded and diversified, he now concluded that the label 'person-centred approach' seemed the most accurate (Rogers 1980, p.114). Following considerable success in the field of psychotherapy, Rogers and his colleagues could now see the potential for person-centred therapy in other areas where people were in relationships, such as management and patient care (BAPCA, 2015).

The work of both Buber and Rogers had a significant impact on the theories of Professor Tom Kitwood, an English academic who was a leading figure in the theoretical development of personhood and person-centred approaches in dementia care. According to Brooker and Latham (2016, p.16), Kitwood's adoption of the term 'person-centred' was 'a direct reference to Rogerian psychotherapy', in particular, its focus on authenticity in interactions. A discussion follows on Kitwood's work.

3.2 Kitwood and Person-Focused Care

Following a career in psychotherapy and psychology, Tom Kitwood (1937-1998) became interested in dementia care practices, and his ground-breaking book *Dementia Reconsidered* (Kitwood 1997a) was published a year before his untimely death in 1998. According to Killick (2016), Kitwood persistently advocated for fundamental change in the care of people living with dementia, and this revolutionary publication was 'a time bomb lobbed into the middle of the dementia establishment' (2016, p.6).

Being a highly skilled communicator, Kitwood's observation skills and ability to think clearly resulted in his development of a comprehensive and integrated model of personhood and dementia care (Woods 1999). He successfully contributed innovative insights to understandings of dementia and paved the way for future psychosocial research and practice (Killick 2016). According to Marshall (1997), Kitwood made a considerable contribution to dementia care through his capacity and skills to communicate about the experiences and needs of people living with dementia.

Building on the work of Kitwood, the argument of this doctoral study is that configuration and practice of personhood should be positioned at the forefront of dementia care. Recognising the reluctance of the aged care industry to fully adopt Kitwood's conceptual framework on dementia care, my original contribution to knowledge highlights societal and organisational cultures which stigmatise and undervalue people with dementia. In order to reverse this trend, this doctoral study advocates for dementia care to be reframed in a culture of personhood principles. Given the close alignment of this study with Kitwood's work, it is essential to closely explore Kitwood's philosophies and developments in the areas of personhood and dementia care.

Influences on Kitwood's Work

Even though Kitwood spent only ten years working in the field of dementia, his work has had a significant impact on contemporary dementia care. According to Baldwin and Capstick (2007), had Kitwood not died suddenly at the age of 61, it is almost certain he would have continued developing his approach to the understanding of dementia and the importance of personalised care.

As already noted, Kitwood's views on meaningful relationships within dementia care were partially influenced by Buber's thoughts on two contrasting modes of being in relationship. The terms *I-Thou* and *I-It* were chosen to describe these modes (Buber 2010). As noted by Kitwood (1997a), the terms *Thou* and *It* do not imply there are two separate types of objects in the world, 'rather the difference is in the method of relating' (1997a, p.10). Kitwood's interpretations of these relationship modes were that typical *I-It* interactions would consist of 'coolness, detachment and instrumentality', and would occur at a 'safe distance', therefore 'avoiding risks'

(1997a, p.10). On the other hand, he saw *I-Thou* relationships as ‘going out towards the other’ like a ‘journey into uncharted territory’ and comprising characteristics such as ‘self-disclosure’ and ‘spontaneity’ (1997a, p.10).

Kitwood (1997*a*) agreed with Buber’s thoughts that ‘to be a person is to be addressed as *Thou*’ (p.10), and that true connection is achieved through *I-Thou* interactions. Buber believed that ‘all real living is meeting’ (Buber 2010), and Kitwood (1997*a*) suggested that in such meetings ‘there is no ulterior purpose, no hidden agenda’, rather there is great potential for ‘openness, tenderness, presence and awareness’ (p.11).

In his quest to improve dementia care through the establishment of meaningful relationships, Kitwood (1997a) suggested it was necessary to view personhood through the lens of relationship if we are to comprehend dementia. He maintained that relationships with people with dementia which continue to impose an *I-It* mode of relating portray a ‘diminution of persons as a norm in everyday life’ (1997a, p.89). Rather than burdensome *I-It* connections, and, therefore, ‘the repeated failure to meet a person as *Thou*’ (p.89), Kitwood advocated for interactions which aim to nurture capabilities, strengthen positive feelings, and assist in healing psychosocial pain.

Because of the similarities in their thoughts, McCormack et al. (2012), believe that Kitwood drew on the work of Rogers to develop his theories on personhood in dementia care. Rogers (1980) made the eventual decision to label his work the ‘person-centred approach’ (p.115), while simultaneously maintaining his belief in the need for a ‘definable climate’ (1980, p.115) to facilitate effective engagement.

Likewise, Kitwood (1997a) based his work on an unwavering belief in placing the focus of care on the person rather than on their diagnosis of dementia, as well as providing an environment which supports quality of interactions and relationships.

The lack of attention to personal experiences of dementia in textbooks at that time resulted in Kitwood (1997b) being highly motivated in his search for theories to facilitate a deeper understanding of the subjective experiences of dementia. He struggled with the rationale for using traditional personality measurement tools because they were used mainly for classification and selection of people for purposes which did not necessarily benefit the person, effectively framing psychometric methodology as ‘a servant of the *I-It* mode’ (Kitwood 1997a, p.15). As an alternative, he believed in the need to recognise the individuality of each person and the high probability that each will have unique experiences (Kitwood 1997b).

Similarly, while working in the field of social psychology, British philosopher Rom Harré was frustrated with prevailing research methods in which ‘psychologists reconstructed the person so that persons could be treated as experimental subjects’ (Harré 1993, p.25). Harré noted with interest how ethologists transformed studies of animal behaviour by physically moving their research from laboratories out into the actual world in which animals and birds lived their daily lives (1993, p.26).

Human ethologists study behaviour of humans primarily in their natural setting using observational methods (Polit & Beck 2012). This ethological style of research appealed to Harré (1993) because it broke the tradition of experimentation in the way he had been promoting for social psychology. Subsequently, he adapted the method to create a new research paradigm known as ethogenics. Within an ethogenic framework, various concepts of an interaction are studied, including the person, actions, and act, resulting in a more accurate assessment about the dynamics and emotions involved in that interaction.

Kitwood (1997b) was drawn to Harré's ethogenic approach, where 'each individual is taken to be an agent and a meaning-maker' (p.14) and there is the ability to obtain a deeper level of detail than other psychometric methods. Kitwood went on to develop a 'broadly ethogenic model' (p.14) where someone with dementia is seen 'as a person in the fullest possible sense', and a 'sentient, relational and historical being' (Kitwood 1993a, p.541).

One of Kitwood's earliest publications sought 'to understand what it is to be human' (Kitwood 1970, p.7), believing that this question is the one that matters to us the most. Although also providing alternative world views to answer this question, he stated that humanism 'brings a spirit of calm and order into a world where violence and chaos are escalating' (1970, p.47). From this point on, Kitwood (1995a) relentlessly advocated for a replacement of the 'old culture' of dementia care, describing it as a culture of 'domination, technique, evasion and buck-passing' (p.11), resulting in an authoritarian and alienating model of care.

Kitwood's Critique of an Authoritarian Culture

Kitwood was critical of an authoritarian culture of dementia care because it was based on a medical model which, for the most part, ignored personal and social components fundamental to the person with dementia (Kitwood 1998a, p.23). He termed this model 'the standard paradigm' (Kitwood 1989, p.23), which he described as having ‘several major anomalies’ and, at times, fell into ‘blatant reductionism’ (Kitwood 1997a, p.20).

The standardised authoritarian culture of dementia care originated from societal structures during the 17th century when the focus was on production and profit. As a result, large numbers of marginalised individuals were removed from mainstream society and placed in asylum-like institutions (Kitwood 1995a, p.7). During that period of time, which Foucault (1965, pp.38-64) described as ‘the great confinement’, progressive patterns of treatment methods laid the foundations of ‘uncare’ which featured in this alienating culture of dementia care (Kitwood 1995a, p.7). Although most of these institutions had ceased to operate, Kitwood’s concern was that society would see the harsh standards of the past reconstructed, especially given the ‘shallow, technical and money-obsessed mentality of our times’ (1995a, p.7).

Environments operating under such a culture were characterised by ‘a sense of deadness, apathy, boredom, gloom and fear’, with staff often appearing to be ‘patronising, cynical and uninvolved’ (Kitwood 1995a, p.7). Occurrences of detachment, disconnection and alienation were part of this authoritarian culture, contributing to the distancing of human beings (Kitwood 1995a, p.11) and causing the ‘person’ to virtually disappear (Kitwood 1993a, p.541).

According to Kitwood (1995a, pp.8-11), characteristic of this culture were attitudes which:

- perceived dementia care as a backwater
- saw no recognition of the impact of human environment on a person with dementia
- disregarded personhood, therefore limiting dementia care to physical care only
- aimed to control and manage behaviours deemed to be problematic
- held a blatant disregard for respecting the personhood of care staff

Kitwood strongly believed that personhood needed to be the dominant focus in dementia care, and clearly saw the dominance of authoritarianism and alienation as an opportune time to significantly improve care practices. He formed the opinion that much more could be done to help people living with dementia than was generally assumed.

Discourses of Dementia in the Standard Paradigm

Over the years, dementia has been constructed by an assortment of discourses, the most notable one based on medical science (Kitwood 1993b). Clearly, ideas and proposals are conveyed through discourse, often leading to significant outcomes. Discourse is a powerful tool within organisations and will often determine how people unite together to deal with situations that are often very painful and overwhelming. As noted by Kitwood (1993b), supported and maintained through control and reputation, the impact of the dominant discourse generated by medical science has a direct influence on all people living with dementia and those caring for them.

Medical Discourse

Because the framework for understanding dementia was based on a medical model, processes and care were predominantly viewed from a technical perspective. Kitwood labelled this concept the ‘standard paradigm’ (Kitwood 1997a, p.1). He found the medical model to be flawed and incomplete in its premise of a ‘linear causal relationship’ suggesting that dementia is a consequence of neuropathological issues alone (Kitwood 1990a, p.34). He was critical of the fact that the standard paradigm overwhelmingly focused attention on the brain rather than on personhood, meaning that most work is done at a ‘technical rather than personal’ level (Kitwood 1992, p.131). Although valuable for scientific research, Kitwood (1992) believed that the medical approach to dementia had been substantially inadequate in providing constructive theoretical insight into dementia care practices.

Undoubtedly, medical science has made enormous contributions to the field of dementia, providing very complex depictions of the progressive nature of dementia and its various impacts (Kitwood 1997a, p.22). Medical research identified that ‘dementia is a disease process in the brain’ and not part of the normal ageing process (Kitwood 1993b, p.52). Intensive research provided clarification and focus for collective concern and support, as well as education for doctors about their responsibilities when a person presented with indications of cognitive impairment. Although the medicalisation of dementia offered some clarification, Kitwood (1993b, p.53) raised questions about the limitations of this medical model, claiming it to be significantly inadequate (Kitwood 1997a, p.35). He was also critical that diagnoses of dementia focused only on the brain, with ‘the crucial question of how brain and mind are related’ being mainly ‘ignored or bypassed’ (Kitwood 1993b, p.53), believing instead that thorough attention must be given to the whole person.

While supportive of the need for a paradigm in order to address issues around dementia, Kitwood was critical of the hypothesis on which the medical model was based, stating it was ‘logically flawed’ and did not contain the entire spectrum of evidence available (Kitwood 1997a, p.35). He challenged the ‘simple linear causation’ (Kitwood 1993b, p.53) theory underpinning the medical discourse, which is expressed as:

$$X \rightarrow \text{neuropathic change} \rightarrow \text{dementia}$$

In this linear equation, the identity of X remained unexplained, with some ‘controversy over whether one or several causal agents are involved’ (1993b, p.53).

X does, however, represent a ‘failure of blood supply at the capillary level’ (p.53), while neuropathology is defined as ‘the study of human nervous tissue’ (Kitwood 1997a, p.22).

Critical of the simplicity and narrowness of this linear causal theory, Kitwood maintained that the nature and progression of dementia reach far beyond neuropathic changes. As an alternative, he suggested that a new framework was needed, preferably incorporating ‘personal experience and social psychology’ (Kitwood, 1997a, p.36) alongside brain function.

Sharing the same view as Kitwood, Sabat (2012) believes the medical model places emphasis on ‘the disease the person has’ rather than ‘the person the disease has’. In effect, this medical approach to dementia overlooks the person’s ‘intact cognitive and social abilities’, and education is limited to medical knowledge about the disease (2012, pp.96-97). From this perspective, the person with dementia is restricted to neurological issues only, thus reducing them to a person with deficits and impairments.

Kitwood (1997a) was concerned that the standard paradigm did not present an accurate and realistic picture of people living with dementia, such as ‘the diversity of their backgrounds, personalities and ordinary lives’ (p.37). Similarly, this paradigm offers no framework for providing effective care for a person living with dementia, and, in fact, ‘leaves the caring process vague, opaque [and] untheoretised’ (1997a, p.37), thus offering few signs of hope for the future of dementia care. In this way, as expressed by Kitwood (1997a, p.37), the standard paradigm presents an ‘extremely negative and deterministic view' which would seem to reinforce the widespread perception that dementia is 'the death that leaves the body behind'.

Behavioural Management Discourse

Closely aligned to the medical construction of dementia, Kitwood (1993b) notes that a 'behaviour management' (p.54) discourse was formed by professional caregivers. The emphasis in this discourse was on supposed problem behaviours of people living with dementia, such as aggression, wandering, sexual indiscrimination, incontinence and sleeplessness. The task of caregivers was to reconfigure these behaviours 'into a more acceptable mould' (1993b, p.54). Kitwood (1993b) noted that, significantly, ways of addressing these so-called behaviours are repeatedly found in care policies and in the talk of professional caregivers.

'Them and Us' Discourse

The perceived need to manage behaviours implies that people living with dementia are seen as a problem because 'they do not fit comfortably into the structures to which we are accustomed' (Kitwood 1993a, p.543). Thus, these behaviours are interpreted as problems from the perspective of the healthcare professionals (Kitwood 1993b, p.62). According to Kitwood (1992, p.133), implications of a problem potentially set up a 'clear division between *us* (members of the 'normal' population) and *them* (people with dementia)'. There is no doubt that situations involving dementia sometimes cause problems, but instead of a '*them* and *us'* scenario*,* Kitwood (1993a) suggests that *we* are also part of the problem, therefore the situation should be viewed within an interpersonal context.

Kitwood’s Conceptual Framework

Recognising substantial problems with the standard paradigm of dementia care, Kitwood set about developing a new conceptual framework. One of the inadequacies of the standard medical paradigm of dementia is its failure to portray a full appreciation of the real person. Neither does it provide guidance on how to provide effective care for a person living with dementia (Kitwood 1997a). Although obviously valuable for research purposes, the medical model tends to focus on the brain and not on the person, conveying a technical perspective in preference to a personal focus. This perspective means that most care work is done at a ‘clinical rather than personal level’ (Kitwood 1992, p.131). Although, of course, there are various standards of care – some better than others – the medical paradigm places focus of care on the ‘disease process in the brain of someone, who as a person, remains unknown and irrelevant’ (Kitwood 1990a, p.49).

Research over many years clearly indicates that progression of dementia is due not only to neuropathology, with interpersonal and social issues also playing a large part (Kitwood 1998a). For this reason, Kitwood believed that an approach which was purely technical was no longer sufficient for providing good dementia care, and recognised that a theoretical basis was needed in which personhood is fully recognised (Kitwood 1993a). As stated by Jenkins, Ginesi and Keenan (2016), Kitwood subsequently developed a framework which continues to acknowledge that neuropathic change plays a part, but broadens the definition of dementia to incorporate other factors, all of which interact with each other.

An alternative to the medical model is a more realistic assessment of the progression of dementia. This perspective acknowledges that dementia is the outcome of a dialectical interplay between two factors. Firstly, neurological impairment sets ‘upper limits to how a person can perform’ (Kitwood 1992, p.132). Secondly, and with equal significance, the process of dementia is impacted by the ‘personal psychology an individual has accrued’, as well as the ‘social psychology with which he or she is surrounded’ (p.132).

Kitwood (1993a, p.541) expressed this conceptual framework in the form of an equation:

$$\text{Dementia} = \text{Personality} + \text{Biography} + \text{Health} + \text{Neurological Impairment} + \text{Social Psychology}$$

Personality refers to resources and aspects of coping styles and defences against anxiety; Biography is about life and its many changes; and Health refers to physical health status. Neurological Impairment is acknowledgement of a level of nerve damage which differs in impact ‘according to its location, type and intensity’. Social Psychology ‘makes up the fabric of everyday life’, and, importantly, takes into account whether it improves or reduces the person’s sense of ‘safety, value and personal being’ (Kitwood 1993a p.541). The process of dementia is now seen as a continuing interplay between both neuropathological and social-psychological factors (Kitwood 1997a, p.50).

Kitwood referred to his framework for understanding the progression of dementia as the ‘dialectical theory’. This theory introduces social psychology into the concept of dementia care because it is equally important, and occasionally more important, than the neuropathology (Kitwood 1990a, p.49). To some extent, the equation is relatively simplistic, but, on the other hand, it is effective in demonstrating the variety of indications, both cognitive and non-cognitive, which coexist with dementia. Of major significance to a person living with dementia, this framework clearly establishes that each person will travel their own unique course within his or her experience of dementia (Kitwood 1993a, p.542).

The benefits of a theory for dementia care are significant. Without a comprehensive theory, care practices are generally deficient in some areas, rendering them much less effective at the clinical, educational, and political levels. However, a complete theoretical foundation ‘provides awareness, a sense of value, and the basis for concerted action’, enabling the person living with dementia to be in a position of comparative wellbeing (Kitwood 1992, p.132). It was Kitwood’s wish that, as dementia care was increasingly developed with personhood as the focus of care, the medical model would become obsolete. As a result, increasing numbers of people with dementia would experience greater levels of personal wellbeing, including those with advanced cognitive impairment (Kitwood 1993c).

An Opportunity to do Something Better

Kitwood’s reflections on the dominant medical discourse led him to conclude ‘that this is a time of opportunity to do something better’ (Kitwood 1995a, p.7), and that a new discourse with personhood as the focus was essential. He envisaged that this new discourse would not be inferior to the dominant medical discourse, but that the medical discourse ‘would occupy a certain space within a framework that puts the person first’ (Kitwood 1993b, p.63).

Care

According to Kitwood (1997e, p.3), before the term ‘care’ was attached to the language of nursing, it was closely linked to the field of ethics. The ethical context of care means to value the person for who they are, to honour what they do, to respect the person's unique qualities and needs, to protect the vulnerable person from harm and danger, and to undertake actions that will nurture their personal being (1997e, p.3). Gadow's exploration of the ethical differences between curing and caring confirms that care is the 'alleviation of vulnerability', and often requires abandonment of the professional objectives entrenched in the medical model Gadow (1988, p.7). Since it is clearly appropriate that people with dementia need to be supported using this model of care (Kitwood 1997e p.3), dementia care practices should uphold such ethical principles (1997e, p.4). These principles are facilitated in some cultural environments, but, to a certain extent, are blemished and unrecognisable in other settings (1997e, p.3).

The concepts of caring and personhood are closely connected. As with caring, personhood has ethical foundations because 'it implies a standing or status that is accorded by others' (Kitwood 1997e, p.4). When an individual is not acknowledged as a person they are very likely to feel devalued, violated or abused, as was frequently the case in the complex and inconsistent tradition of the authoritarian culture of care (1997e, p.8).

Dementia Care

Dementia is an umbrella term which incorporates several progressive conditions, all of which negatively impact on memory, comprehension and behaviour. For this reason, and also the fact that each person experiences dementia in their own unique way, people living with dementia experience differences in individual cognitive strengths and weaknesses, and, consequently, areas of dependence. Therefore, traditional methods of providing care are not appropriate models for dementia care.

Several centuries ago (around 1500-1800), people who were deemed to be ‘mad’, ‘insane’ and ‘demented’ were confined to specifically built institutions (Foucault 1965, p.65), and, consequently, treated in a ‘deeply dehumanising’ manner (Kitwood 1997d, p.10). Moving into the 20th century, as human beings began to live longer, dementia became more prevalent. Those with dementia continued to be placed in institutions, and, on the whole, received very poor care. As stated by Kitwood (1997d), for many years little was done to improve quality of care, and the personhood of those with dementia was rarely given any consideration.

Contemporary literature informs us that the word ‘dementia’ is a broad descriptive term which indicates a ‘clinically identified condition’, and, importantly, refers ‘to the whole person and not to the brain’ (Kitwood, 1997a p.21). A person living with dementia is experiencing two kinds of change occurring concurrently. First, there are the gradual cognitive changes due to declining function in the brain, and evident in areas such as comprehension, memory and reasoning. Second, changes are occurring in the social-psychological environment, evident in fluctuating ‘patterns of relationship and interaction’ (1997a, p.20). According to Kitwood (1997a), the progression of dementia is the result of both types of change.

Within the medical model of dementia care, a diagnosis of dementia highlights the disease process in the brain of someone who, as a person, remains insignificant, and, therefore, has virtually disappeared (Kitwood 1990a). Hence, the medical sciences have tended to decontextualise the person and focused attention on behaviour and deficits. As a result, the real-life difficulties and dilemmas of the person were rarely given consideration, and actions deemed as problematic were merely accredited to the progression of disease in the brain (Kitwood 1993a).

The overall aim of dementia care is to care for the whole person and to ‘maintain personhood in the face of advancing cognitive impairment’ (Kitwood 1997d, p.18). Increasingly, there are signs that the person living with dementia ‘is being reinstated as a person’ (Kitwood 1993c, p.100), largely through growing recognition that they are living with a disability rather than being viewed as victims of psychiatric illness.

In spite of welcome advances in dementia care, many obstacles still exist including, to some extent, a ‘pitiful insufficiency’ of effective care provision (Kitwood 1993c, p.100). Caring for older people presents challenges at the best of times, and is made more difficult when ‘resources are cut to the bone’ and there is a predominant atmosphere of ‘resentment and demoralisation’ (Kitwood, 1990b, p.119). In looking to the future of dementia care, Kitwood (1997d) stressed the importance of establishing effective care practices based on the concept of personhood. He believed this must be achieved in spite of overwhelming challenges such as ‘negative traditions in care practice, the severe lack of public funding, and the many corrupting pressures of the market’ (1997d, p.21). Kitwood believed that lack of knowledge could no longer be blamed if effective care was not delivered. Rather, the reasons would be located in the inadequacies of the ‘social, educational, political and economic’ systems (1997d, p.21). On the other hand, if effective care were to be successfully delivered, positive indications would exist that it is possible to construct society on the qualities of integrity and compassion.

Personhood Theory

According to Kitwood (1997d), the most notable improvements in quality of life for people living with dementia are not from medical advances, but from the recognition of their personhood. He strongly believed that people living with dementia should remain ‘in the world of persons’ Kitwood (1989, p.32) and be seen as individual persons ‘in the fullest possible sense’ (Kitwood 1993a, p.541). However, he did recognise the potential for inconsistencies presented in this viewpoint. There is a strong sense that a person living with advanced dementia continues to be a person, yet, on the other hand, the progression of dementia seems to take personhood away. Kitwood (1992) believed, therefore, that these conflicting views indicate a need to pursue the nature of personhood and its place in dementia care.

Kitwood (1997a, p.7) was adamant about the need to acknowledge people living with dementia ‘in their full humanity’, and maintained that, rather than the focus being on the dementia which was often the case, the focus should be on the person. In the context of dementia, various descriptions and characterisations tend to diminish the person, creating a category for the purpose of convenience when, in actual fact, the situation is about a ‘unique and sensitive human being’ (1997a, p.7).

The concept of personhood needed a theoretical basis to provide a much-needed voice to those involved in dementia care (Kitwood 1997d). To commence filling this theoretical space, Kitwood described how personhood intersects between two types of discourse – namely ethics and social-psychology. Personhood serves its intended role when both its ethical and social-psychological meanings are taken into account. In its broadest sense, ethical discourse considers what should be done, and social-psychological discourse is concerned with how it should be done. Ethical discourse depicts the absolute value of each person, meaning that each individual has a responsibility to treat others with great respect, an obligation which sits alongside human rights policies. Social-psychological discourse is concerned with the circumstances of a person within a social group, and with concepts around self-esteem, stability and integrity (Kitwood 1997a).

Viewing personhood from each of these perspectives led Kitwood to define personhood as ‘a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust’ (Kitwood 1997a, p.8). Therefore, personhood is to be viewed as essentially social, and clearly signifies that persons are in relation to other human beings. Sitting alongside the social component is the ethical stipulation that being a person automatically incurs the status of being worthy of respect (Kitwood 1992).

However, in Kitwood’s mind, the ethical component did not satisfactorily clarify the question of who is a person, in particular whether someone with dementia is a person. He argued against the popular view that the concept of person was largely based on autonomy and rationality, claiming this view provided absolute validation for excluding those with serious disabilities from the ‘personhood club’ (Kitwood 1997a, p.9). In a similar vein, Stephen Post (2000) wrote that the ‘task of ethics is to include rather than exclude the vulnerable’ (p.81). Post believed that too much emphasis was placed on rationality and memory which, of course, ‘wrongly suggests an exclusion of people with dementia from the sphere of human dignity and respect’ (2000, p.4). Furthermore, he claimed that those who are cognitively fragile are ‘conveniently stigmatised as non-persons by those who are strongest of mind’ (p.5). Kitwood (1997d) also believed in the need for inclusion, and suggested that ‘emotion, feeling and relational capability’ (p.13) are more appropriate criteria for the concept of person than autonomy and rationality. From this perspective, people with dementia ‘are undoubtedly to be viewed as persons’ (1997d, p.13).

Having established that all individuals with dementia are, in fact, persons, Kitwood recommended several criteria for inclusion in a model or theory of personhood in dementia care (Kitwood 1997d, pp.13-14). From a social-psychological perspective, he suggested the following principles as being essential to a theory of personhood:

- The theory must be reflexive – the categories applicable to people with dementia must also be applicable to those who are engaging with them.
- The person must be viewed as a social being, not as an isolated individual as has often been the case historically. For this reason, Kitwood (1997d, p.14) maintains that ‘a moral theory that speaks of persons and obligations’ is more compelling than one which simply refers to individuals and their rights.
- The theory must reflect that people can change and develop throughout their lives.
- Recognition must be given to relevant psychological differences between people.
- It is essential that the theory is compatible with up to date neuroscientific evidence about how the brain develops and functions.
- The theory must acknowledge the psychological complexities of people who have dementia and address their needs.
- Ideally, the theory is able to instruct and educate about the nature and meaning of good dementia care.

Underlying all dementia care is the wide-ranging goal to maintain personhood in the face of advancing dementia (Kitwood 1997d), and, as the new culture of dementia care began to develop, consistent themes relevant to maintaining personhood started to emerge.

Integrating Personhood Principles with Dementia Care

One of the most significant themes in maintaining personhood is the acknowledgement of the uniqueness of each person, and Kitwood (1997c) believed this to be the main issue distinguishing ‘good care from bad’ (p.36). Each person has their own unique identity which is comprised of a combination of individual factors relating to such things as history, likes, dislikes, personality, values, abilities and interests (Kitwood 1997e). Dementia care requires an openness to such elements of uniqueness, and, as aspects of individuality are genuinely recognised, the dementia itself seems to be less significant. While recognising that advances had been made in dementia care, Kitwood (1997c) expressed disappointment in lingering aspects of the authoritarian culture which saw ‘eradication of personhood’ (p.36) due to non-appreciation of uniqueness in persons with dementia.

According to Kitwood (1997c), for the uniqueness of each person to be completely appreciated, both personal knowledge and empathy must be incorporated into care practices. An in-depth knowledge of the person’s life history paves the way for meaningful interactions. Equally important to know is information about their interests, preferences and experiences as well as an ability to interpret actions and reactions. An empathic relationship at a deep level requires ‘time, commitment and communication’ (1997c, p.38), and, when personal knowledge and empathy are combined in care practices, ‘miracles can happen’ (p.39). Strong recognition of uniqueness requires more than factual knowledge; it requires a deep openness to the individuality of the other person’s way of existing (Kitwood 1997e).

A second theme which assists in shaping care practices is the subjectivity of the person with dementia. With the deliberate intention of avoiding interactions which lean towards objectification, the knowledge and recognition of each person’s way of experiencing life is vital. Of course, it is not possible to truly know another person’s subjectivity, but an inquiring mind which asks: ‘What is it like for this person to be experiencing dementia?' (Kitwood 1997e, p.11), will assist in understanding aspects of the person's experience of events, interactions, feelings and emotions.

The third theme of relatedness seems to contradict the human trend of independence. However, personhood is relational and 'requires a living relationship with at least one other, where there is a felt bond or tie' (Kitwood 1997e, p.11). These close bonds or connections can be found in individual relationships as well as group connections and it is these relationships which maintain personhood. Unfortunately, the need for meaningful connections is often overlooked in dementia care, with many interventions being only 'short-term fixes, without regard for lasting attachments' (1997e, p.11). In many cases, the consequences of such care are loneliness and isolation for the person with dementia. On the other hand, good dementia care practices will provide opportunities for appropriate social connections and ongoing relationships which result in a feeling of 'coming home' (1997e, pp.11-12) for the person with dementia.

The Significance of Social-Psychology

The concepts of care and personhood can be connected through their ethical connotations. From a basis of ethical understanding, the status of personhood is granted by others, therefore it is possible for a human being not to be acknowledged as a person. As noted by Kitwood (1997e), in dementia care environments where personhood is not acknowledged, it is highly likely the person with dementia will feel devalued, abused, rejected and violated.

People with dementia become increasingly dependent on others to meet their psychosocial needs, with the nature and quality of social and interpersonal factors significantly impacting on the dementia process (Kitwood 1998a). Therefore, given that the purpose of dementia care is to preserve personhood in the face of advancing dementia symptoms (Kitwood 1997d), the social-psychological environment is crucial to the well-being or ill-being of the person with dementia (Kitwood 1996).

Kitwood's theoretical framework for the process of dementia clearly identified that social psychology plays an important role in dementia progression, with the process of dementia seen as a continuing interplay between both neuropathological and social-psychological factors (Kitwood 1997a). As discussed previously, Kitwood (1993a, p.541) expressed this framework as: Personality + Biography + Health + Neurological Impairment + Social-Psychology. Referring to the structure and substance of interactions and experiences on a daily basis, social-psychology takes into account whether those daily experiences improve or reduce the person's sense of safety, value and wellbeing. Traditionally, the significance of social-psychology in dementia care has been virtually disregarded, however, when it is incorporated into the framework as suggested by Kitwood (1993c), the consequences of good and bad care practice become very clear.

As a general rule, by the time the person is experiencing advanced dementia, three of the factors in this framework are already determined. Personality has largely been formed, the greater part of biography has been created, and neurological impairments are already present and, more than likely, will continue to advance. On the other hand, a person's health is variable to some extent, while social-psychology varies frequently depending on the social environment at any given time (Kitwood, 1993c).

While acknowledging that all people are potentially affected by negative interactions, Kitwood (1996) argues that, when a person's cognitions are intact, he or she has 'inner stabilisers' which help to defend against intrusion by anxiety and develop capacity for rational understanding. Thus, when most people are involved in hurtful or insensitive interactions, their inner resources will assist in balancing any negative consequences with factual knowledge. However, a person with advanced dementia is unlikely to possess the inner stabilisers necessary to assimilate the negativity arising from the interaction, a consequence which very likely contributes to the effects of dementia. Therefore, the social-psychology of the surrounding environment is particularly significant to the person with dementia as it contributes to their well-being or ill-being. A destabilising environment in which personhood is regularly undermined places a person with dementia in a vulnerable position and susceptible to negative social-psychological processes.

Although Kitwood (1997b) acknowledged there had been improvements in dementia care in recent times, he believed there was still care being practiced which did not produce real connections as espoused in Buber's *I-Thou* mode of relating. It seemed to Kitwood (1997e) that *I-It* modes of interaction had become so common that they were accepted as normal, and people with dementia were some of those most harshly affected. He pointed out the reasonably high likelihood of dementia care practices in existence which stipulated thorough assessments, care planning and service delivery without any of the *I-Thou* interactions of which Buber speaks. Therefore, in a healthcare environment where *I-It* modes of interaction are considered standard practice, it is possible for a person with dementia to rarely experience true acknowledgement, or to feel truly understood and comforted

(Kitwood 1997e). In these cases, a significant component of Kitwood's framework for dementia care is being either ignored or diminished.

While researching the psychosocial environment of dementia care, Kitwood discovered it is possible to identify the types of interactions which maintain personhood and those which undermine personhood. This identification exercise enabled Kitwood (1997a; 1998a) to create two separate lists of interaction types, thereby creating a framework for integrating personhood principles and dementia care.

Undermining Personhood

During observations of the authoritarian culture of dementia care, Kitwood identified several types of interactions which contribute to the undermining of personhood and described them as being indicative of a malignant social psychology (Kitwood 1998a). He intentionally chose the word 'malignant' to suggest a controlling social environment (Kitwood 1998a) which is seriously detrimental to personhood, and also has the potential to negatively impact physical health (Kitwood 1997a). However, Kitwood clearly stated that the term malignant did not suggest conscious or deliberate malicious intent by staff members. He noted that, for the most part, staff undertook their work with kindness, commitment and the best of intentions, notwithstanding they worked in challenging situations and were often under-resourced (Kitwood 1990a). Rather, he believed the malignancy to stem from strong cultural traditions, inherited from ingrained practices built around unawareness, ignorance and unrealistic workloads (Kitwood 1998a). The devastating effect on the person with dementia is what determines this type of social psychology to be malignant (Kitwood 1990a). Kitwood’s categorisations of interactions which form the basis of malignant social psychology are listed in Table 3.1.

Table 3.1: Interactions which Undermine Personhood

Interaction	Explanation
Treachery	The use of dishonest representation or deception in order to obtain compliance
Disempowerment	Not allowing a person to use the abilities that they have; failing to help them to complete actions that they have initiated
Infantilisation	Treating a person very patronisingly (or ‘matronisingly’); implying that a person with dementia has the mentality or capability of a baby or young child
Intimidation	Inducing fear in a person; the use of threats, commands or physical assaults; the abuse of power
Labelling	Using a category such as dementia as the main basis for interacting with a person and for explaining their behaviour
Stigmatisation	Treating a person as if they were a diseased object, an alien or an outcast, especially through verbal labels
Outpacing	The delivery of information or instruction at a rate far beyond what can be processed
Invalidation	Failing to acknowledge the subjectivity of a person’s experience, and especially what they are feeling
Banishment	Sending a person away, or excluding them – physically or psychologically
Objectification	Treating a person as if they were a lump of dead matter: to be pushed, lifted, pumped or drained, without proper reference to the fact they are cognisant beings
Ignoring	Carrying on (in conversation or action) in the presence of a person as if he or she were not there
Imposition	Forcing a person to do something, overriding desire or denying the possibility of choice on their part
Withholding	Refusing to give asked-for attention, or to meet an evident need
Accusation	Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation
Disruption	Intruding suddenly or disturbingly upon a person’s action or reflection; crudely breaking their frame of reference
Mockery	Making fun of a person’s ‘strange’ actions or remarks; teasing, humiliating, making jokes at their expense
Disparagement	Telling a person that they are incompetent, useless, worthless, etc., giving them messages that are damaging to their self-esteem

Source: Adapted from Kitwood (1997a, pp. 46-47); Kitwood (1993a, pp. 542-543).

Kitwood (1997a) maintained that interactions and relationships centred on malignant social psychology not only undermine personhood, but, along with neuropathological impairment, are major contributors to the progression of dementia. He noted that outcomes or interventions based on malignant social psychology practices are sometimes dismissed as normal existence in dementia care (Kitwood 1998a). This type of mindset often stems from those with good intent, but who may not have an accurate understanding of the nature of dementia (Kitwood & Bredin, 1992). Dementia care which is predominantly constructed around malignant interactions tends to devalue the person, and is, therefore, very likely to negatively impact their physical and mental health, particularly through increasing resentment, anger, grief and anxiety.

Maintaining Personhood

Kitwood observed that good dementia care seemed to be a network of spontaneous interactions merging and functioning in continuing development and renewal. The underlying tone of these interactions was warm and rich in feeling, and this type of environment appeared to maintain and increase personhood in various ways: through encouraging skills and abilities, reinforcing positive feelings, or facilitating in the healing of emotional issues (Kitwood 1997a). Because of the high potential for these types of communication to significantly reduce the negative impact of dementia, Kitwood (1998a, p.27) termed these interactions ‘positive person work’. Kitwood’s list of types of interactions which form the basis of positive person work are listed in Table 3.2.

When interacting with a person with dementia, these modes of interaction and forms of communication are undoubtedly beneficial to the maintenance of his or her

Table 3.2: Interactions which Maintain Personhood

Interaction	Explanation
Recognition	The person with dementia is acknowledged as a person, known by name, affirmed in his or her own uniqueness. However, recognition is not purely verbal – it need not involve words at all, and may be simply direct eye contact
Negotiation	People with dementia are consulted about their preferences, desires and needs, rather than being conformed to others' assumptions. Skilled negotiation takes into account the anxieties and insecurities that often pervade the lives of people with dementia, and the slower rate at which they handle information
Collaboration	Two or more people aligned on a shared task, with a definite aim in view. The hallmark of collaboration (or working together) is not something that is 'done to' a person who is cast into a passive role; it is a process in which their own initiative and abilities are involved
Play	Whereas work is directed towards a goal, play in its purest form has no goal that lies outside the activity itself. It is simply an exercise in spontaneity and self-expression, an experience that has value in itself
Timalation	An interaction which directly engages the senses by providing pleasurable stimulation, but in a way that respects a person's boundaries and values, for example, through aromatherapy and massage. The significance of this kind of interaction is that it can provide contact, reassurance and pleasure, while making very few demands. It is particularly valuable when cognitive impairment is severe
Celebration	The ambience here is unreserved and welcoming. It is not simply a matter of special occasions, but also creating opportunities for sharing in the beauty, fun and joy of living. An interaction in which any division between caregiver and a person with dementia comes nearest to vanishing completely
Relaxation	The interaction with the lowest level of intensity. Possibly in solitude, but, with their particularly strong social needs, many people with dementia are only able to relax when others are near them
Validation	To accept and acknowledge the subjective reality of a person's emotions and feelings without an obsessional concern with cognitive correction. Attempting to understand their entire frame of reference, even if chaotic, paranoid or filled with hallucinations
Holding	In a psychological sense, to provide a safe environment where hidden trauma and conflict can be brought out, and areas of extreme vulnerability exposed. A safe space where psychological pain can be experienced without feeling overwhelmed
Facilitation	Enabling a person to do what he or she would otherwise not be able to do, by providing those parts of the action – and only those – that are missing. The task is to enable interaction to get started, to amplify it and to help the person gradually to fill it out with meaning
Creation	A person with dementia spontaneously offers something to the social setting from his or her abilities and social skills, such as beginning to sing or dance
Giving	A person with dementia expresses concern, affection or gratitude, makes an offer of help, or presents a gift

Source: Adapted from Kitwood (1997a, pp. 90-92); Kitwood (1997d, p. 19).

personhood and overall wellbeing (Kitwood 1998a). In an environment which is favourable to general health, momentum and will-power is increased and levels of stress are minimised. Similarly, because quality care potentially improves nerve function, it is possible that some degree of neurological regeneration is enabled (Kitwood 1997a).

Within environments where personhood is consistently maintained, Kitwood observed various interactions between people who have dementia, sometimes without staff involvement. These communications appeared to have several positive outcomes, such as the formation and sustaining of relationships, and mutual exchanges of assistance. He also noted that, in many cases, verbal communication between people with dementia seemed irrational but this did not appear to matter because the essence of the interaction was at ‘a non-verbal level’ (Kitwood, 1998a, p.29). Fundamental to this approach to care is that people with dementia are enabled to participate in the emotions and relationships of life in spite of advancing dementia symptoms (Kitwood 1997d).

Psychological Needs

The various impacts of dementia on a person mean that, at some point, they will become considerably dependent on others, in both a physical and psychological sense (Kitwood 1998a). Human beings are fundamentally unable to function as persons unless basic psychological needs are met, and, significantly, these needs are closely aligned with the functioning of the nervous system. People with dementia are vulnerable to not having their psychological needs met because they are usually limited in their ability to take the necessary initiatives to meet those needs. As expressed by Kitwood (1997a), the basic psychological needs of people with dementia are comfort, attachment, inclusion, occupation and identity. All these needs are closely connected with interconnecting boundaries, and all are clustered within the encompassing need for love. Descriptions of these psychological needs are set out in Table 3.3.

These needs are present in all human beings but are not obvious most of the time. It is usually when a person is under enormous pressure or undergoing great adversity that psychological needs are outwardly discernible. As a general rule, these needs are relatively obvious in people with dementia because they are often more vulnerable and usually less able to take initiatives that would lead to their needs being met. The primary goal of dementia care is to maintain personhood in spite of advancing dementia, and the sensitive meeting of these psychological needs on an

Table 3.3: Psychological Needs of People with Dementia

Psychological Need	Description
Comfort	The need for tenderness, closeness, soothing of pain and sorrow, calming of anxiety, feeling of security. A need for warmth and strength, particularly when the person is dealing with a sense of loss.
Attachment	The need for feelings of attachment to others, particularly to achieve a sense of security when bonds have been broken. A need for a safety net, especially during times of uncertainty and anxiety.
Inclusion	The need to feel an integral part of a face-to-face group. If overlooked, decline, retreat and isolation are likely.
Occupation	The need to feel involved in the process of life that is personally significant and uses the person's abilities and powers. If overlooked, boredom, apathy and futility are likely.
Identity	The need to know who one is in cognition and in feeling, to have a sense of continuity with the past, and a narrative to present to others. Caregivers need to know details of the person's life history, and to possess the quality of empathy.
Love	The all-encompassing context essential for maintaining personhood and meeting psychological needs. A context dominated by this type of love portrays generosity, forgiveness and unconditional acceptance, without any expectation of direct reward.

Source: Adapted from Kitwood (1997a, pp. 80-84) ongoing basis will enable this goal to be achieved. The ultimate result is that the person with dementia will experience a sense of self-worth and feel valued by others, resulting in ongoing positive experiences (Kitwood 1997a).

Culture of a Dementia Care Organisation

When exploring Kitwood's comments on organisations which provide dementia care, it is important to remember that he was writing twenty years ago and, clearly, changes have occurred since that time. However, it is also important to note the context of his writing. According to Baldwin and Capstick (2007), most of Kitwood's publications were centred on the personal and relational aspects of dementia care and it was not until just prior to his untimely death that he began to expand his thoughts to include organisational culture. He did so in order to better understand the organisational frameworks within which dementia care was being practiced (Kitwood 1997f), and he would have very likely continued this line of research had his work not ended so unexpectedly (Baldwin & Capstick 2007). Consequently, Kitwood's personal thoughts on organisational culture and dementia care remain incomplete.

Nonetheless, consistent with the theme of this thesis, it is useful to consider Kitwood's preliminary views on culture, values, attitudes, and care practices at the organisational level. These views ultimately represent a benchmark which, ideally, can be progressed as new knowledge emerges, thus creating an evolving model of an organisation providing high standards of dementia care. As stated by Kitwood (1997a), the issue of care practices in dementia care can no longer be confined to a mentality which searches for 'technical fixes to human problems' (p.144). Instead, a broader search must be undertaken for practices which provide just and equitable solutions relevant to the real needs of people with dementia, and to which organisational culture must be prepared to adapt.

The term culture refers to structured patterns of thoughts and actions which provide meaning for a specific demographic or organisation. Each culture emerges as the result of adjustment to the environment, and Kitwood (1997a) identified three aspects of a culture especially relevant to dementia care. The first aspect is the organisation which carries its own principal interests and relationships of power and will usually operate to subtly defend the organisation’s current agenda or state of affairs. Second, are the acceptable standards and patterns of behaviour, or norms, especially in roles which are more visible, and the third aspect revolves around the principles and beliefs of the culture.

In advocating for a change from the authoritarian culture of dementia care, Kitwood (1997a) noted that established cultures are particularly resistant to change. As a rule, each organisation has its own established interests and operates in ways to justify those interests. Norms become internalised within the cultural environment and are adhered to almost instinctively. Therefore, any potential to change a culture entails challenges to freedom, rights and power, and will, more than likely, encounter deep internal opposition.

Kitwood (1997a) was pleased that some progress had been made in recent times in transitioning from the old to the new culture and was particularly appreciative of improved care practices which had virtually abandoned ‘gross psychological neglect’ and the ‘warehouse model of residential care’ (1997a, p.86). Yet he remained frustrated with the reluctance of organisations to bring about lasting cultural changes in acceptable forms of practice, possibly because of distortions in common beliefs about dementia as well as issues around organisational traditions and structures of power. Perhaps the biggest hurdle to overcome was the tradition of care for vulnerable people. He was mindful of historical attempts by individual campaigners to reform care, but with no culture in place to maintain their undertakings, their work was effectively ignored.

Another obstacle to permanent culture change was that financial issues were the dominant deciding factor in decision-making about dementia care. Updated styles of nursing homes may have appeared to deliver improved standards of efficiency and comfort, however, Kitwood (1997e) wondered whether it was more likely that the dehumanising trends of older institutions might be replicated as priority was given to ‘the relentless pursuit of profit’ (p.9). There is no doubt that dementia care is comparatively cheap when personhood is ignored. Expenditure is significantly reduced when psychological needs are ignored and behaviour deemed to be problematic is managed through sedation. Concerned about this disregard for personhood and the common practice of reducing staffing levels to minimise costs, Kitwood (1997a) maintained that dementia care which truly respects personhood ‘requires a typical staffing ratio of one to four’ and, where physical dependency is high, ‘a ratio of one to three’ (p.141). Kitwood (1997a) predicted that, given the costs of increased staffing levels, it is likely some organisations will claim that genuine respect of personhood is too expensive and will ignore the evidence, thus continuing to operate under the authoritarian culture of care.

It is possible, of course, for gradual internal modifications to be undertaken by staff who are genuinely committed to acknowledging personhood in people with dementia. However, for these practices to be embraced in a permanent change of culture, a commitment is needed by organisations to provide adequate resourcing in both financial and staffing areas (Kitwood 1997a). Essential to a culture of care which embraces personhood is a properly trained and supported workforce, especially in the areas of pay and conditions, teamwork, supervision, training and staff development, and quality assurance. Staff at all levels need to be adequately trained, not only for essential physical tasks, but also the psychological components of care, particularly the skills of meaningful interaction and engagement with people with dementia. Working in dementia care requires a high level of skills and knowledge, and the status of work must be raised and released from ageist stigma and connotations (Kitwood 1997a).

All organisations need to address their administration and management requirements, meaning that regulations and procedures influence the nature of daily activities. Equally, however, an organisation providing dementia care needs to recognise the need for flexibility and leniency in daily routines. Kitwood (1995b) found lower levels of wellbeing were observable in people with dementia in environments where the staff emphasis was on maintaining routines and procedures. Staff were also negatively impacted when their work environment revolved around the organisation’s routines, reporting that they often found themselves ‘in conflict with the needs of routines and physical tasks’ (1995b, p.154). Conversely, when organisational culture empowered staff to work flexibly and imaginatively, higher levels of wellbeing were observed and staff reported greater job satisfaction. Organisational cultures which persisted with a ‘relentless pursuit of profit’ (Kitwood 1997e, p.9) as their priority meant that people with dementia were particularly vulnerable to dehumanising models of care.

The progress in dementia care in the latter years of Kitwood's life obviously pleased him, and he was hopeful this trend would continue. He remained sceptical, however, that organisational culture would ever fully embrace the importance of personhood and, therefore, truly commit to resourcing dementia care with the necessary services, staff training and personal development. In acknowledging the enormity of the task ahead, Kitwood (1997d) recognised that some of the barriers to overcome included long-standing negative traditions and an acute lack of funding.

In spite of these barriers, Kitwood maintained his belief in the need for cultural changes, especially as he saw glimpses of enthusiasm and enjoyment in the new culture. He anticipated that the ultimate responsibility of changing organisational culture would be motivated by factors such as the gratification of working for improvements in peoples' lives, the satisfaction of commitment to a worthy cause that transcends oneself, and the inner peace that is the consequential outcome of integrity. As Kitwood noted (1997a, p.143), the spirit of these motivations far outweighs some of the motives that are frequently evoked in contemporary society, such as 'greed, self-interest, love of power and the fear of being found out'.

Personhood of Staff

The argument for unconditional recognition of personhood is well established in this thesis. When exploring organisational culture in dementia care, it is ethical and judicious to also comment on recognition of the personhood of staff members. Kitwood (1997a) believed that an all-inclusive culture of personhood is a vital component for any organisation providing dementia care. In other words, an organisation which states it is committed to the personhood of their residents must inevitably be committed to the personhood of staff. Disappointingly, Kitwood (1995a) discovered that some organisations who claimed they were committed to the new culture of dementia care did not, in fact, include personhood of staff members in their policies.

An obvious fact which is sometimes overlooked is that, just as each individual with dementia is a person, so also, each individual who works in dementia care is a person. This is a crucial point for all staff in RACFs, but is particularly vital for those working in dementia care. While staff clearly have responsibilities towards the organisation, likewise, recognition of the personhood of staff members must be incorporated into the culture of the organisation. Staff can only deliver effective long term care 'if their own personhood is acknowledged and nurtured' (Kitwood 1995a, p.10). If an organisation exploits and abandons their employees, it is very likely staff will treat people with dementia in the same manner. On the other hand, if employees are encouraged and supported and, consequently, feel their wellbeing is important to the organisation, they will convey those same standards of personhood values to the dementia care environment (Kitwood 1997a).

Research conducted by Kitwood, Buckland and Petre (1995) identified that the wellbeing of people with dementia is greatly enhanced by improving the motivation and morale of staff. Interviews with staff members revealed that most staff were committed to their work, but ongoing motivation was essential. Surprisingly, money was seldom named as triggering dissatisfaction. Rather, lack of motivation was more often linked to 'feelings of being restricted at work and lack of support' (1995, p.150). Generally, staff members upheld high standards in their work and often felt they needed more feedback on their performance as well as increased training opportunities. Significantly more must be done to increase the welfare and morale of staff, and organisational culture must enable training and development of staff to make the role of caregiver ‘fun, interesting and rewarding’ (1995, p.150).

Demands on a staff member’s personal resources are substantial, often with the requirement to spontaneously engage their own intuitions along with personal skills. Staff frequently need to consider the needs of several people simultaneously, and the moral dilemma experienced by staff as they attempt to address all needs in a timely manner has been noted by Kitwood (1998b). Stress and burn-out are likely outcomes for staff members endeavouring to provide high standards of care but who are not appropriately supported by the organisational culture. Kitwood (1997a) noted that many outstanding staff members have resigned from dementia care because the culture of their employer conflicted with their own personal values.

Although Kitwood (1997a, p.115) recognised that personhood care was not in tune with contemporary trends such as ‘routinisation, standardisation and cost-cutting’, he believed there was ample evidence to justify the moral significance of personhood. Believing that aged care providers wanted to be seen as providing high quality dementia care, Kitwood’s hope for the future was that organisations would unequivocally adopt a culture of respecting personhood of residents and staff rather than merely maintaining a façade.

Kitwood’s Vision for Dementia Care

The aim of Kitwood’s framework for dementia care was to maintain a focus on the subjective world of dementia, and to provide care which addressed individualised needs of the person. Gaining insight from intense observations and listening, he wrote this imaginative depiction of the experience of a woman with advanced dementia living in residential aged care (Kitwood 1997b, pp.20-21):

> You are in a garden at the start of a summer's day. The air is warm and gentle, carrying the sweet scent of flowers, and a slight mist is floating around. You can't make out the shape of everything, but you are aware of some beautiful colours, blue, orange, pink and purple; the grass is green as emerald. You don't know where you are, but this doesn't matter. You somehow feel 'at home', and there is a sense of harmony and peace.
>
> As you walk around, you become aware of other people. Several of them seem to know you; it is a joy to be greeted so warmly, and by name. There are one or two of them whom you feel sure you know well. And then there is that one special person. She seems so warm, so kind, so understanding. She must be your mother, how good it is to be back with her again. The flame of life now burns brightly and cheerfully within you. It hasn't always been like this. Somewhere, deep inside, there are dim memories of times of crushing loneliness and ice-cold fear. When that was, you do not know; perhaps it was in another life. Now there is company whenever you want it, and quietness when that is what you prefer. This is the place where you belong, with these wonderful people, they are like a kind of family.
>
> The work that you do here is the best you have ever had. The hours are flexible, and the job is pleasant; being with people is what you have always enjoyed. You can do the work at exactly your own pace, without any rush or pressure, and you can rest whenever you need. For instance, there is that kind man who often comes to see you – by a strange coincidence his name is the same as that of your husband. He seems to need you, and to enjoy being with you. You, for your part, are glad to give time to being with him, his presence, strangely, gives you comfort.
>
> As you pass by a mirror you catch a glimpse of a person who looks quite old. Is it your grandmother, or that person who used to live next door? Anyway, it is good to see her too. Then you begin to feel tired; you find a chair and you sit down, alone. Soon you become aware of a chill around your heart; a sinking feeling in your stomach – the deadly fear is coming over you again. You are about to cry out, but then you see that kind mother-person is already there, sitting beside you. Her hand is held out towards you, waiting for you to grasp it. As you talk together, the fear evaporates like the morning mist, and you are again in the garden, relaxing in the golden warmth of the sun. You know it isn't heaven itself, but sometimes it feels as if it might be half-way there.

Kitwood's vision was for a determined and sustained attempt to meet the psychological needs of people living with dementia within residential aged care. He felt that, if such an approach to dementia care became standard practice, people living with dementia would 'feel far better supported [and] far less alone' as they experienced a 'new chapter in life, with its own special delights and pleasures' (Kitwood 1997b, p.21).

3.3 Beyond Kitwood

Regrettably, Kitwood’s untimely death occurred while much of his work was still in the developmental stage, and it is almost certain he would have continued to progress his ideas (Jenkins, Ginesi & Keenan 2016). Consequently, many of his theories remained untested by him, and, in fact, a few months prior to his death, he commented that many of his views on personhood and dementia care needed to be validated by long-term research (Kitwood 1997a, pp.100-101). Of greater significance to him was the fact that dementia was now better understood, and that people with dementia had ‘begun to be recognised, welcomed, embraced and heard’ (p.133). Nevertheless, the enormity of the challenges ahead raised concerns for Kitwood (1997a, p.144), mainly because of the intensity of need and the massive size of the problem. He understood very well the need for constructive transformations in care practice but suspected that people generally would be deeply challenged by such a transformation. In particular, he was unsure of society’s ability to now accept the fact that human services, such as dementia care, could no longer be delivered from the perspective that persons are ‘consumer durables’ (1997a, p.144).

The essence of Kitwood’s work has been widely appreciated, with overwhelming acceptance and integration of his theories into dementia care. Unsurprisingly, his work has been the subject of a number of critiques, raising both positive and negative perspectives. As Professor of Geriatric Medicine at the University of Western Australia, Flicker (1999) viewed Kitwood’s book (1997a) as a ‘provocative book for the medical profession’ (Flicker 1999, p.2). A large area of concern for Flicker was Kitwood’s lack of supporting evidence for his theories. However, a more recent article co-authored by Flicker (Beer et al. 2010) suggests his criticism of Kitwood’s work may have lessened with time.

Following Kitwood’s death in 1998, his colleague and friend, Bob Woods (1999) paid a touching tribute to Kitwood’s life. Woods tells of his initial reservations upon reading some of Kitwood’s early work, when he questioned the validity of Kitwood’s ‘armchair theorising’ (1999, p.5) about the efforts of those providing dementia care. He was soon satisfied, however, that, if Kitwood ever was an armchair theorist, the armchair would be ‘located firmly in the day room of a residential home in the midst of people with dementia’ (1999, p.5). Woods paid tribute to Kitwood’s passion and integrity, and to his powerful legacy which demonstrates processes for integration of personhood and dementia care.

Both criticism and appreciation were the outcomes of an early analysis of Kitwood’s writings undertaken by Adams (1996), a health and medical sciences lecturer at the University of Surrey. While commending Kitwood’s focus on personhood, psychosocial factors and moral frameworks, Adams suggested there were a number of problems with Kitwood’s research methods which, potentially, reduce the validity and reliability of the data. Some of these perceived problems involved interview techniques and data analysis. In spite of these concerns, however, Adams (1996) believed that Kitwood’s work had the potential to inspire and substantially assist those working in dementia care, and he continued to draw on Kitwood’s theories in his own practice and research (Adams & Gardiner 2005).

As Professor of Psychology at Georgetown University, Steven Sabat (1994) has a long-term interest in Alzheimer’s disease. He welcomed Kitwood’s criticism of the medical model and agreed that not enough consideration had been given to the social environment of the person with dementia. He wrote that, to the extent that the environment is ‘unsupportive, impatient, unsympathetic or depersonalising’ (1994, p.158), personhood will be affected beyond any neuropathological damage. In referring to various case studies, Sabat (2001) consistently alludes to examples of Kitwood’s malignant social psychology (p.264), such as stigmatisation (p.107), disempowerment (p.107), labelling (pp.107, 123, 317) and invalidation (pp.107, 319). Kitwood’s own observation of depersonalisation (Kitwood 1997a, p.47) rings true for Sabat (2001, p.338) as he urges society to realise that ‘we as people deserve better’ (p.340).

Having worked as a communicator in the field of dementia for several years, John Killick (2016) believed that Kitwood instigated ground-breaking changes to dementia care. Although very supportive of Kitwood’s work, Killick acknowledged the existence of various critiques of Kitwood’s writings. Such criticisms included Kitwood’s apparent lack of understanding of real-life dementia care settings, as well as his significant focus on psychological aspects, possibly at the expense of ‘wider societal and economic movements’ (2016, p.7). Killick was also aware of criticisms suggesting that Kitwood’s concept of personhood was too limiting, and that his understandings of relationships lacked consistency. Killick, however, remained supportive of Kitwood’s exceptional achievements in dementia care, claiming that he had provided fresh understandings about dementia and paved the way for psychosocial care practices.

In his role as Professor of Practical Theology and Pastoral Care at the University of Aberdeen, John Swinton has worked extensively in the disability sector, which includes the field of dementia. Swinton (2012) acknowledged Kitwood's deep influence on dementia care practices, in particular his different ways of 'looking at, describing and defining dementia' (p.71). He agreed with Kitwood's views on the significant relationships between neurology, psychology and social interactions, and commented that, for the person with dementia, every neurological occurrence is simultaneously a psychological occurrence, meaning, therefore, the two occurrences are simply different manifestations of the same experience. Although supportive of Kitwood's belief that human beings benefit significantly from relationships, Swinton (2012) believes that Kitwood is mistaken in viewing relationality as a condition of personhood. Swinton maintains that people can exist separately from their relationships and should be valued solely because of their humanity. Given that Swinton's argument is stated within the context of a theological discussion, it is somewhat difficult to compare with Kitwood's thoughts, but, possibly, some confusion exists between the concepts of person and personhood. Kitwood clearly separates the two concepts, and believes that, from an ethical perspective, every human being is a person. On the other hand, he believes that personhood is a status rendered to one person by another through relationship (Kitwood 1997a). In a sense, Swinton balances out this argument in another discussion where he states that personhood is not an individual attainment, rather it is 'the product of a particular type of relational encounter' (Swinton 2007, p.46).

Ten years after Kitwood's death, two of his colleagues from the University of Bradford edited a compilation of Kitwood's articles and provided commentary (Baldwin & Capstick 2007). They acknowledged Kitwood's major influence on society's understanding of dementia, and, while admitting their commentary engages in both endorsement and criticism of his work, Baldwin and Capstick pay tribute to

Kitwood's 'originality and vision' (2007, p. xv). Their critique reveals Kitwood's non-resolution of some themes, the diversity of theoretical approaches, and inconsistencies in his work (2007, p. xviii). As stated by Baldwin and Capstick (2007), in no way does Kitwood hold the key to every aspect of dementia care and, as is to be expected, dementia care and practices are moving on. However, they unreservedly acknowledge that Kitwood 'contributed greatly to our understanding of dementia and the practice of dementia care' (2007, p.16) through his research programs, data and activities.

Indeed, Kitwood's work continues to make significant contributions to dementia care research and practices. In recent times, Kitwood's theories have been used to frame practices around topics such as: effects of interactions (Beerens et al. 2018); ethical practice in dementia care (Mitchell 2019); gender issues in dementia theory (Sandberg 2018); human rights (Cahill 2018); institutional care (Kristiansen, Rasmussen & Anderson 2019); person-centred care (Chenoweth et al. 2019; Fazio et al. 2018); and professional caregivers' perceptions of awareness in advanced dementia (Rice, Howard & Huntley 2019). Thus, Kitwood's work remains relevant and influential in contemporary dementia care.

Brooker's Development of Kitwood's Theories

Professor Dawn Brooker (Brooker et al. 2014; Brooker et al. 2016; Brooker & Latham 2016) has been significantly influenced by Kitwood's work on personhood and dementia care, and, having spent many years at the Bradford Dementia Group, she now heads the Association for Dementia Studies at the University of Worcester. Her extensive practice development and publications continue to build on Kitwood's work, and she believes that his theories form the foundation for person-centred care as it relates to people with dementia (Brooker 2004).

Kitwood used the term ‘person-centred’ to integrate relationships and communication in dementia care (Brooker & Latham 2016, p.16). In his writing, however, Kitwood rarely refers to the term ‘person-centred’, concentrating mostly on the term ‘personhood’ as the foundation for care. As discussed earlier in this thesis, personhood is the recognition that an individual is a person and, therefore, deserving of the status of personhood. Characteristics of person-centred care have been developed from Kitwood’s theories on personhood and, as stated by Brooker and Latham (2016), person-centred care aims to maintain and foster personhood. People with dementia are at risk of having their personhood destabilised, hence the need for effective person-centred approaches in dementia care (Brooker & Latham 2016).

The term person-centred care has now become widely accepted as the standard for dementia care in many countries around the world (Brooker & Latham 2016). In spite of this appreciation of its value, however, person-centred care remains difficult to define, and seems to ‘mean different things to different people in different contexts’ (Brooker 2004, p.216). Consequently, as stated by Brooker and Latham (2016), there is often a wide gap between the language and the reality of person-centred care. In response to misinterpretations of person-centred care as visualised by Kitwood, Brooker (2004) developed a definitive equation to clarify the necessary components of person-centred care. These components are set out in Table 3.4.

Brooker continues to develop Kitwood’s work by valuing the personhood status of people with dementia and those who care for them, the psychological needs of

Table 3.4: VIPS Definition of Person-Centred Care

	Description
V	A **value** base that asserts the absolute value of all human lives regardless of age or cognitive ability. This assertion obviously includes all people with dementia and those who care for them.
I	An **individualised** approach to care, recognising uniqueness.
P	Understanding the world from the **perspective** of the person identified as needing support.
S	Providing a **social** environment that supports psychological needs.

Source: Adapted from Brooker & Latham (2016, p. 12)

people with dementia (Brooker & Latham 2016), and the significance of relationships and communication in personhood (Brooker & Latham 2016; Houghton, Murphy, Brooker & Casey 2016). Of particular relevance to this study is Brooker's agreement with Kitwood that the organisational culture is a key concept in providing quality dementia care (Killett, Burns, Kelly, Brooker et al. 2016).

The significant contribution by Professor Tom Kitwood to the field of dementia care has resulted in substantial improvements to care practices. Some of these improvements occurred during his lifetime, a fact he very much appreciated. He was concerned, however, for the future direction of dementia care if appropriate resourcing was not available. The release of his major publication (Kitwood 1997a) just prior to his untimely death paved the way for other researchers to build on his work, of which this doctoral thesis is a part.

Having discussed early influences on Kitwood's thinking, this chapter has explored his critique of the traditional understanding of dementia and standard medical model of dementia care. In response to this critique he created new frameworks for care based on his view that the progression of dementia is determined as much by the person's social environment as by any neurological impairment. Motivated by his longstanding belief that dementia care must focus on the person rather than on the diagnosis of dementia, he strongly advocated for the integration of personhood and dementia care.

Kitwood identified several forms of interactions between residential care staff and people with dementia which either undermine or maintain personhood in dementia care. In declaring that the primary goal of dementia care is to maintain personhood in spite of advancing dementia, he identified psychological needs of the person with dementia, the meeting of which enable this goal to be achieved. According to Kitwood (1997a), the culture of an organisation providing dementia care must be such that it supports and resources staff to effectively enable personhood care, as well as recognising the personhood of staff members themselves.

In spite of some criticism of his theories, Kitwood’s work continues to be foundational to research, policies and processes within dementia care to this day (see, for example, Beerens et al. 2018; Cahill 2018; Cooke 2018; Fazio et al. 2018; Goldberg et al. 2018; Rapaport et al. 2018; Vernooij-Dassen, Moniz-Cook & Jeon 2018). However, there are still occurrences of care which do not support the personhood of people with dementia or those caring for them, resulting in the need for further moral and ethical improvements in the culture of dementia care organisations. For this reason, it has been timely to revisit Kitwood’s philosophies and theories in order to research current cultural perspectives of those involved in dementia care. It seems appropriate to close this chapter with some of the final words written by Kitwood (1997d, p.21):

> Among the historically new features of our time, none is more significant than the widespread presence of people with dementia. If we fail them at this point, it will not be because of lack of knowledge, but because our social, educational, political and economic arrangements are inadequate to the task. If we succeed, it will be

> one of the most hopeful signs that it is yet possible to build a society in which compassion and integrity prevail.

The strength and applicability of Kitwood’s theoretical framework to investigate the reconfiguration of personhood practice in residential dementia care has been established in this chapter. According to the results of the literature review in Chapter Two, the basic needs of people with dementia today closely resemble those of twenty years ago when Kitwood created his conceptual framework for dementia care. The psychological needs he identified, along with the nature of interactions which either maintain or undermine personhood continue to be relevant to contemporary dementia care. Through his many publications, Kitwood provided strong evidence for personhood to be a dominant feature of dementia care, yet more than two decades later, many people with dementia struggle to be recognised and to have their personhood maintained.

As mentioned previously, just prior to Kitwood’s untimely death, he was expanding his understandings of the alignments between organisational cultures framing dementia care practices. This doctoral study contributes to the body of work which has continued to research these connections, and, therefore, the investigation of organisational culture is an important component of this study. Thus, the need to select research methods with the capacity to explore cultures was essential. The next chapter discusses the methodologies and methods used in this study to explore the current cultural configurations of personhood practice in residential dementia care.

Chapter Four: Methodological Structures

The Power of Identification

A groundswell of discontent around several aspects of dementia care exists in society. But this discontent regularly encounters strong cultural structures of resistance to fully implement a standardised personhood approach to care. As a means of effectively overcoming these constructs of resistance, this doctoral study applies appropriate methodological structures to investigate a reconfiguration of the cultural framework around dementia care. The need for such reconfiguration is well established.

As stated in the previous chapter, the prediction was made that society might continue to fail people with dementia (Kitwood 1997d). In today's world, not all people with dementia experience failure in their care needs, but there are many who do. So, for as long as society is failing any person with dementia, the opportunity exists to do something better. No longer, in 2019, can society say this failure is due to 'lack of knowledge' (Kitwood 1997d, p.21). Rather, failure is due to the inadequacies of 'social, educational, political and economic arrangements' as stated by Kitwood (1997d, p.21). These are major societal issues, controlled by powerful influences, therefore, strong and compelling arguments are needed to cease this ongoing failure of people with dementia.

To counteract this powerful domination of societal issues, strong frameworks and methodologies are needed to identify and characterise the negative cultural influences of dementia care practices. Thus, in order to achieve the aim of this doctoral research, which is to investigate the reconfiguration of personhood practice in residential dementia care, it is necessary to explore the current culture around personhood in residential aged care facilities. This chapter describes the research strategies for this investigation and provides justifications for their use. A qualitative approach was adopted using the methodology of ethnography. Therefore, the philosophical assumptions underpinning qualitative research will be discussed, along with the ethnographic methods used to gain cultural understandings of the settings. The outline of the chapter is adapted from Denzin and Lincoln's (2005; 2018) framework of the research process which portrays the progression of a qualitative study and justifies the choice of ethnography to explore the culture within residential dementia care.

Research is a means of generating knowledge, and the knowledge gained from social research is used to instigate policy change, make decisions on intervention strategies or implement new services (Erickson 2018). The research question for this study aimed to generate a deeper social understanding of the prioritisation of personhood in dementia care. The research was located in residential dementia care settings and had a particular focus on care practices relating to the personhood of people with dementia and the staff who care for them.

As discussed in the review of the literature (Chapter Two), there are numerous benefits for people with dementia when they regularly feel included, respected and valued as persons. However, the literature continues to reveal evidence of care practices which result in disrespect and disempowerment of people with dementia (see, for example, Anderson et al. 2016; Baldwin et al. 2015; Fetherstonhaugh et al. 2016; Stein-Parbury et al. 2012). Therefore, the main objective of this study was to examine the current culture around care practices relevant to personhood, while a further aim was to explore the organisation's configuration of personhood in order to understand where personhood sits as a priority amongst the other competing responsibilities of an aged care organisation.

The previous chapter detailed Kitwood's (1997a) conceptual framework of dementia care based on the integration of personhood theory into residential dementia care. Kitwood's framework forms the theoretical basis of this research. Qualitative research has been widely accepted as a way of understanding healthcare because of its ability to explore 'service provision, care delivery and organisational cultures' (Jones & Smith 2017, p.100) and was, therefore, appropriate for researching configurations and practices around personhood in dementia care.

As a qualitative research methodology, ethnography studies the cultural patterns of a group, aiming 'to understand another way of life from the native point of view' (Spradley 1979, p.3). Rather than following a specific study design, ethnographic data collection responds to what is found in the field, and data analysis seeks to gain meaning and understanding from the data. Through its emphasis on context and culture, ethnography is able to make links between daily interactions in the field and wider cultural constructions, making it especially useful for researching issues in healthcare (Jones & Smith 2017). The ethnographic methods of interviews, observations and field notes were chosen to help understand the cultures within the residential dementia care sector around personhood.

This chapter is divided into sections which describe and interrogate the phases of the qualitative research process undertaken for this study. These sections are adapted from a framework proposed by Denzin and Lincoln (2018, pp.55-62) which assisted with the synchronisation of the phases in this research process, in particular, the phases for undertaking ethnography. The adapted sections are : 1) Conceptions of the Researcher and the Researched; 2) Qualitative Research and Theoretical Perspectives; 3) Research Strategy; and 4) Methods of Collecting and Analysing Data. These phases of the research process are discussed throughout the remainder of this chapter.

4.1 Conceptions of the Researcher and the Researched

Ethnography positions the researcher in the organisational system for an extended period of time, during which attitudes of personal accountability and capacity for empathy are required (Denzin & Lincoln 2018). It is appropriate, therefore, to reflect on the understandings and position of the researcher as well as the researched, or the participants. As a starting point, this phase reminds the researcher – in this case, myself – of the role that my worldview and life experiences bring to this research. Behind each of the activities involved in the research process ‘stands the personal biography of the researcher, who speaks from a particular class, gender, racial, cultural, and ethnic community perspective’ (Denzin & Lincoln 2018, p.54). Therefore, my personal biography as it relates to this study needs to be declared.

Conceptions of Self

Born and raised in Australia, I am the proud mother of three adult children, grandmother of four amazing young people and life partner of an incredibly supportive person. The environments of residential dementia care are very familiar to me. Along with my siblings, I spent considerable time caring for my parents after they transitioned into a RACF where they lived for several years. Similarly, my parents-in-law were both living in RACFs at the time of their deaths, so I was regularly involved in residential dementia care as a family member witnessing the culture of these organisations.

My involvement in dementia care also includes my professional life as a chaplain in aged care facilities. In this role, I gained significant insights into the perspectives of many stakeholders, including residents and their families, management and all levels of staff. Adopting a broad and inclusive approach to the provision of spiritual care, I became increasingly interested in the needs and experiences of those living in residential dementia care and their family members. A personal wish to address the needs of family members was achieved in earlier research (Slape 2013; 2014), and this current doctoral study reflects a strong desire to reconfigure aspects of residential dementia care. The biography of this researcher, therefore, includes the hope that all people living in residential dementia care are respected as persons and enabled to maintain their identity and dignity through individualised care practices. Having declared my personal biography as the researcher, my conceptions, or understandings, of the researched participants in this study are now described.

Conceptions of the Researched

As familiar as I am with the various roles of participants in this study, my perceptions of them and their current situations could only ever be seen through the lens of my personal biography (Denzin & Lincoln 2018). Hence, I could only presume that my personal experiences of working in very similar environments and caring for people with dementia as they were, provided me with sufficient insight into their lived experiences.

The practicalities of the research methods however, provided extensive knowledge of their individual and collective experiences. Several staff members from various disciplines over two separate RACFs were involved in this research, participating through observations and interviews. Observations were undertaken of interactions between staff and residents, while staff members involved in interviews performed the roles of Enrolled Nurses (ENs), Lifestyle (LS) coordination and support, PCAs, Chaplains and senior management. With clear role definitions, all staff members had specific responsibilities in providing care for people with dementia, with some having more direct care with residents than others.

In general, staff at both RACFs were welcoming of my presence as a researcher, and, mostly, indicated their support for the research topic. However, there was a definite reluctance amongst PCAs to be involved in the interview process, despite some initially indicating their approval, but later withdrawing. Some staff were happy to have an informal conversation with me but would not consent to a taped interview, with no specific reasons being given. I can only presume these instances of unwillingness to formally participate in interviews were reflections of insecurities and confusion in a relatively volatile work environment. This presumption is supported by Koro-Ljungberg (2008), who notes that each participant in research has a connection with their environment, and this is likely to influence their interaction with the researcher. Conversely, if the researcher understands the research context, they are more likely to comprehend the meanings being communicated by the participant. As the researcher, I can verify that my familiarity with these environments did assist in understanding the ‘observations socially situated in the worlds of – and between – the observer and the observed’ (Denzin & Lincoln 2018, p.55). Having discussed personal conceptions of the researcher and the researched, the next phase of the research process explores the qualitative approach.

4.2 Qualitative Research and Theoretical Perspectives

A deep desire to discover and understand what other people are doing in daily life forms the foundations of the qualitative inquiry movement (Erickson 2018). Consequently, a qualitative approach was chosen for this research because of its ability to study the group life of human beings. This approach is frequently used in healthcare research where there is a concentration on personal experience, feelings, conflict or modification (Holloway & Wheeler 2010). Qualitative research is defined by Denzin and Lincoln (2018, p.45) as:

> a situated activity that locates the observer in the world. [It] consists of a set of interpretive, material practices that make the world visible. These practices transform the world.

It is these defined characteristics of visibility and transformation which underscore the appropriateness of qualitative inquiry for this research. As a form of social inquiry, a qualitative approach is well suited to researching the configuration and practice of personhood in residential dementia care. The dementia care environment is frequently silenced, misunderstood and stigmatised, thus enabling the actual experiences of people who live and work in such environments to often be disregarded and dishonoured by society (Nowell, Thornton & Simpson 2011; Talbot & Brewer 2016; Walmsley & McCormack 2016). Qualitative research gives voice to people by providing avenues for participants' personal narratives and language to be heard (Moser & Korstjens 2018). The flexibility and fluidity of qualitative research methods enable researchers to hear 'the voices of those who are 'silenced, othered, and marginalised … as the methods ask not only 'what is it?' but, more importantly, 'explain it to me … what's the significance'?' (Liamputtong 2007, p.7).

Quantitative methodology is guided by positivism which maintains that reality exists externally and must be examined through the fixed designs of scientific inquiry (Gray 2014). On the other hand, qualitative research is valued in the fields of nursing, social work, and education as a means of exploring the personal world of participants and understanding the processes that have led them to this current situation (Flick 2018). Theoretical perspectives of qualitative research will now be discussed.

Theoretical Perspectives

Qualitative researchers are guided by theoretical principles which combine beliefs about ontology, epistemology, and methodology (Denzin & Lincoln 2018). The relationship of these principles is hierarchical in that ontologies create the logic of epistemology, and the nature of methodologies is structured by epistemologies (Sarantakos 2013). The ontological and epistemological structures provide a framework or set of beliefs, that shapes the researcher's view of the world, and how the world should be known and studied (Denzin & Lincoln 2018).

Ontology is concerned with the study of existence and asks questions about what is meant by being, and the nature and constitution of reality (Denzin & Lincoln 2018; Gray 2014). Realism and constructionism are the two main ontologies (Sarantakos 2013). As ontology asks questions about what is real and what merely appears to be real, assumptions begin to develop about knowledge. Epistemology is the theory of knowledge and explores what counts as valid knowledge, and how knowledge is judged to be true. Methodologies consist of research designs which direct focus on research activity and on recognition and extraction of knowledge (Sarantakos 2013). Ontologies frame methodologies about what is to be studied, while epistemologies inform methodologies about where to seek specific knowledge. The relationships of these theoretical principles as applicable to social research are set out in Table 4.1.

Table 4.1: Theoretical Principles of Social Research

Theoretical Principle	Explanation	Questions
Ontology	Ontology deals with the nature of reality	What is the nature of reality? Is it objective, constructed, subjective? What does the research focus on?
Epistemology	Epistemology deals with the nature of knowledge	How do we know what we know? What is the way in which reality is known to us? What kind of knowledge is research looking for?
Methodology	Methodology deals with the nature of research and design and methods	How do we gain knowledge about the world? How is research constructed and conducted?
Research design	Research is the execution of research designs as constructed and guided by ontological, epistemological and methodological prescriptions	

Source: Adapted from Sarantakos (2013, p. 29)

Ontological, epistemological and methodological approaches of the same characteristics are organised into frameworks which determine the domain in which the research is to be conducted. Qualitative methodology, which uses adaptable research designs and qualitative methods, is guided by a constructionist ontology and an interpretivist epistemology (Sarantakos 2013).

Constructivism, used in ethnography, adopts the view that truth and meaning do not exist in an external environment but are constructed through the person’s interactions with the world. Impressions of the world are formed by human beings based on their cultural and historical context, therefore reality is constructed through interpretations and experiences (Sarantakos 2013). Denzin and Lincoln (2018) state that the constructivist framework adopts a relativist ontology (meaning there are many realities), a subjectivist epistemology (researcher and researched co-produce understandings), and a naturalistic methodology (in the natural setting). As explained by Gray (2014), people construct meaning in different ways, therefore, many valid interpretations of the same phenomenon can exist.

Interpretivism is a research approach used in ethnography that places attention on human beings, especially the way they interpret their lived experiences (Holloway & Wheeler 2010). The main aim of interpretive research is to generate meaning and make sense of the area of interest. Focus is placed on the participants' contextual interpretations and understandings as the researcher and participant work in conjunction with each other (Grbich 1999). In this way, people and their traditions are the subject matters of social sciences, enabling the researcher to comprehend the subjective meaning of social action (Bryman 2008).

The purpose of the methodology is to translate the ontological and epistemological theories into guidelines to show how the research was conducted (Sarantakos 2013). The qualitative interpretive methodology of ethnography was chosen for this study to guide the constructionist ontology and interpretivist epistemology, thus helping to explain human and social behaviour (Madden 2017). Ethnography is committed to understanding the context of the researched and their environment and, therefore, has the ability to go beyond establishing generalised rules. This commitment is crucial when personhood is taken seriously and was, therefore, appropriate for this study which is centred on the culture of personhood in residential dementia care. The research design which was sustained by these theories is now discussed.

4.3 Research Strategy

The aim of this doctoral study was to explore the culture around personhood within residential dementia care. Historically, ethnography emerged from the field of anthropology and is now used by researchers to study the social interactions and cultures of groups (de Chesnay 2015). While the term ‘ethnography’ typically refers to the researcher’s period of fieldwork, it also indicates the written representation of culture as interpreted and presented by the researcher (Van Maanen 1995). With its ability to describe and interpret cultural phenomena and behaviour, the ethnographic approach was an appropriate strategy for addressing the research question of this study (Leininger 2006; Markham 2018; Spradley 1979; Van Maanen 1995).

A research design brings motion to the frameworks of interpretation (Denzin & Lincoln 2018) by providing the qualitative researcher with a structure through which to understand and interpret social action (Madden 2017). Ethnographic fieldwork requires the researcher to spend considerable time in the natural setting in order to observe and understand the culture from the participants’ perspective. This ensures the research setting is the naturally occurring location of the phenomenon being studied and the researcher is able to appreciate the social world of the researched. While ethnographers bring an etic, or outsiders’, perspective to the natural setting, they also strive to acquire an emic, or insiders’, perspective in order to understand the view of the participants within that culture (Bergman & Lindgren 2018). The emic and etic views each contribute to a balanced connection between the researcher and researched. As explained by Harrison (2018), by giving opportunities to pass on cultural rules and categories, the emic view gives voice to those being researched, while the etic view enables identification of cultural ideas and patterns of which the research subject may not be aware.

The ethnographic approach provides guidelines for connecting the constructivist and interpretivist frameworks to appropriate strategies for collecting data. Constructivism requires interactions with the social world, and the ethnographer is guided to enter the natural setting and interact with participants through observations and interviews. Interpretivism is an ongoing process for ethnographers as they analyse and interpret data in order to gain an understanding of the culture. During location at the research site for an extended period of time, ethnographers hear and observe the realities of the natural world through their close connection to the persons and groups being researched (Harrison 2018). Phase four of the research process explores methods used for collecting and analysing data.

4.4 Methods of Collecting and Analysing Data

Ethnographic methods offer an approach which seeks to interpret and describe a culture or subculture. The ethnographer spends extended periods of time in disciplined fieldwork undertaking observations and interviews in order to discover what the social world is like for those being researched (Madden 2017). In this study, the chosen methods needed to move beyond the medicalisation of dementia to acknowledge the social context of residential dementia care ensuring that the integrity of personhood was maintained throughout the research process.

Fieldwork

Having worked in several RACFs, I found the environment of a residential dementia care unit to be familiar and comfortable. One of the challenges, however, was to acquaint myself with the role of researcher as opposed to my former role of staff member. In this research context, it was not my role to provide physical, emotional or spiritual support to residents, family members or staff members – a situation which gave rise to a degree of ‘emotional dissonance and a sense of self-estrangement’ (Bergman-Blix & Wettergren 2015, p.698).

On reflection, this dissonance emanated from frequent reminders about the tensions and conflicts within the aged care system and, according to the literature, other ethnographers have also experienced similar internal struggles during their fieldwork (Diamond 1992; Gubrium 1975; Powers 2001; Savishinsky 2003; Tinney 2008; Vesperi 2003). Challenges faced during ethnographic fieldwork include observations of the impact of dementia not being understood. People with dementia often find it difficult to communicate their needs, yet on those occasions when their communications are misunderstood or ignored, their actions are often interpreted as ‘behavioural’ problems which need to be managed (Borbasi et al. 2012), thus resulting in their personhood being undermined. Similarly, as noted by Tinney (2008, p.210), tensions between the perceived and actual needs of residents have been noted, which often result in routine-centred care ‘privileging the body rather than the whole person’.

As the fieldwork for this study progressed, it became increasingly possible for me to use these internal struggles to gain a broader perspective of the social setting. Because of a significant knowledge of daily life in residential dementia care, I was able to fluctuate between ‘stand[ing] in the shoes of others’ (Savage 2000, p.326) and ‘fight[ing] familiarity’ (Hammersley & Atkinson 2007, p.81) in order to construct meaning and provide interpretation to actions within the research setting. Consequently, an ability to practice reflexivity and maintain attentiveness to the research role, notwithstanding the familiarity of the environment, ensured an ongoing commitment to the social setting being studied (Pereira de Melo et al. 2014). As stated by Gelling (2014), reflexivity ensures that ethnographers uphold an awareness of how personal knowledge and experiences may impact their research, particularly when constructing meaning from the data.

Having divulged some of the personal challenges of fieldwork, attention is now directed to the collection of data during fieldwork. The ethnographic methods of observations, field notes and interviews were the ‘instruments employed’ (Sarantakos 2013, p.29) to collect data for this study.

Observations

Ethnographers observe human activities and the physical settings in which these activities occur to gain an understanding of the cultural behaviour of the group. Observation provides insights into the nature of interactions, views the bigger picture of context and process, reveals impacts of the physical environment on those being researched, and provides data on whether what people say they do is consistent with their actions. As noted by Jones and Smith (2017, p.98), the social context of the research setting can be understood through the art of ‘seeing, learning and interpreting reality’ of participants in their natural environment.

The researcher approaches the process of observation with an even and impartial mindset about what may occur and remains mindful of the purpose as stipulated by the research question. Non-participatory observation is unstructured in that flexibility exists around the exact location of the observer, the time of day, and length of each observation period (Hammersley & Atkinson 2007). However, a systematic plan is organised prior to the commencement of the study which stipulates location of the area to be observed, the specification of what will be observed, how the observation will take place and how data will be recorded (Sarantakos 2013).

Fieldwork for this study took place at two RACFs during 2015 and 2016. During discussions with each Site Manager (SM), plans for non-participatory observation sessions were put in place prior to commencement. As researcher, I was given permission to access both dementia units at any time for the purpose of observing interactions between staff and residents. To maintain the privacy of residents, observations were limited to public areas of the dementia unit which meant I was visible to those being researched but did not participate in delivering care to residents.

Field Notes and Personal Diary

During observational sessions, notes were written by hand and typed into field notes either later that day or the following day. These field notes became a significant component of the data set and analysis along with a personal diary in which I recorded personal thoughts and feelings about the observational experiences. Field notes are the traditional way of recording data during ethnographic observations and, as such, serve the purpose of mapping ‘the ethnographer’s evolving understandings and perceptual experiences’ (Harrison 2018, p.75). The actions of people and descriptions of activities are recorded in the field notes for future reflection, analysis and interpretation about the culture of the group.

In a separate activity to interviewing, I engaged in several informal conversations with staff members during the fieldwork process. Notes were taken either during or immediately following these discussions and recorded in field notes. Most of these conversations were with staff members who had initially agreed to participate in interviews, but, in the end, did not consent to the conversations being audio-taped. However, they were all willing to participate in informal one-on-one conversations, aware that I would be taking notes which would be incorporated in the field notes.

With the focus of this study being personhood practices in residential dementia care, the field notes were constructed around observations which either directly or indirectly impacted on a resident's personhood. The initial focus of observations was the nature of interactions between staff and residents. However, after only a short time in the field, it became clear that a broader perspective was needed to incorporate factors beyond the nature of interactions. Therefore, the content of the field notes also included observations of the physical environment, working practices of staff and the welfare of residents and staff, all of which appeared to influence in some way the personhood of the residents. The remainder of the data set arose from transcripts of interviews with staff.

Interviews

Ethnography typically includes a large amount of interviewing, principally because interviews provide opportunities for the researcher to directly hear accounts of the issues in which they are interested (Peräkylä & Ruusuvuori 2018). Knowledge and interpretation are expressed through the ethnographic interview enabling the researcher to gain an understanding of cultural meanings (Spradley 1979). Qualitative interviewing offers flexibility through various interviewing styles but, as suggested by Harrison (2018), a semi-structured approach using a flexible interview guide has the capacity to offer deep insights into the participant's worldview.

During this study, semi-structured interviews were conducted face-to-face with staff members across the two sites, most of whom were selected in order to gauge a multi-disciplinary approach to personhood. The ten interview participants were from various staff disciplines: Site Manager (n=1), Registered Nurse (n=1), Enrolled Nurse (n=2), Personal Care Assistant (n=1), Lifestyle Coordinator (n=2), Lifestyle Support (n=1) and Chaplain (n=2). One of the ENs volunteered to be interviewed, while another EN and a PCA were specifically invited to do follow up interviews following observations of their interactions with residents.

Semi-structured interviews are aligned to a conversation in that participants are genuinely invited to communicate their stories and experiences. However, the semi-structured interview cannot be reduced to simply a conversation because the ethnographer does have a research agenda and, therefore, needs to maintain a level of control over the session (Hammersley & Atkinson 2007). The interview discussion points in this research were directed by the interview guide (Appendix 7). Prior to each interview, a rapport had been established between the researcher and participant, and many of the participants expressed their appreciation for the opportunity to contribute to this study. Each interview was audio-taped, with tapes being transcribed by the researcher for analysis.

From a personal perspective as the researcher, I assumed the reluctance of some staff members to consent to taped interviews was due to heightened instability within the organisation at that time causing feelings of insecurity amongst staff. Refusal to participate in recorded interviews is not unprecedented. Baez (2002) described how one participant refused permission for the interview to be recorded. The participant suggested that ‘to do so would place him at risk of retaliation from his colleagues’ (2002, p.39). While it is acknowledged that no such reason was given in my experiences in the field, it seems reasonable to assume that reluctance to participate may be indicative of insecurity within the workplace, and, quite possibly, the aged care industry in general.

The use of the ethnographic methods of observations, field notes, and interviews were well suited to studying a residential dementia care environment. These methods provided a data set which focused on ‘participant’s experiences, perceptions, thoughts and feelings’ (Moser & Korstjens 2018, p.12), thereby enabling understandings of care practices and interactions impacting personhood for people with dementia. The theoretical perspectives of analysing this data will now be discussed.

Analysis of Data

Qualitative research generates a large amount of textual data which may appear attractive in its richness but also overwhelming as a path to analysis is sought (Jones & Smith 2017). Analysis of ethnographic data, however, is not a set stage in the research progression but, typically, is an iterative process. Cultural issues emerge during field work and are represented in the written text which contributes to the formation of the data set. The ethnographer then connects with the data and searches for conflicting or inconsistent data, establishes thematic categories and creates presumptions about the culture within the field (Flick 2018).

The data set for this study comprised transcripts of audio-taped interviews, records of observations in field notes, and a personal diary created during field work. Regular analysis and reflection of the data were undertaken during the field work process leading to the final data analysis process on completion of field work. Analysis of the data was underpinned by the theoretical structures of Leininger's (1997) analysis of qualitative data and Kitwood's (1997a) conceptual framework of personhood in dementia care as set out in Chapter Three.

Leininger's model of analysis incorporates four phases which provide a framework for collecting, processing and analysing data in a 'systematic, credible, consistent, and accurate way' (Leininger 1997, p.50). Implementation of Leininger's model in this study enabled progression through the phases from lower to higher levels of abstraction, resulting in the formulation of major cultural themes (Leininger 2006). The four phases of Leininger's model are set out in Table 4.2.

Once data collection was completed, the first phase of analysis included documentation of interview transcripts, field notes and a personal diary in readiness for the second phase which involved coding and classification of the data based on Kitwood's (1997a) conceptual framework. However, additional themes outside of Kitwood's framework were identified as being relevant to the question, therefore, these themes were also coded and classified. The inclusion of these additional themes is aligned with interpretivism which aims to generate meaning and make sense of the area of interest. In this study, Kitwood's themes were used to categorise interactions between staff and residents, while the additional themes gave meaning and reasons for the nature of these interactions, thereby achieving a more accurate

Table 4.2: Leininger's Phases of Analysis for Qualitative Data

Phase	Aims	Tasks
Fourth Phase	Identification of major themes and research findings	Abstraction and presentation of major themes, research findings, and recommendations
Third Phase	Analysis of patterns and contexts	Scrutiny of data to discover saturation ideas and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations relevant to the question under study
Second Phase	Identification and categorisation of descriptors and components	Data are coded and classified as related to the domain of inquiry and questions under study
First Phase	Collection, description, and documentation of raw data	The researcher records data from interviews, observations and participatory experiences; identifies contextual meanings, makes preliminary interpretations

Source: Adapted from Leininger (1997), p.50.

interpretation of the culture around personhood. The third phase involved scrutiny and review of themes until the main themes were developed in the fourth phase. Themes identified in each phase of this data analysis are shown in Table 4.3.

Each phase of data analysis involved the identification of concepts that helped to make sense of what was going on in the field (Hammersley & Atkinson 2007), and the discovery of relationships between those concepts. In particular, the second phase of coding identified a large number of themes and, at the time, the ability to classify them seemed overwhelming. However, recognition of recurrent patterns during the third phase and then placing those patterns in their individual contexts enabled the identification of third phase themes. The process of working through the phases revealed the connections between concepts and, ultimately, supported the groupings of sub-themes under the two major themes. All identified themes provided significant insight into cultural configurations of personhood practice.

Table 4.3: Second, Third and Fourth Phase Coding

Fourth Phase (major themes)	Third Phase	Second Phase
Personhood Violation	(1) Organisational Disconnectedness	(i) Misunderstandings about dementia care (ii) Organisational barriers to psychosocial care (iii) Struggling to maintain a psychosocial voice
	(2) Problems with Staffing	(i) Roster cuts (ii) Insufficient and absent staff (iii) Staff are persons too (iv) Come walk in our shoes
	(3) Marginalisation of People With Dementia	(i) Control (ii) Stigmatisation (iii) Exclusion
	(4) When Home is not Home	(i) Living in an institution (ii) Intrusion of space (iii) Contested space
Personhood Preservation	(1) Organisational Connectedness	(i) Valuing and understanding staff (ii) Stability and continuity in staffing (iii) Supportive management style
	(2) Confident Staff	(i) Staff feeling supported (ii) Working from the heart (iii) Relationships (iv) Psychosocial environment
	(3) Valuing the Person	(i) Psychological needs: connections, identity, spiritual and emotional comfort (ii) Personhood interactions: respect and dignity, contentment, inclusion
	(4) Homelike Environment	(i) Home, safety and security

This chapter has described the research strategies of this ethnographic study along with justifications for their use. The first four phases of Denzin and Lincoln's (2018) research process were used as a framework to discuss the researcher's conceptions of self and the researched, the theoretical perspectives of qualitative research and the ethnographic methods implemented in this research. The use of Leininger's (1997) coding phases facilitated identification of sub-themes and major themes which form the outline for discussion of the study outcomes in Chapters Six and Seven. Prior to that discussion, the final phase of Denzin and Lincoln’s (2018) research process, interpretation and evaluation of the data, is presented in the following chapter. The following chapter serves as a connecting point between theories and persons in this thesis.

Chapter Five: Connections to Personhood

A Bridge between Theories and Persons

The motivation behind this research is to not lose sight of the person who is living in residential dementia care. Surrounded by a world of regulations, busyness, structures and tasks to be completed, the essence of the person can be difficult to locate. A concerted effort may be needed to truly connect with that person and, in so doing, to build a meaningful relationship with them. Symbolically, that connection describes the purpose of this bridging chapter. The theoretical and methodological issues discussed up to this juncture of the thesis are essential to the research process in that they formulate guidelines for investigating the reconfiguration of personhood practice in residential dementia care. But, as the final research processes are discussed in this chapter, the focus commences movement to the personalisation of the lives of men and women with dementia and to the staff who provide their care. Thus, this chapter separates personal issues from theoretical issues ensuring the person is locatable, yet builds a bridge between the two issues, thus recognising their important connections.

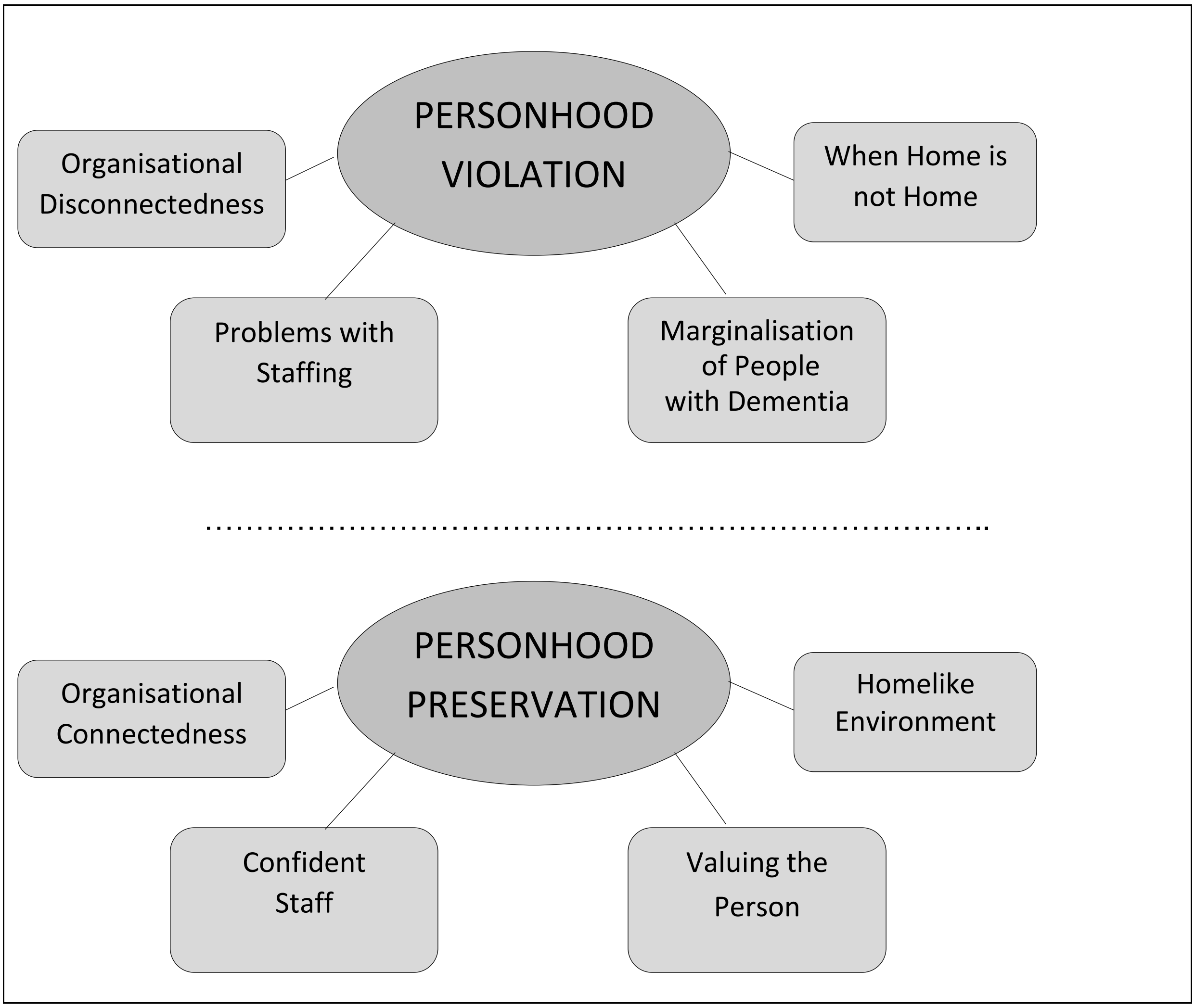
The aims of this PhD, to investigate the reconfiguration of personhood practice in residential dementia care and to argue for the positioning of personhood at the forefront of dementia care, have been progressed in the previous chapter by the identification of themes directly related to personhood. Those themes are used to present the research outcomes in Chapters Six and Seven. To facilitate the movement of the thesis from theoretical to personal, this current chapter presents interpretation of the data, followed by a discussion on matters regarding ethics and rigour. Descriptions of the two field settings precede stories from the data which, importantly, act as an introduction to the personal nature of the research outcomes in the following two chapters. Hence, the themes for this chapter are: 1) The Art of Interpretation and Evaluation; 2) Ethical Considerations; 3) Establishing Rigour; 4) Research Settings; and 5) Powerful Stories that are True. The following discussion on interpretation and evaluation of the data is the final phase of Denzin and Lincoln's (2018) research process, as introduced in Chapter Four.

5.1 The Art of Interpretation and Evaluation

The role of the qualitative researcher at this stage of the research process is to interpret and evaluate the data and present a written version of the findings. Evaluating qualitative research requires creative interpretation of the 'situated, relational, and textual structures' (Denzin & Lincoln 2018, p.62) resulting from the fieldwork experience. As with previous stages of the research process, the practice of reflexivity during this interpretation and evaluation stage acknowledges the degree to which researchers shape the studied phenomena and, therefore, enables the transformation of the social world into a socially interpreted text (Hammersley & Atkinson 2007). This adaptation into text becomes a pathway through which the voices of those studied can be heard, thereby creating a 'sequence of representations connecting the parts to the whole' (Denzin & Lincoln 2018, p.548). As presented in the previous chapter, Personhood Violation and Personhood Preservation were the interpreted patterns and main themes in this study (see Table 4.3). These themes, along with their relevant sub-themes, are diagrammatically presented in Figure 5.1.

A further step in interpreting and evaluating the data in this study was to clarify the relationship between each sub-theme. As can be seen from Figure 5.1, three cultural

Figure 5.1: Thematic Framework – Personhood Violation and Preservation



domains with similar contributing factors were identified under the main themes of Personhood Violation and Personhood Preservation. These cultural domains and their corresponding sub-themes are presented in Table 5.1, with the themes set in bold print being factors which contribute to personhood preservation.

As the cultural domains emerged, the influence of individual domains on each other became evident, as did each domain’s impact on personhood. Psychosocial environment refers to the social and emotional space in which the person was living, and, subsequently, where they were either marginalised or valued, thus impacting on

Table 5.1: Cultural Domains of Personhood

Themes	Cultural Domains
Organisational Disconnection **Organisational Connection**	Organisational Culture
Problems with Staffing **Confident Staff**	Personhood of Staff
Marginalisation of People with Dementia **Valuing the Person** When Home is not Home **Homelike Environment**	Psychosocial Environment

their personhood status. Likewise, the extent to which the person was likely to feel 'at home' in the environment also contributed to their personhood. A conceptual framework of the culture around personhood is presented in Figure 5.2.

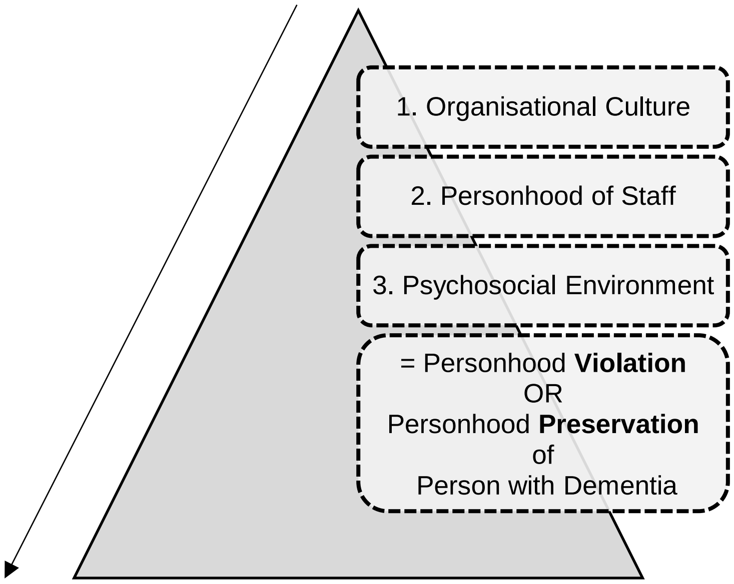


Figure 5.2: Conceptual Framework of Cultural Domains around Personhood

The domains of Organisational Culture, Personhood of Staff and Psychosocial Environment are placed in a specific order in this framework to indicate the influence that the Organisational Culture has over the Personhood of Staff which, in turn, influences the Psychosocial Environment in which people with dementia experience either personhood violation or personhood preservation. Each domain is surrounded by dotted lines to indicate that the activities and culture within that domain are rarely stand-alone features because the activity within each domain filters through to the one below.

In line with the principles of personhood, representation of the person with dementia would ideally appear at the top of the triangle. However, the direction of the arrow indicates a need to drill down through several layers of organisational culture and workforce issues to locate the person within the psychosocial environment. It is then possible, within the location of the psychosocial environment, to interpret and evaluate the nature and status of personhood.

5.2 Ethical Considerations

Ethical issues must be considered when conducting qualitative research in order to protect participants. As stated by Cannella and Lincoln (2018, p.188), researchers should strive 'to 'join with' and 'learn from' rather than 'speak for' or 'intervene into'. The researcher must respect the values and principles of participants to ensure the ethos of qualitative research is maintained. The goal of ethnographic research is the creation of knowledge, however, this goal should not be pursued at the expense of disregarding participants' values (Iphofen & Tolich 2018). It is, therefore, the responsibility of ethnographers to protect research participants from harm and have respect for their rights. In Australia, the formal protection of human subjects involved in research is regulated by the National Health and Medical Research Council (NHMRC 2007), with an update of these regulations undertaken in 2018.

Ethical responsibilities in qualitative research can be understood as sets of values or principles which influence decisions made during the research process. The principles of non-maleficence, beneficence, autonomy, and justice are described below, followed by a brief discussion on confidentiality.

Non-Maleficence and Beneficence

The principle of non-maleficence requires that researchers avoid harming participants (Aita & Richer 2005; Flick 2018). In the context of human research, harm is defined as:

> That which adversely affects the interests or welfare of an individual or a group. Harm includes physical harm, anxiety, pain, psychological disturbance, devaluation of personal worth and social disadvantage (NHMRC 2007, p.101).

Conversely, beneficence is doing good to others, therefore, this principle advises researchers to advocate for the wellbeing of those affected by the research (Aita & Richer 2005; Flick 2018). In order for the principle of beneficence to occur in research on human subjects, the research should produce benefits that are discernible and constructive instead of merely being undertaken for its own sake (Christians 2018; Murphy & Dingwall 2001). Ethnographic research should include some dialogue with participants about the benefits of the study (Harrison 2018). Because this study was focused on personhood, it was important that respect for personhood was demonstrated by the researcher during interactions with staff members. In this way, the beneficence of personhood itself was validated.

Autonomy

As an ethical principle, autonomy, or self-determination, requires that the researcher respects the values and decisions of participants (Flick 2018; Murphy & Dingwall 2001). Adherence to this principle ensures that participants are presented with enough information to make a rational choice about participation and are given the freedom to choose if they wish to participate, thus bearing responsibility for their choice (Aita & Richer 2005; Christians 2018).

Justice

The principle of justice involves fair and equal treatment of participants by the researcher. This principle warns researchers against gaining the perspective of only the powerful, or, indeed, the less powerful, in the research setting. Rather, a fair and just approach to all participants is required (Flick 2018; Murphy & Dingwall 2001).

Confidentiality

When the confidentiality of participants has been assured, research integrity stipulates this promise must be upheld (NHMRC 2007). Maintaining confidentiality requires that names of participants are not included in any documentation or publications connected to the research. All information made public must ensure there is no likelihood of that information being linked to a particular participant (Harrison 2018; Sarantakos 2013).

Prior to the commencement of fieldwork, ethics approval was granted by Flinders University Social and Behavioural Research Ethics Committee (see Appendix 2 for ethics approval notice). Field work was conducted at two aged care facilities, both owned by the same organisation. Permission to undertake this research at the two facilities was granted by the Care Services Executive of the aged care organisation, and, subsequently, by the SM of each facility.

Upon entry to each site, the researcher informed the staff about this study through presentations at staff meetings, and conversations with several staff members prior to the commencement of fieldwork. Information presented to staff included details of observations and invitations to participate in audio-taped interviews. Letters of Introduction (Appendix 3) and Information Sheets (Appendix 4) were distributed throughout each facility which included an open invitation for all staff members to participate and provided details on how to confidentially contact the researcher if they wished to contribute.

Also included was an assurance of confidentiality, as well as a statement that the option of withdrawal was available at any stage during the research process. The researcher obtained signed consent forms from staff members who participated in interviews, observations and informal conversations (see Appendices 5 and 6). Pseudonyms for all participants, the aged care provider and both aged care facilities were used throughout the research process. During interviews, two participants became emotional when describing circumstances at their site. On both occasions, the tape was paused and each participant was asked if they wanted to end the interview. They each chose to continue, so, after a few moments, the tape was turned on again and the interviews resumed. Alongside the need to maintain ethical practices throughout the research process is the need to establish rigour.

5.3 Establishing Rigour

Evaluation and critique of all research studies are important in order to determine their reliability and validity. Historically, qualitative research has been critiqued as lacking scientific rigour compared to the experimental methods of quantitative studies (Cope 2014). In recent times, however, qualitative research has become an area of investigation in its own right, locating the researcher in the real world in order to interpret and understand the experiences of subject matters (Denzin & Lincoln 2018).

Rigour is required to evaluate qualitative research, and, as suggested by Tracy (2010), the quality of the research is indicated by the richness of the rigour itself. Rich descriptions and interpretations are gained from methodological coherence, theoretical thinking, appropriate sampling, and the simultaneous collection and analysis of data (Morse et al. 2002; Tracy 2010). According to Harrison (2018), there is an ‘ever-expanding list of terms and concepts’ (p.182) by which qualitative research is evaluated. Whatever the terminology used, the criteria standard is constant. Trustworthiness, frequently substituted for the word ‘rigour’, seeks assurance that research findings can be trusted (Korstjens & Moser 2018), and can be verified through credibility, transfer, dependability and reflexivity. Credibility assures that confidence can be placed in the truth of the data and certainty of the research findings (Cope 2014; Harrison 2018; Korstjens & Moser 2018), while transferability is achieved through thick description and describes the degree to which the findings can be transferred to another context (Flick 2018; Korstjens & Moser 2018). Dependability refers to the constancy of the data in a similar context and stability of results over a period of time (Cope 2014; Korstjens & Moser 2018). Reflexivity describes the ongoing process of critical self-reflection as a researcher, specifically reflecting on one’s transparency, authenticity and honesty (Harrison 2018; Korstjens & Moser 2018; Tracy 2010).

Incorporating these criteria into the design and implementation of this doctoral study assisted with enhancing trustworthiness. Methodological coherence was ensured between the research question, which sought to understand the culture, the ethnographic design of the research, and the thematic analysis of the data. A selection of participants from across several staffing disciplines achieved a cross section of sampling, and adequacy of sampling was indicated by saturation. The concurrent practice of collecting and analysing data guided the researcher in the direction of what information was still required, and theoretical thinking enabled the gradual emergence of specific perspectives which ultimately led to the identification of themes. Integrating these verification strategies into the design and implementation of this study assisted with the cohesive development of the research process and its outcomes, and added to the richness of the study. Having ensured the establishment of rigour in this study, the fieldwork settings will now be introduced.

5.4 The Research Settings

Fieldwork was conducted in two RACFs owned by the same organisation. To maintain confidentiality, the RACFs were given the pseudonyms of Site 1 and Site 2. Having prior knowledge of both facilities, there was already an awareness of significant differences between the two. Site 1 was a relatively small facility, with a reputation for being homelike and friendly. Site 2 was a larger facility, with the physical characteristics of a contemporary institutionalised RACF. The setting and entry to both sites are discussed below.

Setting and Entry to the Field: Site 1

The entrance to Site 1 was situated on a quiet suburban street, with the pathway passing through a small garden. It was an older style building, having been established for several years, although there was a major refurbishment a few years ago. The Memory Support Unit (MSU) was home to 15 people living with dementia.

The unit comprised residents' rooms along the outer walls with two corridors enclosing the nurses' station, dining and lounge areas.

The lounge area of the MSU was a very awkward space. It was not a separate room, but a relatively small space surrounded by two walls and a corridor either side. A piano sat against one wall and a television hung on the wall above the piano. There was a row of chairs along one of the walls where residents frequently sat. Due to a lack of windows in this space, there was no sunlight and no views to the outside. It was a dismal area, physically and psychologically. Residents in princess chairs were placed randomly in this lounge area throughout the day.

A conservatory-style area was located at the far end of the corridors. A door (which was sometimes locked, sometimes unlocked) led outside to a small garden enclosed by a secure fence. At the end of each corridor was a door leading out to the reception area. Until recently, these doors were closed and secured with a code, meaning residents could not leave the unit unaccompanied. However, a recent decision had been made to keep the doors open giving independently mobile residents the freedom to walk outside the unit if they chose. Those residents who were mobile were fitted with an alert bracelet which discreetly activated if they approached an exterior door.

Although not aware of it at the time, my initial meeting with management set the tone for the period of fieldwork at Site 1. The SM was very supportive of this research and remained so for the duration of data collection. During our initial meeting, however, she mentioned that recent and ongoing decisions made by head office were causing unrest at the site. These decisions were around budgetary issues and had resulted in extensive roster cuts to staff hours. Although she attempted to remain positive about the future, it was clear from her verbal and body language that she was very concerned about the consequences of these roster cuts.

Previous dealings with this site had been very positive, therefore I had not been prepared to enter such a tense and unstable environment. Consequently, that first day I left the site very surprised by the unexpected volatility of the situation and feeling somewhat unsure about the suitability of this site for my fieldwork. In the months prior to entry, this facility had completed an organisation-wide dementia training program and it was hard to comprehend that now, only a relatively short time later, decisions seemingly incompatible with the philosophies of the training program were being made by the organisation. I recorded my thoughts at that time:

> Significant ongoing restructure and management changes within the organisation are causing low morale, job insecurity and anger amongst staff members. It’s like they are waiting for a very big axe to fall. (Personal Diary, S1, p.2)

Nevertheless, I persevered with my familiarisation of the facility and relationship-building with staff members and, consequently, spent seven months at Site 1 undertaking fieldwork. But, the consequences of witnessing these changes to the facility, along with the sadness and frustration of this environment lingered with me:

> Nothing happening in main lounge area, and in dementia unit residents are sitting around TV in lounge area, but no organised activity. So disappointing – I expected so many more meaningful interactions from this organisation. It really feels like a shadow is hanging over this place – fairly depressing. (Personal Diary, S1, p.21)

While several quality personhood interactions were observed at Site 1, the desolation and disappointment captured in the preceding comments were typical of quite a few observations at this facility. The concepts of a ‘shadow’ and ‘depression’ alluded to in these comments were the direct result of roster cuts undertaken by the organisation, the consequences of which were widespread. Although owned by the same organisation, the presentation of Site 1 was, in many ways, in direct contrast to the second facility, as will be seen in the following introduction to Site 2.

Setting and Entry to the Field: Site 2

Built approximately ten years ago, Site 2 was a large facility containing a MSU which was home to twenty people with dementia. The layout of the MSU was dominated by a very large public space for sitting and dining. The exterior wall was entirely glass and looked out to a beautiful garden. The sliding door leading to the garden opened automatically and residents could walk through as they chose. The garden was secured, although the fence was hidden from view by the shrubbery. Several pathways led from the patio area to bird feeders and an abundance of flowers and plants.

Although this was clearly an institutionalised setting, the lounge/dining area was bright and welcoming. An unobtrusive nurses' station at the far end of the room enabled monitoring of residents through a large window. There was a very large bench in the middle of the room with cupboards underneath. The top of the bench was well equipped with easily accessible items with which residents could engage if they chose, such as a basket of clothes for folding, art and craft equipment, an old-style telephone and telephone directory, and wooden boards holding various pieces of tool-shed equipment. Several book-shelves around the room contained an assortment of books and magazines. This was a secure unit, however, rather than feeling closed-in, the area was very spacious and light with adequate room for walking around. Exit doors from the unit were located further down the corridor so could not be seen from inside this room. The residents' private rooms were single and spacious with an ensuite bathroom and large windows offering views out to the garden. Wide corridors led to the residents' rooms, and several alcoves provided seating areas along the corridor spaces.

Following email contact, I received permission from the SM to undertake data collection in the MSU. At our first meeting, she spoke of her belief in personhood care and expressed her support in providing whatever assistance I needed, including her participation in an interview. As with Site 1, staff at this facility had completed the organisational dementia training program and various strategies were in place to maintain the momentum of this program. One such strategy was regular staff meetings, and the SM invited me to attend an upcoming meeting so that I could meet staff and introduce my research.

I was welcomed at this meeting and staff members expressed their support for my research topic. During the meeting, several issues were raised amongst staff about current and future care practices in the MSU, and I sensed a strong sense of teamwork along with a deep commitment to providing high quality care for people with dementia. Following the meeting, the SM commented to me that, given the openness and honesty expressed during the meeting, she felt staff were comfortable with my presence. It was agreed I would commence observations in the MSU the following week. I immediately felt welcomed and accepted into the MSU environment:

> I enter MSU for first observation session and introduce myself to Lifestyle Support staff member. He welcomes me and says he has been expecting me – invites me to observe from wherever I feel comfortable. (Field Notes, S2, p.69)

Because they were owned by the same organisation, there were similarities between Sites 1 and 2. From a personhood perspective, however, the data shows significant differences between the two facilities. At the time of my entry to Site 1 the culture was dominated by organisational disruptions and disconnections, and staff were struggling to maintain their own and the residents' personhood. On the other hand, when I entered Site 2 my first impression was that the facility was functioning in a stable and calm manner with the personhood of residents and staff appearing, for the most part, to be intact. This impression was gained from initial observations of supportive teamwork between staff members, respect and communication between management and all levels of staff, and residents within the MSU appearing to be content, comfortable and engaged with their surroundings.

In due course, the data from Site 2 did reveal early signs of unrest created by decisions being made at the organisational level. Staff were aware of substantial budgetary restrictions and roster cuts at other facilities which had resulted in an apparent organisational shift away from personhood practices. Up to this time, Site 2 had only been minimally affected, however, there were concerns about imminent organisational changes which had the potential to further reduce the focus on psychological needs and, therefore, personhood preservation. Having set the context for each site, the rest of this chapter will present stories about personhood from the data.

5.5 Powerful Stories that are True

As a prelude to the fieldwork results which will be presented in Chapters Six and Seven, this current chapter concludes with two stories as revealed in the data. The justification for telling these stories is also found in the interview data, as explained in the statement: ‘a powerful story that is true’, and discussed below.

Residential dementia care is entrenched in an industry which seeks to quantify and measure outcomes, particularly in order to justify funding. However, many of the issues around personhood, such as spiritual and emotional care, sit outside the parameters of measurability, and, therefore, frequently slip under the radar of funding budgets. As explained by a Chaplain during an interview, there were frustrations around the difficulties of quantifiably justifying more funds to provide personhood care:

> *Our time is all measured now and we’ve got to keep reporting up all the time … it’s all about being able to prove to the Board that it’s worth every dollar in spending, and they’ve got limited … we can still tell important stories. Everyone responds to – well usually - everyone responds to a powerful story that is true*. (Interview, S2, pp.85,86)

It is highly unlikely that those responsible for budgetary decisions would hear the stories of everyday life in the psychosocial environment of the MSU. Because of the hierarchical structure of the organisation, decision-makers were physically separated from the locations of direct resident care, and it seems unlikely that detailed descriptions about daily occurrences would be communicated to them. But, in the context of this thesis, it would seem these are the very people who need to hear personalised stories of those living and working in the dementia care environment. For this reason, two stories, which are both powerful and true, are presented below.

The first story illustrates that, in spite of the very best efforts of staff, external factors over which staff had no control resulted in the violation of the personhood of the resident concerned, as well as other residents in the MSU and staff members.

Before reading further, the reader should be forewarned the remainder of this thesis contains descriptions of personhood violation. As one of the main themes of this thesis, it is essential that instances of personhood violation from the data are contained in the following story and in Chapter Six.

A Powerful and True Story

Jean's story illustrates the challenges regularly faced by staff to preserve the personhood of people with dementia, as well as taking care of themselves. Two weeks previously, Jean was discharged from hospital and admitted to the MSU, resulting in various challenges arising for staff. Prior to her hospitalisation, Jean had been living at home with her husband, but a fall had resulted in admission to hospital. Jean's story, as it unfolded throughout the data, is shown below, with the only exception being the insertion of her pseudonym (Jean) where appropriate:

> It was several days since I had been at the facility – this was at the request of the CNM who had asked me to defer visits because admission of a new resident was causing some unsettling issues in the unit. (Personal Diary, S2, p.42)
>
> The regular Lifestyle staff member (LS) is here this morning (so) … I expect to observe a calm and happy environment. But I very quickly sense things are different. (Field Notes, S2, p.100)
>
> My immediate reaction was that many of the residents looked stressed or tired. I then heard loud yelling noises from a female resident I hadn't seen before … refusing the drink, yelling and making a lot of indiscernible noises. (Personal Diary, S2, p.43)
>
> EN: (Jean) *has had Alzheimer's for 11 years … she's got a lot of chronic illnesses to go along with that. However, they are being managed very well - the Alzheimer's is not … she's an ex dementia nurse …she's very frustrated, she obviously is fighting her dementia the whole way because she knew what she was in for.* (Interview, S2, p.159)
>
> EN: *Unfortunately Jean's family believe that we're sedating her, and because of this her pain relief has been cut and we're back to square one with her. She's calling out, she is in pain. She's attacking staff*

again. We've had quite a few staff incidents where she tried to bite. She actually scratched, dug her nails in – we haven't been able to cut her nails. (Interview, S2, p.160)

EN showed me scratches on her arm … there are several scratch marks, most of them quite long. (Field Notes, S2, p.101)

EN: *Over the weekend a pressure area has actually shown on Jean's foot which has actually come from hospital, there is underlying damage that was done and that is where her pain is coming from … we are trying another doctor today - after many arguments with the last doctor – and we are going to try and get her some more regular pain relief … and explain this to the family as best we can … unfortunately, our hands will be tied if the doctor says no, and if the family say no. And so we are going to keep advocating for this resident as much as we can.* (Interview, S2, pp.160,161)

EN: *The GP doesn't think that Jean has pain … we've done three lots of pain charting to try and support our fight here for her to give her a bit of dignity and pain relief, however, the doctor says how do we know.* (Interview, S2, p.160)

EN: *The pain relief – if we can get on top of it, Jean is actually beautiful, she can communicate, she can connect with people and she is a totally different person. And so her dignity is there when we get on top of the pain.* (Interview, S2, p.159)

EN tells me Jean was a dementia nurse for 30 years, so she knows a lot about dementia care. EN often relates to her in a 'nurse to nurse' manner. When EN thinks she might be in pain, she will ask her: *'Do you think Panadol would help?'* and Jean will usually reply *'Yes, good idea'*. She reads EN's name badge really well and is able to make the 'nurse' connection. (Field Notes, S2, p.101,102)

EN tells me the ripple effect of all this on other residents is very high – they see a new resident who is disrupting their home getting attention and one-on-one time with staff that they don't get.
(Field Notes, S2, p.103)

Jean … is sitting in an armchair and LS is assisting her with lunch … she is very restless, expressing anger and frustration, but is slowly eating. LS is very patient with her – she constantly stands up, sits down. I wonder if she is trying to relieve pain in her foot/leg. (Field Notes, S2, p.103)

EN: (Jean) *yells out … has quite vile language … the other residents are really responding with behaviours as well – the noise in the unit is really quite high, so we are having to medicate them because they don't understand the noise with her, and we don't have enough staff to actually give individual care for every single resident at this stage.* (Interview, S2, p.160)

EN: *We've actually had to remove another resident out of this area at the moment so we can all have lunch … because he was absolutely*

> *devastated with this lady calling out and then his behaviours – he's a very large man and he actually has physical behaviours so he actually could hurt one of these residents. So we've moved him out and he's happily sitting across the hallway having lunch as we speak*. (Interview, S2, p.161)
>
> EN: *We are going to keep advocating for* (Jean) *as much as we can, because we need peace in this unit for everyone to live together at the moment. Our staff are wearing out, we've had a few on sick leave … I've had a day off as well … it's quite hard in here, and it's taken a personal toll.* (Interview, S2, p.161)
>
> Jean was sitting in an armchair in corner of room, yelling and swearing. A male resident walked aggressively towards her … he looked as though he was planning to hit her. Staff intervened and led him away. He was very agitated, wouldn't settle, increasing agitation. EN eventually gave him medication … is now calm and settled. (Field Notes, S2, p.103)
>
> Jean's husband is in for a visit – she is mostly just yelling and swearing at him. He is walking with her to her room – EN has just given Jean medication – awaiting effect. (Field Notes, S2, p.103)
>
> Clinical Leader enters the unit. She has been trying to contact Jean's GP since yesterday afternoon. She tells EN … that a locum will be visiting shortly … requested they print out documentation to show GP in order to support their view that Jean is in pain and needs increased pain medication. (Field Notes, S2, p.104)
>
> When leaving the facility a short time later, I saw Jean's husband in the foyer – he was extremely upset by what had just occurred … I heard the Chaplain inviting him to meet shortly in a coffee shop across the road, an offer which was accepted. (Personal Diary, S2, p.46)

Jean's story contains many occurrences of violation of personhood as experienced by residents and staff, and, of course, Jean herself. These violations are both physical and emotional, with the consequences being widespread amongst all residents and staff within the psychosocial environment. Moreover, it is likely these acts of personhood violation are interpreted by Jean as acts of personal abuse. Elder abuse is defined by WHO (2018b) as a:

> lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person.

Although it is beyond the parameters of this study to establish the effects of personhood violation on a person with dementia, consistent with WHO's (2018b) understanding of elder abuse, it is realistic to assume that Jean is feeling abused as a result of various actions of her husband and staff. Of course, in actual fact, Jean's husband and those caring for her are attempting to provide the best care possible under challenging circumstances, but, due to her dementia symptoms, Jean may not comprehend this reality. It is likely that Jean considers this institutional care as neglectful and abusive behaviour (Fang & Yan, 2017). Jean's story is an accurate representation of a person with dementia and, particularly in light of the violations and abuses within her story, must be told and then, without doubt, heard and comprehended by governmental and organisational decision makers. Jean's story is indeed powerful and true. The next story characterises personhood preservation as portrayed through interactions and the sense of feeling comfortable in the community.

Personhood Preservation: When Residents Feel at Home

The daily routine of serving morning tea resulted in many facets of personhood preservation as shown in this extract from the data which reveals a story of friendship, reminiscence and sharing:

> The morning tea trolley arrived … and residents were offered a hot drink and scones. I heard many comments that the scones were delicious.
>
> EN walked through and heard two residents saying how good the scones tasted. She stopped to chat with them, asking if they used to make scones, which recipes they used - did they use the lemonade recipe? Both residents said they definitely did not! They made scones the good old-fashioned way, and they were always delicious.
>
> One lady told how her children loved her scones and she often had some ready when they got home from school. She said she's not sure now whether it was a good idea or not because they wouldn't always eat all their dinner. But she felt sorry for them because, after eating their scones, they had to do outdoor chores so she was sure they would have needed all that food.
>
> Another resident, who hadn't been involved in this conversation, said the scones were very nice and asked EN if she had tried one. EN said that she hadn't, but that was okay because they were for the residents.

> The resident said they would like to share one with her and that she should walk ‘over there’ to see if there were any left. The EN could see there were still some on the trolley, so she thanked her for being so generous, said she would take one to eat in her office, and walked over and took a scone. A little later she came out and spoke to this group again, saying it was delicious and thanked them again for sharing their scones with her. (Field Notes, S2, p.92)

This story describing interactions during morning tea presents a balanced contrast to Jean’s story by revealing several aspects of personhood preservation. This, also, is a powerful and true story, and, equally, must be told, and then heard by governmental and organisational decision makers. The staff members facilitating the preparation and serving of morning tea and the EN involved in these interactions represent the potential for quality dementia care when personhood policies and practices are in place, and staff are supported to deliver personhood care.

This chapter has discussed the interpretation of the data and presented a thematic framework showing Personhood Violation and Personhood Preservation as the main themes. Considerations around ethics and rigour were discussed and the fieldwork settings introduced. Stories from the data were presented to add personalised voices to the broader discussion on personhood. So, the connection to the persons has been achieved. The two stories related in this chapter are a symbolic bridge to the forthcoming accounts of personhood experiences of residents and staff. Occurrences of both personhood violation and preservation were contained in the stories as representations of the major findings of this research. The outcomes of the study are presented over the next two chapters, commencing with Personhood Violation in the next chapter.

Chapter Six: Personhood Violation

Outcomes of the Study (1)

> *Even though they've got dementia,* ***they are still people*** *… and even though they're not verbally speaking to you, they're taking something in.* (Interview, S1, p.35)

It may seem confronting to use the word 'violation' in the context of dementia care because, understandably, one's mind will likely turn to some form of physical violence being committed against residents. This is not the case in the findings of this research. In the context of this study, 'violation' refers to those occasions where there are strong indications that people with dementia are not receiving sufficient psychosocial care. It is their social, emotional or spiritual needs that are being ignored or delayed. Insufficient care such as this is a disregard, or violation, of personhood. Such lack of support is a concern for any person, but for those living in residential dementia care, the need is more significant. People with advanced dementia are unlikely to possess the necessary skills to meet their own psychosocial needs, therefore, they are reliant on caregivers to meet those needs. Personhood violation occurs when these needs are not met, and, therefore, the core of personhood is not intact.

The previous chapter offered a bridging connection between theoretical issues and the personal nature of the study outcomes, and presented a framework of cultural personhood domains, followed by descriptions of the two fieldwork settings. Extracts from the data were then used as an introduction to the personal nature of the daily experiences of participants in this ethnography. The major outcome of this study was the identification of two main themes: Personhood Violation and Personhood Preservation. The ethnographic data set from which personhood violations and preservations are extracted consists of ten interview transcripts, field notes containing notes from observation sessions and conversations with staff, and a diary in which personal thoughts and reflections about the fieldwork are recorded. The field notes contain significant details about the nature of interactions between staff and residents, the surrounding circumstances of those interactions, and the subsequent effects on residents. Importantly, they also contain notes about periods of inaction and deferral of action. The interpretation of observational notes is enhanced through insights provided in the interview transcripts and the notes from informal conversations. The interview transcripts and conversation notes frequently support each other. The personal diary contains thoughts and reflections on activities, interviews and conversations, and is particularly useful in conveying those things which cannot be seen or heard, such as my personal feelings about a situation and the general ambience of the environment. These data components each add to the integrity and detail of the others, and, when incorporated as a complete set, the data becomes a balanced, informed and rich document.

Under the theme of Personhood Violation, analysis of the data resulted in identification of the following sub-themes: 1) Organisational Disconnectedness; 2) Problems with Staffing; 3) Marginalisation of People with Dementia; and 4) When Home is not homelike. These themes are discussed in this chapter, while the themes of Personhood Preservation will be presented in Chapter Seven.

6.1 Organisational Disconnectedness

The organisation's head office is located a reasonable distance from each site. Although not intentional, this geographical distancing symbolises the disconnection in priorities between staff at head office and staff at facilities. Obviously, there are interpersonal communications and visits between the two locations, however, at no stage did I observe staff from head office in the MSU or interacting with PCAs at either site.

On two separate occasions, I observed staff from head office in or near the administration area, but, to my knowledge, neither enter the MSU (Field Notes, S1, pp.105,127). Therefore, it would appear it is unusual for head office staff to move beyond the boundaries of the administration area while on site. Under these circumstances, they are rarely exposed to the daily practical and emotional demands of holistically caring for a person with dementia, yet they make many crucial decisions which significantly impact that care.

These thoughts on disconnections cannot, of course, be taken as intentional, however, they may be indicative of the organisation’s disconnections from the needs of people with dementia and those who care for them. Organisational disconnections are discussed under the headings of Misunderstandings about Dementia Care; Organisational Barriers to Psychosocial Care; and Struggling to Maintain a Psychosocial Voice.

Misunderstandings about Dementia Care

In the months prior to field entry, the organisation had conducted two separate roster reviews at Site 1, with each review resulting in significant cuts to roster hours. From the perspective of staff members, therefore, a significant disconnection between the organisation and staff was created by the organisation’s apparent misunderstandings of the practicalities of caring for people with dementia. Staff need the organisation to know that good dementia care is more complex and time consuming than it appears to be from the outside, and, crucially, more complex and time consuming than the level to which staff are resourced to provide such care. A staff member at Site 1 expresses her frustrations about the organisation's apparent avoidance of understanding about dementia care:

> [Staff member] believes they look after their residents really well at this site but could always do better … if the powers-that-be would just try to understand the needs of older people – especially those with dementia. They get lonely, scared, confused, or feel sad – they've lost so much of their independence … it takes people with special skills and a lot of time to be able to give residents proper care.
> (Field Notes, S1, p.49)

Although not actually stated in this extract, it is possible that the terminology about 'powers-that-be' is an indication that a better understanding of the processes and practicalities of dementia care is needed by the wider community, especially funding bodies. The context of this conversation is the need to balance the societal stigma of working in aged care with the skills and responsibilities needed to effectively meet the needs of older people. Therefore, the message behind these comments may be that the organisation, along with society, needs to better understand the realities involved in dementia care, as clarified by this staff member:

> The work is often quite hard and has the huge responsibility of looking after people who are so sick and frail. (Field Notes, S1, p.49)

In acknowledging the hard work and huge responsibilities of caring for people with dementia, this staff member is strong in her assertion that the organisation does not fully comprehend the demands of working in a dementia care environment. The challenges and responsibilities of dementia care are dealt with behind the closed doors of aged care facilities and are, therefore, largely unseen and unnoticed by the general public and, so it seems, by the organisation.

A practical example of the unacknowledged time involved in providing dementia care is raised in this extract:

> LS Coordinator: *Being tired pushing princess chairs around … there are so many princess chairs, and the ones that are walking are very slow and they take a long time to stand next to because they are one-assist.* (Interview, S1, p.34)

A considerable amount of time is required to transfer residents around the facility. Apart from those in wheelchairs needing assistance, residents assessed as needing assistance when walking must always be accompanied, and princess chairs are heavy and difficult to manoeuvre around corners and doorways. These are necessary tasks that are undertaken several times a day, but the considerable amount of time required to transfer residents is not necessarily understood by the organisation when allocating staff hours.

The recent roster cuts caused a major reduction in lifestyle activities, including a program which had provided emotional support to people with dementia:

> LS Coordinator: *So we haven't got what we used to call the sundowners shift - that has completely gone … because* [other staff member] *finishes at 4.00 now, so when she was working before she was able to spend an hour down there doing relaxation and comforting the residents – and that has just gone.* (Interview, S1, pp.24,43)

The activity referred to is colloquially called the 'sundowners shift' because it is central to the wellbeing of people with dementia late in the day when many of them display symptoms of increased anxiety and tiredness. The removal of this shift is a significant reduction in emotional support at a time when it is crucially needed, leaving residents at risk of additional distress and concern. These extracts show that the need for appropriate stimulation and social support have not been sufficiently understood by the organisation.

As the following extract shows, a further indication of misunderstandings of dementia care by the organisation is the unwillingness to employ LS staff on Sunday evenings and public holidays. While the justification for this decision relates to higher wages for those periods of time, the consequences of insufficient staff are serious:

> EN: *We do have Lifestyle staff Friday and Saturday, but not Sunday. They don't think they need that, and they don't want to pay obviously, and that is huge … meal times on a Sunday can be really difficult because – yeah - that extra pair of hands makes a huge difference, because they're all – you know – they're all agitated … so they need lots of reassurance and prompting … the idea of they don't need Lifestyle on a public holiday or a Sunday… as though their needs differ from one day to the next I mean, we're always going to have issues with that, and management have said there is no way they are going to give us extra staff on a Sunday.* (Interview, S2, p.128,130,140)

The negative consequences of not supporting LS staff to work on Sundays and public holidays are significant. Residents are at high risk of not receiving the level of emotional support they particularly need at those times, potentially resulting in increased agitation and anxiety. Staff are already engaged in the practicalities of physical care at that time of day, and are under-resourced to provide reassurance and emotional support. Thus, residents and staff are under enormous stress. A further negative outcome of insufficient staffing is raised:

> EN: *So you've got four or five people wandering who haven't been able to sit quietly and have the nutritional intake that they should have … that's not ideal for the residents.* (Interview, S2, p.141,142)

Adequate hydration and nutrition are essential for people with dementia, particularly if they are experiencing agitation and anxiety. The consequence of a lack of sufficient staff to calm and relax residents so they can peacefully eat a meal means those residents are not only deprived of the support they need to regain a calm composure, but are also denied the nutrition they need at that particular time. As explained in this extract, under these circumstances, maintaining a safe and calm environment is incredibly challenging:

> EN: *Oh, Sunday afternoon we had a shocking afternoon because they seem to have that – between 3.00 and 3.30 – I don't know whether they sense the change of staff or what it is … you can tell … they're all on edge, one lady's picking a fight and the other man doesn't… so it's kind of like crowd control.*
>
> Researcher: *And that's when Lifestyle would be really beneficial – to have someone else there*
>
> EN: *Yeah.* (Interview, S2, p.128,129)

When staffing levels are insufficient, the potential for the emergence of a risky environment is relatively high. The obvious reason for less staff on Sunday afternoons and public holidays is to eliminate payment of higher wages, however, the needs of people with dementia do not differ dependent on the day of the week. When staffing levels are insufficient, safety, nutrition and wellbeing are jeopardised and residents, staff and visitors are at risk of physical and emotional harm.

This discussion shows that the organisation does not fully understand the complexities of providing dementia care, nor the frustrations of staff who are regularly deprived of satisfactorily fulfilling their roles. It is clear that some decisions made by the organisation raise barriers which prevent staff delivering effective psychosocial care.

Organisational Barriers to Psychosocial Care

Staff at both sites have recently noticed a trend towards the organisation moving away from addressing psychosocial needs and that, in fact, a number of organisational barriers preventing psychosocial care are emerging. Staff are concerned that, if the trend continues, increasing numbers of psychosocial needs will not be met. For example:

> LS Coordinator: *Our care plans … you would open it up, there would be the cultural kit if it needed to be there, then it would be the life history which would be mother, father, children, where they were born – it was rich. Then would come the care plan summary of behaviours. Well now that has all been taken out, so the first thing people see now is the care plan summary. And the first part is the disease, then it's about behaviours* – '[resident] *hits,* [resident] *bites'. Instead of knowing* [resident] *as a husband…*
>
> Researcher: *So, then* [resident] *is defined by those so called 'behaviours'…*
>
> LS Coordinator: *Yep, that's the first impression… but, you know, foremost he's been a father to four children, and he was born in England, you know – I don't understand why they can't get that information first … don't get me wrong, the clinical side is very important, but first impressions do count.* (Interview, S2, p.100,101)

Sensing the LS Coordinator's deep concerns about the removal of residents' life histories from care plans, I encouraged her to speak further about this organisational directive:

> Researcher: *So that was a directive from head office?*
>
> LS Coordinator: *It was*.
>
> Researcher: *So, if staff wanted to find out that lifestyle history, where do they go to find that now?*
>
> LS Coordinator: *They will come to the office for the yellow folders because they will no longer be kept in the nurses' station, or they will need to get on* [computer program] *and actually pull up the resident's file, otherwise they will never know.*
>
> Researcher: *So, if you're a Carer or EN or someone who doesn't know this person you actually have to physically go out of your way either to your office or log in to* [computer program], *which is actually not a quick process anyway if you have to deal with something pretty quickly….*
>
> LS Coordinator: *No, it's not – and if you're an agency person as well – how do you go about that then? Instead of going to those cabinets and pulling out and reading – you know – cultural – ummm…* [name of resident] *is from…. you know – it's so important to know about the culture … I don't get it. I just don't get how they can do that. How head office can only be so clinical now.* (Interview, S2, p.101)

Decisions which render the person's life history less accessible to staff, such as those just discussed, clearly raise barriers to providing psychosocial care. Placing an emphasis on diagnoses and so-called 'behaviours' frames the person's care within a medical model of care, rather than a personhood model. Through the introduction of these barriers, the psychosocial needs of the person are portrayed as inferior to their medical diagnoses and, indeed, inferior to organisational needs because of a perceived reduction in expenditure.

A significant barrier to addressing psychosocial needs has been imposed in the recent roster cuts, with the effects of those cuts drawing a stark contrast between residents' needs and the organisation's decisions. A senior staff member explains:

> They need people to spend time with them – it's not just about showering and dressing and feeding – it's also about needing companionship, about feeling safe, and about staff who have the time to stop and listen while they communicate their needs. Staff need to sit with them, walk with them, build relationships with them. But these things don't seem important to people who make the financial decisions. It's all about money. (Field Notes, S1, p.64, 65)

Implementation of the roster cuts indicates either the organisation's misunderstandings about the needs of older people, or an unwillingness to effectively meet those needs. Dementia care must be provided at the pace required by the person, not the organisation. It is during this slower approach to care that relationships are built which provide feelings of physical and emotional safety, conversation and meaningful interactions. When the quality of dementia care is determined by budgetary considerations, psychosocial needs are frequently ignored.

While watching LS staff interacting with residents, an EN speaks of her admiration for the LS program but believes that LS staff and PCAs could involve residents in many meaningful activities from which they are now prohibited:

> The EN believes the staff do great things for the residents, but they could do so much more if they weren't being held back by health and safety regulations. While realising the obvious need to provide a safe environment, she feels some of the rules are too restrictive and detract from the quality of life of the residents … basic housework like cooking and washing …basic meaningful tasks in which residents could participate and gain satisfaction from … it is sad that all these tasks are done for the residents, and they are not even given the choice of being able to participate. (Fieldnote, S2, p.100)

The EN’s comments reinforce my reflections on residents’ non-participation in regular, everyday tasks:

> I wonder about this dining experience for residents. Food is dished up on plates away from residents – they never get to see a salad bowl, or vegetables in a dish, or fruit in a bowl. Food preparation is never experienced. Would some of these people enjoy helping to prepare the vegetables? Or make their own custard? Some of them may have been able to experience the smell of food – which was rather pleasant – but do they experience the smell of cakes and biscuits cooking or bread baking? Do they ever get to touch a raw potato or carrot?
> (Personal Diary, S1, p.23)

Reflections about non-involvement in meaningful activities cannot be verified within the scope of this thesis. However, because the residents would have previously been involved in these, and other essential tasks of life, it is reasonable to assume they now miss them as part of the ordinariness of life.

More than likely, the issues around care plans, budgetary spending and residents’ activities are symptomatic of other organisational barriers which prevent psychosocial needs being met. Undoubtedly, each specific barrier has some justification unrelated to psychosocial care, such as safety or financial reasons, however, the end result is that barriers to providing various forms of psychosocial care have been created. I reflect on the extent to which decisions made at head office significantly impact on the ability of staff to provide psychosocial care:

> At this stage of my fieldwork, I think my greatest insights have been around the effects of the decision-making power and control of the organisation versus the lack of control within the individual facility. I am seriously questioning whether the priorities of the corporate office actually agree with the priorities of a facility which is tasked with delivering dementia care based on person-centred principles.
> (Personal Diary, S1, p.33)

Seeming to build on my thoughts, a Chaplain comments on the difficulties of measuring the benefits of psychosocial care in order to justify budget allocations, and the ongoing frustrations of continuing to advocate for funding:

> Chaplain: *We live in very difficult times … how do you go measuring these things … tight budgets, dollars … you know, we all say 'yep, we get that' and, I mean, you'd be crazy to bury your head in the sand now … yet in our budget-type era … there are numerous frustrations.*
> (Interview, S2, pp. 85, 87)

Psychosocial care fits awkwardly within an industry which is dominated by the need to achieve guidelines, regulations and standards. The outcomes of psychosocial interventions can rarely be measured in quantifiable terms and are, therefore, resistant to inclusion in budget lines. There are, indeed, 'numerous frustrations', along with a seeming lack of hope that the situation will change any time soon.

This discussion on barriers to psychosocial care describes the continual struggles which staff encounter to provide such care. When psychosocial care is either ignored, untimely or inadequate, personhood is violated because the person's needs are not met. Staff understand this fact, but struggle to maintain a voice which is heard by the organisation.

Struggling to Maintain a Psychosocial Voice

In spite of their best efforts and intentions, staff are finding that increasing restrictions are being placed on their ability to provide psychosocial care. The obvious consequence of the roster cuts is a significant reduction in staff hours, which is described as a loss to residents:

> LS Coordinator: *I'm finding with the residents, to me –* [the organisation] *reckons that they won't suffer – but in my heart – inside of me – they are losing, because of the fact that we are not spending that extra time like we used to … I know I've got all those other residents who are just sitting there waiting to have some support.*
> (Interview, S1, p.25)

The roster cuts bring a sense of helplessness, perhaps even grief, that residents are now not receiving the amount of emotional support they need. The comments expressed about resident care not being affected by staff cuts, is a strong indication of the organisation's disconnection from several aspects of dementia care. Supporting the fact that residents are not receiving sufficient care, a LS staff member comments that she feels increasingly limited in her ability to meet personalised psychosocial needs:

> LS: *I would see the importance in acknowledging those differences, and I guess showing that I see those differences and that I'm addressing them, and I do that in trying as much as I can within the restrictions of the program, which seems to feel more and more restricted as time goes by.* (Interview, S1, p.45)

Recognising and supporting the individuality of each person is an important feature of psychosocial care, and this staff member is frustrated that she is increasingly unable to provide individualised care that she knows is needed. There is a sense of helplessness in having to work in such a constrained manner.

These two data extracts confirm that the psychosocial needs of people with dementia are sometimes ignored for lengthy periods of time:

> It occurs to me that, apart from afternoon tea, none of those residents had any of their physical needs met, e.g. toileting, comfort, etc. And, for the most part, their psychosocial needs for that time were completely ignored. But at least the TV is on! (Field Notes, S1, p.49)

> While it is good to see that residents generally seem well cared for physically, I am seeing so many just sitting around with very little interaction or stimulation – often for long periods of time, and, on several occasions, there are very few staff on the floor. So, I'm struggling to find a connection between this large financial training outlay and residents who often seem bored and alone, with – so it seems – their psychosocial needs being ignored. In my mind, person-centred care is not limited to physical needs. (Personal Diary, S1, p.16)

Observations of people with dementia grouped together in front of a TV are a regular occurrence. It does not seem possible to reconcile the philosophy of this organisation which has recently invested in an extensive dementia care training program with the philosophy that consistently denies people with dementia social interactions for long periods of time.

It is the responsibility of LS and Chaplaincy staff to ensure the provision of emotional and spiritual care for residents. However, the following three comments from a Chaplain and LS staff express frustrations about the responsibilities of their roles not being taken seriously by other staff and the organisation:

> Chaplain: *I think there is still a long way to go just even on the recognition of the effectiveness of chaplaincy, what chaplaincy actually is. I mean there is some progress but I still am frustrated with the way that we do multi-disciplinary team meetings and so on, which are still geared toward the clinical … So we were seen as not professional. So I think there is still a bit of 'what are chaplains?'* (Interview, S2, pp.87, 89)
>
> LS: *Driven by clinical … it becomes so clinically driven so the person is definitely about their illnesses … I can feel that they are just going to get slotted into boxes, and they're going to lose their identity as a human person.* (Interview, S2, p.105)
>
> LS: *So I just feel as the years go on and the way it's looking in the industry it's becoming a lot more people in boxes.* (Interview, S1, p.49)

Concerns are high that there is a lack of balance between psychosocial care and clinical care. Decreasing value is being placed on psychosocial care by the organisation, and efforts to maintain such care for people with dementia are an ongoing struggle. This comment sends a reminder to the organisation about the need to maintain a strong focus on psychosocial care:

> Staff: *They* (the organisation) *need to be reminded … this is our customer, this is what matters the most.* (Interview, S2, p.98)

This staff member clearly feels that the organisation is losing sight of the need to focus on residents and their needs, and there is a strong implication that she feels organisational needs are given priority over residents' needs.

Various disconnections within the organisation have been discussed, including the organisation’s lack of understanding about the complexities of dementia care, barriers to psychosocial care imposed by organisational decisions, and the ongoing struggle experienced by staff to maintain a level of psychosocial care. In some way, all these disconnections have a negative impact on the personhood of people with dementia. A significant indicator of the organisation’s disconnectedness seems apparent in the recent roster cuts at Site 1, resulting in considerable problems with staffing.

6.2 Problems with Staffing

Apart from the staffing hours cut in the recent roster reviews, several staff resignations have occurred due to job insecurity, and a trail of stress and anxiety now exists for staff who remain. Furthermore, of particular interest to this thesis, there are now significantly fewer interactions between staff and residents. The effects of the roster cuts are widespread and, in many ways, impact on the quality of care provision. Problems with staffing are discussed under the themes of: Roster Cuts; Insufficient Staff; Absent Staff; Staff are Persons Too; and Come Walk in our Shoes.

Roster Cuts

Although not personally affected by roster cuts, a Chaplain comments on reactions to the roster cuts:

> Chaplain: *The mood of the staff last week with this now placed upon their shoulders has taken all of the life out of them. So I’m hearing more complaints from residents, and there’s a lot more agency on board, and … it’s terrible. And the staff who are there have got no enthusiasm.* (Interview, S1, p.14)

With an ability to see the larger effects of the roster cuts, the Chaplain is concerned for staff as well as residents, and, interestingly, this description of the negative impacts includes both emotional and physical consequences for staff. The reference to ‘more agency on board’ confirms that many regular staff have left, hence the need to employ agency staff. This, of course, is additional cost for the organisation, as well as initiating ‘more complaints from residents’. So here, within this one comment, is evidence that residents prefer continuity in staffing, and staff are emotionally struggling with the effects of roster cuts. The Chaplain’s concerns are supported by the SM:

> *Obviously the two roster reviews – the first one especially – was massive. Massive. The second one hasn’t had as much impact generally on the floor, but definitely has with Lifestyle. They were most heavily impacted this time. The RN who did the complex health treatments, that shift went and the treatments have been divvied out between all RNs.* (Interview, S1, p.62)

It is clear from this comment that the roster reviews are extensively impacting several staff members and their working day. Seemingly, the organisation has expectations that staff are able to absorb increased duties into their allocated shifts, and that residents no longer need some of the care that was previously provided. A LS Coordinator confirms the SM’s comments about cuts to LS hours, and comments on the heavy impact of roster cuts on their programming:

> *We had to restructure our whole Lifestyle program … there were a few activities that were cut … we would run an hour activity, some have been cut back to 45 minutes ... I actually had volunteers leaving … I lost three good volunteers because they felt like they were doing our work.* (MSU) *is missing out a lot – that’s the one that is really affected.* (Interview, S1, pp.23,37,44)

Being placed in the position of needing to either eliminate activities completely or reduce the allocated times for other activities is an unnerving place to occupy.

Exacerbating the situation is the fact that some volunteers also leave because of a perceived obligation to fill the void left by staff cuts.

The consequences of roster cuts are clearly conveyed by a senior staff manager as she speaks about reduced staff levels. Her comments indicate her concerns that vulnerable people are now at higher risk of not receiving appropriate physical and emotional care:

> Roster cuts obviously mean less staff on the floor, and that is the biggest thing. Older frailer people need enough staff around them to give proper care – and it's not just physical care – it's emotional care as well. (Field Notes, S1, p. 65)

As obvious as it is, the statement that roster cuts 'mean less staff on the floor' is profound in its consequences. The role of a dementia care environment is to provide quality care for vulnerable and frail people. A reduction in staffing levels in such an environment places residents at risk of physical and emotional neglect, and creates a stressful and unstable workplace for staff. As stated in the previous field note comment, older people who are frail need the presence of skilled staff to provide physical and emotional care. Within a social justice framework, this fact is not debatable. It is not as if people with dementia are now somehow in a position to meet their own needs just because the organisation is undergoing cost-cutting exercises. The consequences of insufficient staff are now discussed.

Insufficient Staff

Insufficient staffing levels result in significant consequences which impact on both residents and staff members. In many ways, residents pay the price for the roster cuts, such as being left in bed on days when it is deemed their turn to do so, as explained in this extract:

> (PCA) told me that, in the past, they aimed to have all residents out of bed for lunch, except for those who are not well enough to get up. However, this now rarely happens because, due to recent staff cuts, there are not enough staff to get all residents up each morning. Decisions were made on a daily basis as to which residents would stay in bed for the day. (Field Notes, S1, p.2)

A situation where some residents are left in bed all day due to insufficient staff is quite alarming. The lack of staff is not the responsibility of site management and it is understandable they would make this decision under the circumstances. However, the lack of staff is the responsibility of the organisation, and, although it is unknown if they are aware of this particular consequence of their roster reviews, there must be accountability at some organisational level for enforcing such detrimental care practices.

Linked to the decision of leaving residents in bed for the day are concerns about the elimination of room visits as raised on two separate occasions by LS support staff:

> One of the most significant cuts is room visits … [which were] particularly important for those residents who rarely come out to social activities and for those who may be temporarily or permanently confined to bed … due to cuts in PCA hours, more residents than before are kept in bed each day which means Lifestyle room visits are even more critical. (Field Notes, S1, p.67)
>
> Researcher: *There are no one-on-ones here?*
> Lifestyle: *No, not for staff - just volunteers …*
> Researcher: *One-on-ones with staff are incredibly important…*
> Lifestyle: *Oh, absolutely. Yes, yes.*
> Researcher: *I mean, in a way, that's even more important – or, at least, as important as a group activity.*
> Lifestyle: *Absolutely. Yes, yes. Particularly isolated residents who are isolated for a reason … I just don't have the time … I've got such a minimum number of hours.* (Interview, S1, pp.52,53)

These extracts portray the deeper consequences of an already disturbing situation. The need to leave some residents in bed for the day due to staff cuts is already concerning, but concerns are deepened by the fact that staff cuts also mean these residents receive no allocated social or emotional support for the day.

As explained in the following extract, another consequence of insufficient staff is the level of stress being experienced by a PCA and, consequently, a resident who needs assistance:

> I can hear a female resident calling out 'nurse, nurse', quite urgently. She calls out three times until a PCA comes out of another resident's room and walks towards the female resident's room. As she walks she is yelling out *'I'm coming* [resident's name]'. She enters the room: '*What is it* [resident's name]?' I hear the resident say she needs to go to the toilet but can't get there. PCA asks her if she can wait a few minutes until she's finished what she is doing. The resident replies that she can't wait - it's urgent. PCA says that she will get her on the toilet but then she'll have to wait until she can come back. Resident apologises says for being a nuisance. PCA says it's okay and that she is not a nuisance – they are just really busy. I can hear the PCA assisting her to toilet. PCA hurries out the room and back up corridor, disappearing into room where she originally was … she appears again about 5 minutes later to go back to female resident. As she walks quickly past me she says: *'Sometimes I wish there were two or three of me just so I can get everything done.'* She goes back into female resident's room and helps her back to her chair … when PCA emerges from the room, I ask her if she often feels that rushed, and she says: *'Yes, especially at this time of day. There's just not enough staff on the floor, and I worry if the residents have to wait too long for me to get to them. But, we can only do so much – and obviously we can't rush them'*. (Field Notes, S1, pp.44,45)

This situation is quite distressing because there are so many violations occurring in a short period of time. The female resident is forced to call for help several times, feels as though she needs to apologise for being a 'nuisance', and is left unattended in the bathroom for several minutes. The PCA is obviously under pressure from an overwhelming workload and, because of that workload, distressed by her inability to provide appropriate care. Therefore, the personhood of both the resident and PCA are significantly violated by the decision to cut staffing levels. Reflections on this observation are recorded in my personal diary:

> The PCA who was so rushed clearly had too much work to do in that space of time. Once again – not enough staff on the floor to meet even the basic needs of residents (like toileting) in a calm and timely manner, let alone emotional or spiritual needs. (Personal Diary, S1, p.26)

Adding to the issues of personhood violations just discussed, my reflections broaden the concerns to include the fact that, under such pressured working conditions, there is clearly no opportunity for emotional or spiritual needs to be addressed. This discussion on insufficient staff focuses on data which acknowledges a presence of some staff, albeit inadequate numbers to consistently provide care in a timely manner. There are several occasions when, not only are staff numbers insufficient, but, in actual fact, are absent.

Absent Staff

An ‘absence’ of staff presents a more desolate situation than the concept of insufficient staff, in that ‘insufficient’ infers at least some presence of staff, although they often seem overwhelmed and stressed. The categorisation of ‘absent staff’ implies that residents seem to be ignored or abandoned for reasonably long periods of time, with no staff appearing to be present. In no way does this categorisation suggest any form of physical neglect or oversight, however, the following discussion describes the absence of interaction, connection and communication, thereby suggesting an absence of emotional and spiritual care.

The following scene is typical of many observations where residents receive very few interactions from staff:

> Observation – early afternoon. Wandered around dementia unit – nothing much to observe. Most of the residents are sitting in lounge area with a DVD on. Very few staff around - EN in nurses’ station … the whole unit has a very depressing feel about it – there are no signs of activities or interests for residents, no obvious signs of interactions, just passing comments from a PCA who walks through occasionally. This is becoming the norm – very few interactions, therefore nothing much for me to observe. I am beginning to feel an overwhelming sense of depression in here – do the residents feel the same?
> (Personal Diary, S1, p.15)

Although it is acknowledged that some of these residents may be content to rest in their chairs, the very few occurrences of personal interaction, stimulation and engagement for a long period of time seems only to create a sense of sadness and isolation. It is hard to comprehend that the amount of money saved by reducing staff for this period of time is justification for a near-absence of staff and, therefore, a blatant disregard for the psychological and, possibly, physical needs of people with dementia.

As discussed in the following extract, another example of leaving residents grouped in front of the TV with very little, if any, social interaction is disturbing, as is the fact that two male residents do not receive the support they need:

> It is mid-morning when I enter the MSU … I can hear PCAs in rooms attending to residents … no evidence of Lifestyle staff in unit. Most residents are sitting in lounge area with no activity or interaction other than the movie playing on TV. Two male residents occasionally call out, but they are not attended to. No family members or volunteers in unit. At around 11.45 PCAs begin moving residents to dining rooms for lunch. I was in the unit for around 1½ hours – there was very little interaction between staff and residents sitting in front of the TV in that time. Outside the weather was warm and sunny, but these residents did not get to experience the sunshine that morning, nor get to see it through a window - perhaps only briefly through the window in their room before being placed in front of the TV. (Field Notes, S1, pp.45,46)

Aside from the fact that it appears none of those residents are facilitated to enjoy the sunshine and fresh air during that period, their psychosocial needs are, once again, rejected. Particularly disturbing is the fact that the residents who are calling out are ignored for that period of time. It is possible that they regularly call out, and staff who are busy elsewhere choose to ignore them. There are certainly other occasions when I hear at least one of them calling out. However, an effective psychosocial environment would recognise this regular calling out as the expression of some need, whether or not it is able to be articulated, and would not leave that need unattended for such a long period of time.

Having previously noted a planned activity on the LS program, I enter the MSU on the day specified on the program, but it is clear there is no activity underway:

> On entering the unit, I notice that things seem rather quiet … all I can hear is the TV in the lounge area … I enquire about the planned activity and am told there are no Lifestyle staff available to run the program, which means there is now nothing planned for the residents … When I am leaving the site for the day, I walk past the receptionist who comments on the lack of staff in the MSU that day, a situation which was made worse because there is an agency EN in there. I ask where the regular staff are and she says they are either on sick leave or at head office for the day. (Field Notes, S1, pp.47,49)

This instance of absent staff seems to be, at least in part, due to unsatisfactory back-up plans for sick leave, as well as the organisational requirement for staff to be absent from their workplace to attend head office. Whatever the reasons, residents are, once again, left to watch television.

The concept of 'absent' staff also represents those occasions when agency staff are employed due to the absence of regular staff. At times, the consequences of the absence of regular staff who are familiar with residents' needs are critical. For example:

> EN told me that a few weeks ago, on a weekend when she was not there, [a male resident whose wife lived in an adjoining unit] became very aggressive because he wanted to visit his wife. There was an agency EN on duty at the time, and she was not able to calm him down. He was taken into his room and appeared to be relaxed enough when he was left lying on his bed. However, a few minutes later he actually broke the window in his room – presumably in an attempt to get out to see his wife. Fortunately, he only sustained minor injuries to his hand and was given a sedative to assist in calming him down. The sedative was effective, but he was not taken to see his wife until the scheduled time later in the afternoon.
>
> Because the EN [I was speaking to] seemed to be really in tune with this resident's needs, I asked how she felt about this incident a few weeks ago. She said it had upset her because she could imagine how upset the resident must have been, especially to go to such drastic measures. But she understands how it would have happened – the agency EN obviously would not have known him as well as what she does and probably thought she was doing the right thing in letting him settle himself in his room. (Field Notes, S2, p.114)

This incident highlights the importance of maintaining continuity of staffing so that staff can build relationships with residents, thereby knowing their personalities and needs. Of course, there are occasions when agency staff are needed, but, on this occasion, the agency staff member did not fully comprehend this resident's needs, nor was his need for appropriate emotional support fully understood. The physical consequences are alarming, as is the level of distress experienced by the resident. The consequences of insufficient and absent staff present risky situations for residents. Risky in a physical sense at times, but, more often, emotionally risky as residents are regularly left without meaningful interactions for lengthy periods of time.

These discussions on the consequences of roster cuts suggest that staff are regularly placed in the situation of being unable to provide care for residents in a timely and appropriate manner. It can be concluded that the personhood of residents is violated whenever their needs are not met with a positive and constructive care approach. Likewise, just as each resident is a person and must be respected as such, each member of staff is also a person and must also be respected and supported in their role. Consequently, the impact on staff now working in the aftermath of two roster reviews deserves consideration, particularly in light of a reminder in the data that 'staff are persons too'.

Staff are Persons Too

The Chaplain is someone to whom people often turn when needing assistance, however, he expresses concern that the extent of staff members' needs is often overlooked at the organisational level:

> *So how can we look after our Carers and other staff in order to look after our residents … what about a more proactive and integrated approach that says: 'hey, our staff are persons too'.* (Interview, S2, p.86)

Supporting the principle that ‘staff are persons too’ as stated by the Chaplain, the personhood of staff is discussed under the headings of: Undervaluing Staff and Mental Health of Staff.

Undervaluing Staff

Traditionally, pay rates in aged care are low. Minimal rates carry a covert message that the recipient is insignificant and unimportant, which, not surprisingly, leads to a sense of stigma attached to those who work in the industry. When a person on minimal rates endures a reduction in pay, therefore, it is clear they are affected both financially and psychologically. Caught up in a culture that seemingly finds it acceptable to place people with dementia at risk by cutting staff hours, it is relevant that staff members comment on aspects around the issues of stigma and pay rates.

A senior staff member refers to the recent roster cuts as seeming to portray the organisation’s underestimation of the value of staff as persons:

> It sometimes seems as though decisions are made without considering the effect it can have on a staff member as a person – just like they are a payroll number, rather than a person.
> (Field Notes, S1, p.65)

The suggestion here is that staff are treated more like a number than a person and, in that sense, feel mistreated by the organisation. Decisions which directly affect staff are made at a distance, both geographically and emotionally, with no sense of connection or care about the impact of those decisions.

The SM has no control over pay rates or the wages budget, and, although expressing her support for the organisation, she also cares deeply about the personal impact of the roster cuts on staff members. The SM's thoughts emerge during our interview:

> Site Manager*: And that's always been my argument – you know, when people say 'oh, it's only ½ an hour!' Yeah – but ½ hour is what to them – you know $10, $15 – a loaf of bread, 2 litres of milk. That's what it is to these people … and that's what happens with people who have never had to worry – they don't get that – that pay-day to pay-day existence, and sometimes it's pay-day to two days before pay day.*
>
> Researcher*: And, unfortunately, with the low pay rate in this industry….*
>
> Site Manager: *Absolutely! It's horrendous … so it's really tough for them.* (Interview, S1, p.71,72)

The SM's extent of support for her staff is obvious in this comment. However, the admission that pay rates are 'horrendous' leaves open the argument that this is an issue which must be rectified. At this point in time, it seems there is no person or group of people at a societal or organisational level prepared to rectify this situation.

PCAs and LS staff are significantly impacted by roster cuts, and the comments below from, firstly, administration staff and, secondly, management staff each describe the feelings of disrespect and disregard experienced by those staff members:

> There's a lot of staff complaining at the moment about how they are being treated by head office … it's like they're not cared about at all. There are staff who have worked loyally for [organisation] for years and they are having their hours cut … there's a lot of hurt and anger around at the moment, and many of the staff are certainly not feeling respected. (Field Notes, S1, p.53)
>
> To be really honest, many have felt they have not been supported or appreciated at all by head office ... they felt they had nowhere to go. It's really hard to keep up the momentum of teamwork and delivering good care when you feel as though the people at the top don't care about you. (Field Notes, S1, p.64)

These comments are strong in their expressions of frustration and anger about the organisation's treatment of staff, and many members are feeling devalued and ignored as a result of recent actions by their employer. It would seem almost impossible to work under these conditions, particularly when the actual work involves caring for people in a manner very different to the way in which staff members themselves are being cared for. Because regular working conditions for aged care staff are both demanding and undervalued, it is justifiable to consider the mental health implications for staff members, particularly in light of the extra stress they were now experiencing.

Mental Health of Staff

Staff in residential dementia care are particularly vulnerable to issues which are likely to affect their emotional and mental health. Such issues include the complexities of caring for people with dementia, regular exposure to loss and grief, unrealistic workloads, the stigma of working in dementia care, and low pay rates. These issues are intensified when staff endure periods of instability such as roster cuts and, possibly, loss of employment. Stressful working conditions such as these require an effective and functional level of support, however, this support is usually low, especially for LS staff and PCAs. A Chaplain expresses concern about the lack of effective emotional and spiritual support for staff:

> *How do they – the carers and cleaners and others - deal with grief? You know, this is still not dealt with. We have all these seminars and all the rest of it that some more senior people get to … but, so often - so often the great mass of our carers and others … you know, we talk about collaborative approaches and all the rest of it, but yet in our budget-type era, a lot of it is rhetoric actually, and it doesn't filter down.* (Interview, S2, p.85)

These comments indicate that management and corporate staff are likely to receive training and support, yet any form of grief support is rarely filtered through to the very people for whom it is needed. A large component of working in aged care is the need to regularly experience the death of residents with whom a strong relationship has developed. To a large extent, this relationship is established for the very purpose of being able to provide effective care, yet grief support is rarely provided, and there is no acknowledgement by the organisation of the impact of complex or ongoing grief experiences. The LS Coordinator also comments on the challenges of regularly coping with loss and grief:

> The Lifestyle Coordinator and I were discussing the high number of resident deaths within the last six weeks. She said it is such an emotional drain – not just the death but the lead up time, which could be hours, days or weeks. When there are several deaths in a relatively short time, the emotional drain is so much harder to cope with. She said that, to a certain extent, you harden up to residents dying, but there comes a point where you find it really difficult to cope … She said there is no loss and grief support – you are just expected to keep going without any acknowledgment of sadness or grief. One resident dies, another moves in straight away and you start all over again.
> (Field Notes, S1, p.69)

In articulating the emotional toll of continually dealing with dying and death, the comments of the LS Coordinator support those of the Chaplain. She confirms there is no loss and grief support offered to staff, and no recognition of the effects of regular exposure to grief.

As explained by an EN, the physical and mental consequences of coping with aggression in some people with dementia is another issue which impacts on the mental health of staff:

> EN: *My biggest issue dealing with mental health is the violent aggression for staff, and management not acknowledging the difficulty in that area … we had a resident … he punched … and he attacked staff … I had staff coming to me afraid … it's just awful – when you've got someone trying to attack someone else and then you have to physically restrain them and there's police involved and all that … I didn't know how to deal with this person … it's your own safety and everyone else's as well*.
>
> Researcher: *And I guess the stock standard answer then is medication. I suppose the answer would be to go to their prn – what can we give them?*
>
> EN: *Then it sometimes comes back to the point that they won't have anything – you can hardly get near them, or – you know – unless they want to punch you. They're not going to take medication.*
> (Interview, S2, pp.145,146)

These comments articulate the risks sometimes encountered in dementia care. It is not just the immediate physical risk which presents a problem, but also the potential impact on a staff member's mental health if they face regular aggressive incidents. Although some management support may be available for addressing the aggression, the effect on mental health is less likely to be acknowledged and supported.

Needing to cope with issues such as personal grief and recurring aggression in people with dementia are regular occurrences for staff. However, the consequences of the recent roster reviews have created further layers of stress with which they must cope. A senior staff member describes some of the consequences on the mental health of staff members:

> She feels that many people would say – whether it's right or not – that they were forced into the position of just looking after themselves because it has just been trying to find a way to survive and to keep your job. (Field Notes, S1, p.64)

Several issues are raised in this discussion where staff are 'forced into the position of just looking after themselves'. Mental health is impacted by issues faced on a regular basis by dementia care staff, and the additional stress caused by the roster cuts is an extra layer of mental health burden for many staff members. Consequently, staff feel the organisation has no appreciation of the mental and physical toll of caring for people with dementia. The need for staff to be understood and relieved of some of their stress levels is now discussed with an invitation for the organisation to 'come walk in our shoes'.

Come Walk in Our Shoes

The sub-theme of 'come walk in our shoes' is adapted from this interview extract, and, very broadly, captures the expressed needs of LS staff to feel valued and understood by the organisation:

> *Ask someone who knows more about these things… what you need them to do is to see what we do, and to really look around and go down there into* [MSU] *… I wonder about people at head office, what their understanding is of what it's like in the MSU … just spend a day in our shoes and see what we do.* (Interview, S1, p.57)

Similarly, a further invitation to visit the MSU is extended by another LS staff member as she expresses disbelief about the organisation's apparent perception that resident care will not be affected by the reduction in staff hours:

> *I don't see how they think these residents are not going to be affected. They really need to come down here and have a look and see the fact that they are affected. I know inside they are. Seriously. And that is heart breaking.* (Interview, S1, p.26)

Staff feel intensely frustrated by the organisation's apparent unawareness of what is really involved in dementia care. These invitations, almost appeals, for the organisation to understand and connect with the fundamentals of working in a MSU are desperate requests. The words spoken in these extracts are calling for the organisation to recognise the knowledge and expertise of the staff who work in dementia care, and to take ownership for the devastating effects of the roster reviews on the residents. While personally feeling disrespected and unsupported by the organisation, staff say they are no longer sufficiently resourced to meet many of the residents' needs, and feel powerless to do anything about it.

In the same vein as the 'come walk in our shoes' appeal, an EN explains the need for the organisation to focus on employing PCAs who are able to effectively communicate with people with dementia. The message here is that task-focused skills are less effective than the ability to successfully connect with residents, thus building a meaningful relationship from which personhood care emanates:

> *If you're going to work in a Memory Support Unit, communication is it … I don't care whether you can, you know, shower six people in half an hour or whatever, if your communication isn't there and your connection … but some people don't understand that … it's so underrated – the care in there I think … there's still this stigma around being a nurse … but there's a lot to be said for the basics and having a rapport with someone at the end stage of their life when it's the most important.* (Interview, S2, p.138,139)

This extract suggests that efficiency in showering residents continues to be an organisational expectation of PCA's duties rather than an ability to connect and communicate effectively. The determination of this EN to rise above the stigma, the 'underrated' culture and unrealistic organisational expectations is reflected in her approach of encouraging PCAs to take the time to build relationships with residents. These reflections of the EN make a strong case for rejecting those organisational practices which violate the personhood of staff members.

Continuing the expression of need for organisational understanding, a senior staff member voices her disappointment at how staff have recently been treated by the organisation, and indicates that a more productive alternative to showing disrespect is to focus on inclusion and teamwork:

> [The senior staff member] thinks it would be so nice to feel as though head office were also part of the team at this site – but it often feels as though they have no idea what it is like working in aged care, and doing the day to day things on the floor … they (indicating staff) don't feel valued, respected – even acknowledged … many of the PCAs feel their contributions to the organisation are ignored – especially given the really low pay rates in aged care. (Field Notes, S1, p.65)

In the context of the organisational structure, PCAs are disempowered and devalued, and during the roster review process the disempowerment has been significantly increased. These thoughts by a senior staff member give a voice to PCAs by acknowledging their feelings of disrespect and disempowerment, particularly in light of their loyalty to the organisation. This is yet another expression of the organisation's misunderstandings about the daily experiences of working in dementia care.

This research probing the personhood of staff raises questions about the organisational culture's attitude toward staff members. As expressed in this interview extract, the organisation has good staff who are passionate about the people for whom they care. In return, the organisation is requested to show appreciation for its staff, an action which will have beneficial flow-on effects in the care provided:

> *It's the appreciation of staff I think and when you've got really good staff that are passionate about what they do, you need to look after them, and then they will give great care and it flows on to the families and everyone else.* (Interview, S2, p.147)

In this discussion on problems with staffing it is demonstrated that organisational roster cuts have resulted in inadequate levels of staff to provide effective resident care. The personhood of staff has also been raised in light of staff feeling undervalued by the organisation, as has the potential for mental health issues for staff working in dementia care. In view of the roster cuts and their consequences, staff are experiencing levels of disconnectedness within the organisation. Because many staff members are feeling undervalued and marginalised, it is appropriate, in this chapter on personhood violation, to discuss whether residents for whom these staff are providing care are also feeling disrespected and marginalised.

6.3 Marginalisation of People with Dementia

The approaches to dementia care discussed in this chapter do not describe an organisational culture which is intent on respecting and maintaining personhood. Whatever the cause of, or reason for, any interaction or incident which undermines personhood, the result for the person with dementia is some degree of marginalisation, separation and isolation. Therefore, violation of his or her personhood occurs. Following a brief discussion on ambiguous dialogue, marginalisation of people with dementia is discussed under the themes of Control, Stigmatisation and Exclusion.

Ambiguous Dialogue

The first indication that ambiguous dialogue exists around personhood care is during my preliminary meeting with the SM. She assures me of her support for personhood care and is keen to support my research. However, my concerns about some of our conversation are noted in my personal diary:

> The Site Manager is certain I will find that personhood of residents is very much respected here, and that the standard of care is quite high … she told me that some staff are not happy with recent and ongoing decisions made by head office, but says resident care has not been compromised. The decisions are around financial issues and have resulted in cuts to staff hours. I do wonder, therefore, how she can be so sure that resident care has not been compromised – if there are less staff then surely residents are receiving a lower standard of care. She believes head office are doing the best they can under very difficult financial circumstances – it is the current nature of aged care and will get better. I understand what she is saying, but wonder how she defines 'doing the best they can'. It would seem she is supporting decisions to cut staff as if there were no other options. And I question how and when 'aged care will get better'. In her opinion, what is going to change? (Personal Diary, S1, p.1)

Given the severity of the roster cuts, it is difficult to comprehend how the care of residents has not been affected as suggested by the SM, and I deliberate over her views of the overall situation. Ultimately, however, there are instances of personhood violation, although it is possible that staff involved are of the mindset that, because some care practices are routine, they do not deem such practices as personhood violation. On a personal level, the possibility of this mindset is an uncomfortable thought:

> As I watch staff interacting with residents at lunch time, I wonder if I have become desensitised about some things in aged care, having worked in this environment for so many years. Maybe it is easy to get used to seeing and hearing things being done in a particular way, that you actually accept this is the best way, or perhaps the only way to do things. I'm not sure. (Personal Diary, S1, p.23)

But, regardless of the current mindset or dominating culture, incidents where people are marginalised and, therefore, their personhood is violated, need to be identified. Marginalisation occurs when the person with dementia is controlled, as discussed below.

Control

A form of control occurs when a person with dementia is deceived, manipulated or coerced into compliance. One such incident occurs when a PCA responds to a resident who has been calling out for some time:

> A PCA walks in and turns the TV down … then walks over to the man who was calling out for help, saying '*What's the matter* (name)'? He keeps repeating that he wants help but doesn't name anything specific. She tells him he will have to wait because she is busy with someone else but will be back in a few minutes. I am there for another 45 minutes and she doesn't return in that time. (Field Notes, S1, p.46)

This resident is in need of physical or emotional support, and, because the PCA holds the power at this moment, she is able to control the situation through deceit. However, it must be recognised that the PCA may respond in the only way possible under the circumstances, particularly if she is attending to several residents at the same time and is required to complete many tasks within a time limit.

On another occasion, a similar form of control is observed when a PCA is attempting to seat residents at the dining table:

> PCA: *'Come on, time for lunch'*.
> Resident: *'I don't want lunch, I want to go home'*.
> PCA: *'You need to have lunch first'*.
> Resident: *'Then I can go home?'*

> PCA: *'Yes, you can after lunch.'*
> It was clear from the general vibe of the situation and the PCA's facial expression that this resident was not going home after lunch.
> (Field Notes, S2, p.98)

The PCA's assurance to this resident that he is going home after lunch is a deliberate lie, used to coerce the resident into compliance with the organisation's routine. It is highly probable that the PCA and, indeed, the organisation would argue that this resident will not remember this conversation after a short period of time. Whatever the justification, this resident's personhood is violated through manipulation and control.

In many ways, the dining room setting is a very regimented and controlled space, and some residents are disempowered through interactions with staff members:

> One lady who is sitting at the far end of a table has finished her lunch and attempts to stand up holding on to the table. A PCA asks her where she is going. When she says she wants to go back to her room, she is asked to wait because it is too difficult to get her walking frame passed the others sitting at the table. She sits down again and waits for another 10 minutes or so, until PCA says: *"Okay* [name]*, I can take you back to your room now. Let's go'.* (Field Notes, S1, p.38)

Although it is clear that manoeuvring the walking frame is a little inconvenient, it is possible, and, therefore, this person's needs could have been met when she first asks. This resident is disempowered when her request is not initially granted, and then disempowered again when the PCA states in a paternalistic tone of voice that she is now ready to go. Disempowerment is a clear indication of personhood violation, and is inappropriate in the dining room of this lady's home. But, in that moment, her home is not defined as a home, but as a workplace.

A further example of disempowerment in the dining room occurs over a conversation about menu choices:

> When all food is served, PCAs sit down alongside residents to help feed them. One resident asks what is on his plate and he is told it is fish and vegetables. He tells the PCA that he doesn't like fish, and she tells him that is what he ordered. He perseveres with eating about half the meal and leaves the rest. (Field Notes, S1, p.37)

It is organisational practice that residents are given choices about their upcoming meals, which, for all intents and purposes, is good personhood practice. However, disempowerment can occur through confusion, misunderstanding or not hearing the question, and feeling pressured to give a quick response. In this situation, either the PCA or organisational policies prevent this resident being offered alternative food, with the result that he does not receive all his nutrition needs at that time.

Traditionally, institutionalised care is dependent on adherence to routines and timetables which often result in disruption to residents' thoughts and actions. For example:

> A door is opened and trolley wheeled in. Afternoon tea is now being delivered even though Lifestyle still running the activity – quite disruptive. Residents try to concentrate on the Word Game, while kitchen staff walk around amongst group, setting up small coffee tables, asking residents what they want to drink, distributing afternoon tea. All staff trying to be professional and accommodating but it does seem disruptive and some residents clearly finding it difficult to maintain their focus on the game. (Field Notes, S1, p.13)

This imposition on residents' concentration and engagement is quite troubling to me, as noted in my personal diary:

> I imagine it would have been very difficult for residents to concentrate on the activity while this was going on … I wonder if the afternoon tea interruption is scheduled to happen before completion of the activity so that it fits in with the facility's staff rosters, in other words, giving priority to the facility's needs rather than the residents' needs.
> (Personal Diary, S1, p.12)

On reflection, my diary entry is not entirely accurate. I know for sure that maintaining concentration is difficult for these residents because I can recall the confusion and annoyance on the faces of those sitting nearest to me as they tried to ignore the interruption and continue participation in the game which they were enjoying. Also, there is no doubt the afternoon tea interruption occurs to comply with staff rosters, thereby the facility's needs are clearly prioritised over the residents' needs.

As explained by the LS Coordinator, another form of disruption to residents' activities is the organisational requirement for her to carry her phone at all times, even during engagement with residents:

> *I'm in the middle of an activity, and as the Coordinator as well I have my DECT phone on me, I'll get a phone call so I go 'excuse me, sorry, I'll be back in a minute, I won't be long' and I quickly have to jot down information, you know - carrying pen and paper and everything on you … you know, it's a bit hard.* (Interview, S1, p.27)

This situation just described is confirmed when the LS Coordinator is required to interrupt an interactive music session with residents:

> (Lifestyle Coordinator) suddenly stands up and walks out to the corridor, answering her phone as she goes. She is gone for just a few minutes – as she walks back past me she says: *'I'll deal with that one later'.* (Field Notes, S1, p.23)

Although this disruption is only brief, it does break the concentration of the residents and the LS Coordinator. This is quite significant in the current context of many activities now being cancelled, and the duration of those that remain now reduced due to the roster cuts. Under these circumstances, it is reasonable that alternative arrangements be made for answering the phone.

This discussion shows how various forms of control over residents occur, such as disruption of reflections and actions and a disregard for reasonable requests. Another form of marginalisation is stigmatisation.

Stigmatisation

Older people with dementia already endure a certain amount of societal stigma (Alzheimer's Australia 2017), and it seems the mindset of stigma is infiltrated into dementia care. Stigmatisation involves any interaction which treats the person with dementia as if they are an object or an outcast, actions which, of course, increase feelings of marginalisation. A staff member describes incidents where two residents are treated in a manner resembling objectification:

> [Female resident] *was complaining that she had been left on the bed pan for a long time, and she'd also had two staff members who had spilt her pan when they were taking it so her whole bed had to get changed … then on Friday I went in there after lunch … she was lying down with her plate upside down, food all over her nightie … she had obviously been trying to get some of it into her mouth … and the same with another resident that morning, who I also found at this angle with her weetbix like this all over everywhere.* (Interview, S1, p.15,16)

The indignity and lack of care for the first resident is distressing. Being left on the bed pan indicates significant neglect, and spilling of the bed pan indicates carelessness, both incidents possibly caused by a need to complete too many tasks at the same time. Regardless of the reason, the trauma of undergoing a bed change adds to the humiliation and stigmatisation experienced by this resident. The further indignity caused by inappropriate lunch-time care practices is extreme stigmatisation. Not only is this resident not supported to eat her meal, but she suffers the indignity of helplessly lying in bed with the realisation that she cannot successfully feed herself. Alarmingly, another resident is also found with food spilled on her bed while she is sitting in a dangerous position in her bed. These occurrences of significant indignities and stigmatisations are particularly disturbing.

Staff members are continually under pressure to complete several tasks in a short period of time, and this pressure often leads to residents experiencing objectification.

For example:

> A PCA walks up behind resident who is in a princess chair – she is talking across the room to another PCA. She lowers back of chair without resident even knowing she is there. Resident appears startled. PCA wheels chair away without explaining to resident why or where they are going. This now happens a few times – PCAs moving residents in princess chairs from behind without warning to residents. PCAs seem very task-focused. (Field Notes, S1, p.14)

Moving the chair without first advising the resident reduces the person to the level of the object, in this case, the chair. The message is that a chair is being moved, rather than the chair is being moved because there is actually a person in the chair.

In a further example of objectification, I note an interaction between a PCA and a resident as they walk to the dining room:

> PCA is taking a female resident to the MSU dining room. She is holding her hand but is walking about three paces in front of her as if trying to hurry her. Resident is supporting herself with handrail along corridor and looks a little hesitant. They arrive at dining room door and PCA says: '*Here we go* (name), *we finally made it'* (with emphasis on the word 'finally'). The resident has not spoken during this time – she looks a little out of breath. (Field Notes, S1, p.18)

I was genuinely surprised to observe this incident of a PCA outpacing a resident because I have noted that this staff member is usually gentle and patient with residents. Reflecting on this incident later, I enter the following thoughts in my personal diary:

> Interactions by one of the PCAs were great examples of maintaining personhood – she assisted residents with their lunch with respect and patience … it was interesting that, just prior to lunch, I saw her 'outpacing' a resident – walking faster than what the resident was able to. Having observed her during lunch, I would think 'outpacing' is very much out of character for her – she was under a lot of pressure to get tasks done in this period before lunch … as much as I don't like the consequences, I can see how very easy it would be to slip into a mindset which focuses on tasks – especially when there are strict routines and time restrictions – and clearly not enough staff on the floor to enable sufficient focus on the person. (Personal Diary, S1, p.13)

Labelling is a form of stigma which signifies disrespect for the person with dementia. Although the following incident does not occur in front of the particular resident, it is an example of how staff may undermine the value of a person with dementia. In this case, a staff member has reported to an agency EN that a resident has not eaten any lunch. The EN's response, which is relayed during an interview with the staff member, implies that the person's views are not worth listening to because she has dementia:

> *Look you probably don't know that the residents tell you all sorts of things, there have been three Carers on and we have given everybody their lunch, so if she's saying she hasn't had her lunch don't believe her because that's part of dementia.* (Interview, S1, p.15)

This comment identifies people with dementia with the label that they are not to be believed, thus implying they have no credibility. Also, the EN is attempting to hold control over the resident by stating that what the resident says is wrong, but what she, the EN, says is correct. This entire response is inappropriate in its disempowerment of the resident, as well as attempted disempowerment of the staff member relaying the message who, in fact, has herself worked in dementia care for several years.

In recent times, improvements in dementia care have abolished the terminology around 'babies' in relation to people with dementia. However, remnants of this culture continue to exist through ongoing care practices which lead to infantilisation of people with dementia. As described in this extract, an incident occurs in the dining room which can easily be construed as infantilisation, and on which I later reflect:

> Most residents have clothes protectors placed around their necks, shaped like large bibs and velcro fastened at back of neck. Residents accept this willingly (or so it seems) and it seems to be an automatic task done by PCAs – the PCA would usually tell the resident what they were going to do, but quite often the resident probably wouldn't have heard because the PCA was standing behind them at the time.
> (Field Notes, S1, p.9)

> The placing of clothes protectors around residents' necks has always troubled me … I have never liked this practice all the years I have worked in aged care. It seems patronising and infantilising. But, like so many things, it is just routine and probably not even thought about twice by anyone else. (Personal Diary, S1, p.10)

Another incident describes interactions between a staff member and a resident which, in my opinion, sounds like infantilisation. Following this extract, my personal diary entry acknowledges the slight possibility that this conversation may not have been inappropriate, nevertheless, the PCA's comments are heard by many people in the room:

> PCA pulls up chair and sits alongside a male resident whose food has been on the table for several minutes … long periods of silence while she feeds resident … resident begins to intermittently close his eyes while eating. PCA says: *'Keep your eyes open while you're having lunch.'* Repeats about three times. Each time the resident replies *'I don't want to.'* Eventually the PCA says: *'You're a grumpy bum today, aren't you?'* in a fairly loud voice. The resident replies: *'I'm not grumpy.'* PCA says: *'Yes, you are – you're a grumpy bum'*. (Field Notes, S1, p.10)
>
> I was quite shocked to hear a resident being called a 'grumpy bum'. It may have just been regular banter between the two of them, in which case it could probably be seen as meaningful interaction. But – I'm not sure, I didn't hear it again during subsequent observations, and it was said loud enough so that many other residents could hear.
> (Personal Diary, S1, p.10)

Stigmatisation of people in residential dementia care continues to occur in various ways, in spite of improvements in recent times. Further instances of personhood violation also occur when people with dementia are excluded from meaningful interactions, either through the person or their care needs being ignored.

Exclusion

One of the negative impacts of roster cuts on the residents is that they are frequently ignored emotionally, spiritually and socially. A LS staff member expresses concern that, since her hours have been reduced, she no longer has time to regularly visit a particular resident meaning that he is excluded from emotional support which he needs at this time:

> *He's been very distressed about his daughter being away and so a couple of times I've tried to spend time with him, and I've felt that I can't, that I'm being pushed out and rushed off – you know, come and do this, and this has to be done.* (Interview, S1, p.46)

This resident currently has no family visits because his daughter is away on holidays. Not only is he missing the social interaction, but he is very deeply missing the company of his daughter. Because of the roster cuts, he now is also being excluded from appropriate social interaction with staff.

Attending to the toileting needs of residents in a timely manner is an ongoing issue when sufficient staff are not available, as indicated in this extract:

> Resident: *'I would like to go to toilet'*. Lifestyle staff tells PCA about the toilet request but doesn't acknowledge request to the resident. PCA arrives about 15 minutes later and wheels the resident out of the room, but doesn't speak to him. This seems a long wait for toileting.
> (Field Notes, S1, p.15)

Because the LS staff member did not respond directly to this resident, the request is ignored from his perspective. After a considerably long period of time, he is still excluded from any form of communication when he is eventually wheeled from the room.

The following extracts describe occurrences of psychosocial care being withheld, and residents experiencing exclusion and banishment – in both a physical and psychological sense:

> Those left in main lounge area just sitting there with very little interaction with staff. TV is on … some residents look at TV screen occasionally or watch anyone walking past. (Field Notes, S1, p.3)
>
> I'm finding there is an overwhelming lack of interaction (or at least meaningful interactions) between staff and residents.
> (Field Notes, S1, p.27)

> I do wonder what it is like for the residents sitting in front of the TV. There is no indication of any planned activities or any other form of interaction with these residents. Many of them are dozing in their chairs, or else aimlessly looking at TV or at their surroundings.
> (Field Notes, S1, p.39)

My concerns about residents being excluded from appropriate care are supported by a staff member who is quite alarmed about the severity of roster cuts to LS hours:

> A lot of their social time has gone – group activities, and also personal visits. The volunteers still do some of that, but it’s not quite the same, and, in actual fact, some of the volunteers have left anyway. So that means if a resident doesn’t have family or friends in to visit, they are quite often just sitting around with not much happening.
> (Field Notes, S1, p.54)

Various forms of personhood violation are presented in this discussion where people with dementia experience marginalisation through being controlled, stigmatised or excluded. Personhood is also impacted by characteristics of the physical environment in which the person lives, and the extent to which they feel at home in that environment.

6.4 When Home is not homelike

Over a period of several years, I visited both Sites 1 and 2 on numerous occasions and formed my own opinions about the living experience in each one. However, I have no way of knowing how residents at either site feel living within these facilities which are now their home. This discussion on an aged care facility being homelike is presented under the themes of: Living in an Institution; Intrusion of Space; and Contested Space.

Living in an Institution

Although the scope of this study does not provide any means of learning first-hand the experiences of living within an institutional environment, there are some observational insights into this experience. It seems reasonable to assume that, for most people, living in the privacy of an environment in which they feel comfortable and safe would contribute to their ongoing sense of personhood. It is for this reason that it is important to pursue the topics of home and privacy in the context of discussions on personhood.

Attempting to understand the experience of living in an institutionalised environment, I note stark contrasts between a traditional family home and the environment in which these people are now living:

> A home does not have long and wide corridors, various cleaning signs placed on the floors, and notices and signs stuck on doors and walls. A home does not have excessively large public areas yet almost no private space. But maybe residents are happy enough to have their own room with their own possessions around them … what possessions they do have are sitting amongst the institutionalised items in their rooms – the over-way, the single bed, the hand basin in the corner, the soap dispenser on the wall. (Personal Diary, S1, p.7)

On one occasion, I pay particular attention to a resident's room, trying to view it as a home rather than just another room in the facility:

> I am sitting in the corridor facing into a resident's room. No one is in the room at the moment. It is a single room furnished with a bed, bedside table, armchair, small TV on an entertainment unit, and an over-way table alongside the bed. Room is clean and tidy. Judging by the pink flowers on the bedspread I presume this room belongs to a female. It strikes me how unhomely the room looks. I walk over to the door and can see a few personal items scattered around the room. I wonder what has happened to the rest of this lady's possessions, and how she now copes without them in this home. There is very little space here for her to have personal possessions. (Field Notes, S1, p.24)

Even though I am only standing at the open doorway of the room just described, I do feel that I am intruding on this person's privacy. Intrusion of a person's space in residential dementia care occurs so frequently that it is rarely given any consideration, however, from a personhood perspective, it is an issue which requires further discussion.

Intrusion of Space

This space called home is regularly visited by people who, to the residents living here, could easily be viewed as intruders. At various times during observations, it occurs to me that I could be construed as one of those intruders. I find this thought to be a little distressing:

> At times I feel quite uncomfortable here as a researcher. I am intruding in other peoples' homes. The people who live here didn't invite me, they had no say in whether I could come, don't know who I am or why I am here. They may see me writing notes or just watching them – does that worry them? I would be very upset and anxious if someone came to my home uninvited, walked around or loitered and was writing notes of their observations. And rightly so. So it doesn't feel right that I can walk into the home of these people and do this … I feel uncomfortable. To me, this is symptomatic of how we treat older people in residential aged care. On the one hand, we tell them that this is their home and they are welcome to treat it as such. But we also say it is okay for a stranger to walk into their home and observe what they are doing. I know that mine is not the only role that does this. Apart from other researchers (student or academic) who feel this is their right, there are government accreditation staff, staff from head office or other sites, visitors, maintenance people, and many other people from the general public. This is just second nature to those of us who visit, but each time I visit it becomes increasingly apparent to me that I am intruding … just because it is widely accepted by most people that it is perfectly okay to be here, that doesn't necessarily mean it is acceptable from the residents' perspective. Yet they have no power to change this. (Personal Diary, S1, p.25)

Following my reflections on intrusion of space, I note the lack of privacy for residents, even from within their rooms:

> There's the constant noises outside, people walking passed residents' rooms – most of them looking in through the open door as they pass.
> (Personal Diary, S1, p.8)

> It strikes me that there is nowhere that is private for residents and where they will not be disturbed. Not even their own rooms. There is no peace and quiet. Staff (and sometimes other residents) walk into private rooms, sometimes touching private possessions.
> (Personal Diary, S1, p. 26)

Of course, these thoughts on intrusion are my own personal reflections and it is beyond the scope of this thesis to test their accuracy. However, if there is even a small element of truth in my reflections, it is likely that violation of personhood is experienced by some residents if they perceive that someone is invading their private space. On the other hand, some may gain comfort, security and social connection from knowing that other people are within the environment which is their home.

My reflections raise questions. But these questions are worth asking in the context of researching what are meaningful experiences for people with dementia. It is worth considering whether the many 'outsiders' who enter the homes of those with dementia contribute or detract from the personhood of those whose home it is.

Contested Space

Although a RACF is, to a limited extent, a building which is open to the public, there can be disregard for the fact that the facility is home to the resident, as well as a workplace for staff. Visitors to the facility have the potential to interrupt the provision of quality care for residents and, therefore, disrupt the processes of personhood preservation. In one such incident, the lines are blurred around the contexts of 'home' and 'workplace'. These comments describe the consequences of the actions of a visitor who works externally to the facility:

> *It shook me to my core … all that I was doing was making sure that the residents' needs were being met, and all that I could see was the fact that there was somebody in the way … I will be forever fearful of that person … and then I think that – oh, my goodness, this is how he makes me feel, and I'm a very articulate, confident person – what do the residents feel from him?... If they had given me the courtesy … people from head office ... they kind of step into a role here – when this is their* (indicating residents') *life … it definitely feels like control … and I just don't get that in the sense that this is a caring industry.*
> (Interview, S2, pp.98,102,103)

The descriptions in this interview extract are clearly distressing to this staff member, as recorded in my personal diary:

> [Staff member] was very concerned that the culture was changing … the 'person' seemed to be decreasing in importance. She mentioned an incident where the overbearing nature of an employee from another location had significantly hindered interactions with residents and had longer-term implications for staff and volunteers. The incident clearly had a huge impact on this staff member – especially the fact that an employee of this organisation would have such an uncaring and controlling attitude towards staff and residents. (Personal Diary, S2, p.47)

This incident symbolises the concept of contested space in several ways. The external person visits the facility without invitation, and is occupying a meeting room without seeking permission from anyone at the facility. The lack of courtesy in obtaining permission from facility staff indicates he feels this space is his to occupy when needed. As it happens, although the room is unoccupied when he enters, it is, in fact, needed a short time later to assist in meeting the needs of residents. Therefore, the function of this room at this point in time is in contention between three purposes – the residents' home, the workplace of facility staff, and the meeting room of an external staff member. While this scenario involving external staff is probably rare, more regular occurrences of space being contested as both a home and a workplace are obvious, such as the dining room:

> Kitchen staff wheel in trolleys of food to servery area. The food is served on dinner plates by kitchen staff while PCAs stand and wait, and then PCAs take to each resident. Fairly loud chatter amongst staff during this time, mostly talking to each other, not residents. Quite a noisy process – as well as talking there are sounds of banging plates/dishes and lifting and replacing of lids on bain-maries.
> (Field Notes, S1, p.9)

In the workplace context of this situation, it is reasonable to expect that trolleys, crockery and metal lids will make considerable noise and, when people are talking to each other against the backdrop of that noise, their voices will be slightly raised in order to be heard. However, this scene is also occurring in a home, and those seated at the tables – the residents of that home – may well consider the extreme level of noise to be excessive and stressful.

An EN's approach to distributing medication during lunch time indicates that, in his opinion, the dining room is a workplace:

> EN enters dining room with medication trolley. Delivers medications to various residents with very little verbal interaction – only occasionally 'here you go' as he delivers medications to residents, then supervises to ensure meds are swallowed. When finished he leaves room having said very few words to anyone (residents or staff) and made very little eye contact with anyone. Seems like a very regimented and impersonal process. (Field Notes, S1, p.11)

The impersonal manner in which these medications are given to residents is indicative of a regulated workplace, and the presence of the medication trolley adjacent to a dining table is representative of the medicalised approach to dementia care. The EN's overall demeanour implies that he considers this space to be a workplace, with no acknowledgement that the space is, at the same time, a dining room in a home.

This chapter has presented insights into care practices which result in personhood violations for residents and staff, with various organisational and physical issues contributing to such a result. The physical environment is institutionalised, therefore, people with dementia are confronted with living in a home that is not homelike, mainly due to regular intrusions into their private space and the need to live in a home that, on a regular basis, is treated more like a workplace than a home. As a result, it is possible that many of these people feel misplaced and unsettled. Problems with staffing stem from organisational implementations of roster cuts which result in inadequate numbers of staff available to effectively address residents' needs. The personhood of staff is undermined when staff feel undervalued and unappreciated in their efforts to provide a high standard of care. Levels of organisational disconnectedness are evident when an organisation does not appear to understand the essentials of quality dementia care and, consequently, imposes barriers on the delivery of psychosocial care. Although it is highly unlikely that personhood violation is the intention, evidence is provided that, even in aged care facilities which espouse to person-centred care values, the personhood of people with dementia is violated in various ways.

The violations occur because the power of aged care organisations succeeds in psychosocially disempowering those for whose care they are responsible, as well as disempowering those to whom they have given the responsibility of providing that care. No matter what justifications an organisation may convey for its decisions, the consequences are that vulnerable and marginalised people with dementia are disrespected and devalued, and their quality of life is impacted. Likewise, care staff, who are already on low wages, experience cuts to their hours, job insecurity, overwhelming workloads, and, frequently, the inability to perform their roles to the standard which they know is necessary. In contrast, the following chapter discusses care practices which enable personhood preservation in dementia care.

Chapter Seven: Personhood Preservation

Outcomes of the Study (2)

> *It's somehow what we do continues to* ***make a difference for this person*** *and for our world and we become better communities, we become better people in the process of this as well.* (Interview, S2, pp.81)

Issues around the care of vulnerable people are framed by social justice and human rights agendas. Therefore, the previous chapter on Personhood Violations sits uncomfortably in a social justice framework of caring for people with dementia. And it should feel uncomfortable, no matter how powerfully any attempts to justify such violations may be presented. The following statement by Sabat (2018, p.xii) clearly articulates why personhood violations are not acceptable:

> How a society treats its most vulnerable members clearly reflects that society's character. A 'right' is something that requires no justification. People possess human rights as a matter of definition. People living with dementia have not, as a result of their diagnosis, lost their humanity or their human rights unless those of us deemed healthy decide to strip that humanity and those rights from them, in which case dementia alone is not to blame.

Following the previous discussion on the first major identified theme of Personhood Violation, this chapter discusses the second theme of Personhood Preservation under these sub-themes: 1) Organisational Connectedness; 2) Confident Staff; 3) Valuing the Person; and 4) Homelike Environment.

7.1 Organisational Connectedness

An organisation which is focused on personhood preservation endeavours to maintain positive working connections between all levels of staff. Connections within the organisation are discussed under the themes of Valuing and Understanding Staff; Stability and Continuity in Staffing; and Supportive Management Style.

Valuing and Understanding Staff

> If an organisation is genuinely committed to providing excellent care for its clients – if it is committed to their personhood – it must necessarily be committed to the personhood of all staff.
> (Kitwood 1997a, p.104)

As noted in Kitwood's comment, personhood of dementia care staff is very closely aligned to the personhood of the people for whom they are caring. The previous chapter contained a discussion on personhood of staff, which emphasised the Chaplain's reminder that staff are also persons. A longer extract from that interview is included here to highlight the importance of maintaining the personhood of staff:

> Chaplain: *What about a more pro-active and integrated approach that says 'hey, our staff are persons too'*.
>
> Researcher: *... when I'm talking about persons, I'm talking about staff members and residents. I don't see how you can separate those.*
>
> Chaplain: *No.*
>
> Researcher: … *if you are not looking after your staff, how can your residents be well looked after?*
>
> Chaplain: *Yes, that's right. Correct. That's right.* (Interview, S2, p.49)

This discussion on valuing and understanding supports the above comments which state that staff are also persons and, therefore, the organisation has a responsibility to value staff members as persons and to understand and support their working role.

The role of the Clinical Nurse (CN) includes management of PCAs, therefore she has a good understanding of the daily experiences of staff as they care for people with dementia:

> She [Clinical Nurse] believes staff want to feel appreciated and to be able to come to work and have some fun. And that sounds a bit weird, because this is not the sort of place you associate with fun, but aged care is such hard work – physically and emotionally. There are so many people who are frail and generally not well, and it can be so draining caring for people with dementia. And there's the deaths – staff are constantly caring for people who are dying, and then they die, and next thing there's someone else in that bed, and there's no time to get over the last death. She said it can really drain you, so when she refers to fun, she means they need something to balance out all of that. When

> anyone is constantly giving out, they need some positives back in return. (Fieldnote, S1, p.63)

The CN's comments acknowledge the physical and emotional intensity of working in aged care, as well as the ongoing grief featured in this type of work. Yet she also explains that this hard work can be balanced by being appreciated and enjoying the 'fun' of being at work, which, perhaps, could be interpreted as job satisfaction, relationships with residents, and friendships with other staff. In another extract, the CN explains the importance of teamwork and peer support in helping staff to feel valued:

> CN believes that, for a person to enjoy coming to work they need to have friends – have a good relationship with the people at work. Although a person will always get on with some people more than others, staff need to know there are at least some who will support them, they can talk to, to feel part of the team. Teamwork is really important – and that spirit of teamwork hasn't been at this site much recently, but is now slowly coming back. Feeling part of a team, so that the person feels supported, but they also need to play their part to support others in the team. And that includes everyone – especially in a place like this – management, carers, maintenance, lifestyle – every team member has to contribute, but also needs to know others are there for you. (Field Notes, S1, p.64)

In expanding on the value of teamwork, the CN explains the need for both giving and receiving support from other staff members. These comments are supported by the Site Manager (SM) who speaks of the need for staff to gain job satisfaction from their work:

> *I think they just get better job satisfaction from it. It's one hell of a job – it's a tough job, but to be able to go home - and this is what we discuss at interview too – you need to go home knowing you've done a good job – hard job – but know that, even if it's just one person you made smile, or, you know, you really felt good as you left them in their room or whatever you did – I mean, the staff need that every bit as much as the residents do.* (Interview, S1, p.34)

These comments suggest that staff at Site 1 are not sufficiently supported by the organisation to deliver care capable of preserving personhood, and, to a large extent, that is supported by the data as discussed in Chapter Six. It is possible, however, that the ongoing support of management at Site 1 creates a sufficiently high level of personal worth and wellbeing within staff, which, for the time being at least, is enough to engender a feeling of being valued and understood as a person in the role of caring for people with dementia.

Much of the data presented in Chapter Six relates to the consequences of extensive roster cuts undertaken by the organisation. Irrespective of the organisation's justifications for these roster cuts, there are several negative outcomes, such as instability and anxiety amongst staff members and, on several occasions, insufficient staff available to adequately meet residents' needs. These outcomes significantly contribute to violation of personhood for both residents and staff. However, with the focus of this chapter on personhood preservation, it is now appropriate to discuss evidence around stability and continuity in staffing.

Stability and Continuity in Staffing

Currently in Australia, residential dementia care exists within a challenging economic climate, and, historically, when finances are limited, reducing staff levels is considered an appropriate step towards reducing expenditure. However, as will now be discussed, an organisational culture which maintains a stable working environment is an important factor in supporting personhood preservation.

As indicated in these two extracts from Site 2, stability in management personnel provides an effective framework for a stable working and living environment, and is appreciated by staff:

> Clinical Leader: *We are really lucky here because there has been really stable management – yeah, our management is really stable*

> *which might not be the case at other places, and that really helps with security and other things.* (Interview, S2, p.55)

> Researcher: *But the stability of this place, to a large extent, has been because so many of you guys have been here for so long – you are key people.*
>
> Lifestyle Coordinator: *So long. And we are extremely respectful for our team leaders, and that is why there are so many things that they have rolled out here at* [this site] *which haven't been taken to other places because we do – we respect them, we just think we'll give it a go, our minds are open. You know, the communication is very good, it's not about being told 'this is what you are doing' so – you know – it's really interesting when you are open it doesn't seem to be hard work.* (Interview, S2, p.59)

Stability in management plays a vital role in providing security, respect, trust and open communication between all levels of staff. Likewise, as explained by a senior manager, a stable workforce helps provide security and relaxation for residents:

> The familiarity of regular staff – especially for people with dementia – helps the residents to feel more secure and relaxed. It's important to have a stable pool of staff to call on. (Field Notes, S1, p.63)

An environment of familiarity and routine for people with dementia is easier to provide when stability in both management and the workforce are in place.

The benefits of a stable management and workforce at Site 2 are obvious to me, as noted in this personal diary entry:

> This facility has a very stable staff structure – a large number of original staff are still here from when it opened around 10 years ago. The management have been very good at maintaining a reasonable amount of autonomy, and seem able to satisfactorily absorb any corporate issues. There is a tremendous sense of teamwork here – across all levels of staff. (Personal Diary, S2, p.48)

Such stability enables confidence and autonomy amongst staff members, creating a combined ability to withstand a certain amount of external pressure. Many of these staff began working together when this facility opened ten years ago, and, in so doing, they worked as a team to overcome the challenges of bringing together a large number of new residents into one facility. From these beginnings, this facility is built on strong teamwork, confidence and stability.

The constant need to employ agency staff interrupts stability in staffing. In spite of recent roster cuts and staff resignations, the SM at Site 1 reports that the need to employ agency staff is gradually decreasing:

> *Our use of agency staff has been one of my major KPI issues – it's been in the red for a while. Last week we were in the green – so we have gone from about 19% - gradually dropping by about 1% every week with recruitment. 13% was the best that I got - last week it was 3%. I'm so pleased - it is brilliant. Brilliant!* (Interview, S1, p.35)

Although the SM's comments reflect the organisation's budgetary considerations rather than personhood issues, a reduction in the use of agency staff is still an outcome which benefits personhood preservation.

Management at Site 2 go to great lengths to avoid employing agency staff whenever possible. These extracts reflect the views of two ENs who are grateful for management's efforts to limit use of agency staff:

> Management go to great lengths to avoid agency staff in MSU if at all possible, so that the residents have continuity of familiar faces around them, and routines can be maintained as much possible. It is very rare to have an agency EN during the week, but on weekends it does happen more frequently. She says she often notices escalation in behaviours when agency staff are on – she knows this either from reading progress notes or from verbal reports from PCAs who are on duty at the time. But she did express her gratitude that management do the best they can to maintain continuity of staff.
> (Field Notes, S2, p.115)

> Researcher: *Do you normally have the same Carers?*
>
> EN: *Normally I do. There's an odd occasion – because they've put the rule in place about not having – preferably not having agency in there, which is good and it makes a huge difference to their care and behaviours, and staff that prefer to work in there makes a huge difference – they're more thorough and they understand that it's the little things that matter.* (Interview, S2, pp.72,77)

Although it is not always feasible to maintain continuity of staffing, the use of both nursing and PCA agency staff is restricted as much as possible. This discussion on staffing describes the benefits of maintaining stability and continuity in the workforce. A supportive style of management helps strengthen a stable workforce.

Supportive Management Style

As discussed in Chapter Six, the roster cuts at Site 1 resulted in negative outcomes for many of the staff and, consequently, are contributing to violations of personhood. However, the SM's management style and ongoing advocacy for residents and staff enable some level of personhood preservation to be maintained. Despite widespread challenges, the SM remains committed to the organisation and its stated values, but, at the same time, believes it is her role to act as a buffer between the organisation and her staff:

> Site Manager: *I have never ever and will never ever criticise* [organisation] … *we can't be as free and easy with our cash as we used to be - I will always argue that it's not* [organisation], *it's aged care. I would never do anything to compromise* [organisation], *but I feel as though it is my role to be the advocate for residents and staff here. Because if I'm not, who will?*
>
> Researcher: … *I'm hearing and observing that you … absorb a lot of the anger as well as the directions that come from head office – you're the buffer in between.*
>
> Site Manager: *Absolutely. And I think that's part and parcel of the role.* (Interview, S1, pp.40,41)

Perhaps it is this unwavering commitment to the organisation which strengthens the SM's resolve to advocate for residents and staff at her site. The Chaplain describes the leadership style of the SM:

> *She just has the best interests of the residents, the family, the staff so much there, and works to work the whole thing as a team … and she doesn't judge, she gives staff encouragement, opportunity, but also sets boundaries so that the staff member knows I need to work within those boundaries, I need to fulfil that, and then she'll set another boundary, not shifting the boundaries but a goal that that staff member can actually achieve so that staff member can grow.* (Interview, S1, p.8)

The Chaplain’s comments are reflective of the SM’s attitude and supportive stance she takes towards her staff. However, the ongoing exposure to stress resulting from the recent roster reviews eventually takes a personal toll on the SM:

> I arrived for a scheduled meeting with the Site Manager, but [administration staff] advised me she was away sick and was very apologetic that she had not contacted me to cancel the meeting. She thought the Site Manager must be feeling very unwell, because she’s hardly ever away sick … [administration staff] said the Site Manager had been coping fairly well - she’s very strong and determined and will just keep going, but it has been really tough going for her lately. [Administration staff] said the Site Manager will do just about anything to protect the residents and staff because she really cares for them.
> (Field Notes, S1, p.57)

There is no doubt the SM is a very strong person, but the unrelenting pressure of two major roster reviews is causing genuine concerns about her health. As a researcher, I am also concerned for her welfare as indicated in the following extract from my personal diary:

> This appointment had been cancelled twice already, once because she was sick and then because she had arranged another meeting. So it was great this interview finally went ahead today. When I walked into her office, the Site Manager appeared somewhat overwhelmed with various tasks, but was very welcoming and soon relaxed … her demeanour portrayed that, in spite of the current difficulties in the aged care industry generally and this organisation specifically, she is very pleased with the current situation at this site and positive about the future. Perhaps, given the Site Manager’s resilience, personhood preservation will once again dominate at this site.
> (Personal Diary, S1, p.27)

In spite of experiencing tremendous organisational pressure in recent times, the SM’s dedication to the residents and staff at Site 1 does not waiver. She protects her staff as much as possible from external pressures, and remains positive for the future.

Supportive management styles are also in place at Site 2. While expecting a high standard of care provision from her staff, the SM says she understands the challenges faced by PCAs:

> The Site Manager cited a case where a resident in MSU had escalated 'behaviours' and was yelling, staff were not happy and complained to her saying: 'we don't get paid to put up with this.' The Site Manager said she knows staff shouldn't have to put up with such behaviours, but reminds them that they have chosen this career – it is what it is. They need to find other ways to deal with 'behaviour'. They need to see how important the person is – what is happening for that person – why is he yelling? … the Site Manager recognises that staff are 'persons' as well – that they do hard work. She said: '*I get it, I've done it*.' (Field Notes, S2, pp.107,108)

Because the SM has been in the position of caring for people with dementia, she has a deep understanding of the challenges experienced by staff. Her responses to staff show she has trust in their ability to find personhood solutions to situations as they arise. Further aspects of her management style are included in this extract:

> The Site Manager said she is in constant communication with staff, therefore role modelling that staff need to communicate … she reads progress notes every day if possible – a time consuming task with 100 residents … but this keeps her updated on what is happening with each person. She has trust in Clinical Leaders' advice.
> (Field Notes, S2, pp.107,108)

The responsibilities of managing a 100 bed aged care facility are enormous, but the SM indicates that she is coping well. She demonstrates her trust in the Clinical Leaders, her dedication to keeping up to date with the status of each resident, and a willingness to stay in regular communication with care staff. These features all show her trust in her staff and concern for the wellbeing of residents, indicating a strong and supportive management style.

The supportive management styles at both Sites 1 and 2 help to maintain connections between staff at each site, thereby supporting personhood for both residents and staff. Connectedness within the organisation has been explored through discussions about valuing staff, stability in staffing, and a supportive management style. When these issues are in place it is likely staff feel confident in performing their roles.

7.2 Confident Staff

Staff who feel assured of support from management and their peers are likely to feel confident in their ability to perform their roles in a positive and constructive manner. Presented under the themes of Staff feeling Supported; Working from the Heart; Relationships; and Psychosocial Environment, this discussion demonstrates that staff who feel confident in their work are able to provide quality care by building positive relationships with people with dementia.

Staff Feeling Supported

The degree to which staff feel supported in their roles is an indication that they are enabled and encouraged to provide care which preserves personhood. Although the LS Coordinator at Site 1 is facing several challenges as a consequence of roster cuts, she feels supported by the SM in meeting some of those challenges:

> *I believe [Site Manager] is doing her utmost to support us – Lifestyle…. Yeah – management – I reckon they are trying to do the best they can to help us through … I feel [Site Manager] is trying to do the best for the staff here to try and make it so that we're all working together as a team and with the Care staff and Lifestyle staff working as a team together and putting that towards everyone.* (Interview, S1, p.19)

The LS Coordinator is overwhelmed by the pressures caused by the roster reviews, and feeling supported by the SM is one of the few positives that she seems to be experiencing. While acknowledging the difficult situation of the SM, the LS Coordinator is grateful for her support and encouragement of teamwork.

As shown in these extracts, the LS Coordinator and Clinical Leader at Site 2 both feel supported by management:

> Researcher: *Having supportive management who will support you …*
>
> Lifestyle Coordinator: *They've always been supportive – they have always listened to me, they have always validated me. Even* [name] *– our new Business Manager … when I go to him he always comes up and says: 'Well, okay let's sit down and talk about it'. He's another one who's very open, definitely suits* [this site] *… there is no 'us and them' and there's no sense of hierarchy – they do stop and listen.*
> (Interview, S2, pp.59,68)

> *I feel really supported in my role – yes. The Nurse Manager, Site Manager, there's a lot of support. I feel really supported and I try to pass that on to Carers and ENs. Everyone's really approachable – we have created ways so they can communicate with me when I'm not here, so that all seems to be working really well. Management have been really open to suggestions on how we can improve or change.*
> (Interview, S2, p.89)

Both the LS Coordinator and Clinical Leader indicate that open communication is one of the features helping them feel supported by management. They feel respected and validated, and know they will be listened to if they approach management for support. It is suggested here this continual validation and support from management provide the LS Coordinator with renewed confidence in her ability to perform her role. The Clinical Leader states that, not only does she feel supported, but she has developed strategies to ensure that the care staff also feel supported by her.

In spite of various challenges, staff feel supported by management in their efforts to provide resident care in a psychosocial environment which enables personhood preservation. It is likely this level of support contributes to the willingness of staff to 'work from the heart'.

Working from the Heart

The manner and approach of a particular PCA towards the residents is a significant contribution to the quality of dementia care provided within the MSU at Site 2. This PCA has a very quiet and unassuming personality, which assists with her gentle interactions with residents. As she explains, she clearly loves her work and feels deep compassion for the residents:

> PCA: *…they've been taken away from their loved ones, so that's hard, so – yeah – it's just a rapport that we've got to build with them.*
>
> Researcher: *That's obviously how you feel personally – do you feel that the management here … share those same values with you and support you?*
>
> PCA: *Yes, I do think that. Yes, sure. I mean, it's all in the umm - you know – our responsibilities and all that…*
>
> Researcher: *In your job description….*
>
> PCA: *Yeah, that's right, but – you know – you don't have to read anything like that, you know – it comes out in the personal care … I've been doing this job for a long, long time … and I still love it … you've got to work from the heart, and I work from the heart every day.*
> (Interview, S2, pp.84,85)

Although not naming it as such, this attitude of 'working from the heart' has been embraced by many of the staff in the MSU. From an observational perspective, the characteristics of 'working from the heart' appear to include a willingness to be involved with resident care beyond the expectations of a job description:

> Staff are very resident-focused – certainly not seeming to be task-focused. Tasks that need to be done are covertly undertaken while giving residents focused attention. (Field Notes, S2, p.74)

This field note extract reflects my observations of many staff members, including ENs, who regularly create opportunities to interact with residents. There is a real sense that staff enjoy their relationships with residents and frequently take time to step outside their stipulated roles to spend time with them, as in this example:

> The EN walks over to the clothes folding basket on the bench, and helps a resident fold tea towels. It is encouraging to see an EN engaged in this way – very often ENs seem to be (for whatever reason) disengaged from residents and needing to be in the nurses' station. (Field Notes, S2, p.76)

Similarly, another EN, who works on the evening shift, prefers to move beyond the requirements of her job description to engage with the residents:

> *I just love working in there. I think they're the most vulnerable people that we have, and just to make them smile … I'm very hands-on – I would prefer to be helping with ADLs and settling them than giving meds and whatever. I like to be organised and get my meds done so that I can help with the night-time routine … our job description is to do medication rounds and wounds …. but, to me, you're there to help them, and I can't watch a resident looking for a toilet or needing to be fed and say 'oh, not in my job description'.* (Interview, S2, pp.70,77,81)

These comments demonstrate this EN's willingness and ability to organise her shift around interacting with the residents. Even though her job description only requires focus on medication and documentation issues, she frequently assists PCAs with resident care. Consequently, she has built a good rapport with residents and staff.

Many of the LS staff also embrace the concept of 'working from the heart', in particular the LS staff member who was frequently in the MSU during morning observation sessions:

> I was really impressed with interactions between staff and residents – especially the Lifestyle staff member. He knows the residents very well – their names, their likes and dislikes, interests – and would frequently sit down alongside, or walk with a resident chatting with them. He has the ability to move from one resident to another with ease and confidence, as well as chatting with a group of residents and including them all in the conversation in some small way. (Personal Diary, S2, p.35)

This diary entry confirms the inclusive and gentle attitude to dementia care of this LS staff member, an attitude which is modelled by the LS Coordinator whose own approach to caring, as shown below, is focused on addressing each person's needs:

> Researcher: *I'm really interested in this determination in you to put the resident – that person – first, the needs, choices and respect for that person first.*
>
> Lifestyle Coordinator: *I don't know how you cannot – I don't know how else you could do this job. Because –* [name of resident] *– what a huge challenge he is at the moment. He is just absolutely shattered that he's*

> *here – he feels like he is in prison. A highly intelligent person who has delusional thoughts – his wife comes in – but it's his mum. He is still very articulate – he writes in his diary, he does the whiteboard down there, and he – I just cannot see how you could not see that man as the most amazing person. And now my job is to make every day as bearable as possible to get him through, because – wow – that is all I can say. For me, it's the norm.* (Interview, S2, p.66)

The LS Coordinator's dedication to personhood preservation and her passion for people with dementia characterise not only her own attitude to care, but also describe her approaches to training and support methods for her staff. The passion she feels seems to drive her ability to deeply understand the needs of each resident and, in turn, to find a way of meeting those needs.

This discussion entitled 'working from the heart' illustrates the dedication and commitment of most staff in MSU at Site 2 to provide the best dementia care that is possible within organisational limitations. It seems appropriate to end this discussion with a supporting clarification from the PCA who initially articulated the concept of 'working from the heart'. The following extract further encapsulates her commitment, and, by implication, the commitment of several staff members, to dementia care:

> *And we are a family too, you know. I see the residents as family – I've known them that long, and they are part of my life, and I do respect them. And it's respect.* (Interview, S2, p.84)

The notion of staff 'working from the heart' indicates that the culture of the psychosocial environment at Site 2 is based on healthy relationships and connections between staff and residents. Relationships, which are a vital factor in personhood preservation, will now be discussed.

Relationships

Although the value and characteristics of relationships are beyond the realms of testing and quantifying, it is clear that relationships are essential to the preservation of personhood (Kitwood & Bredin, 1992). When an individual is treated as a person rather than an object (Kitwood, 1997a), a deep form of relational care is possible, and indeed, highly beneficial for a person with dementia. As discussed earlier in this chapter, stability in staffing is a vital factor in enabling staff to build relationships with residents:

> It’s always better for the residents when they have regular staff who know them really well and have time to build a relationship with them. (Field Notes, S1, p.63)

This staff member acknowledges the need for staff to build relationships with residents. Through such relationships people with dementia are provided with familiarity and security, and their needs and personalities are well understood by staff.

An EN explains that a relationship with residents enables staff to more promptly identify issues that need attention:

> EN: *You get some excellent agency and some are really good in there, but it’s just the familiarity I think, even though – I mean, obviously they’ve got – their memory isn’t great, but there still is some point where they remember us - I’m sure of that … you get to know them in there and their personalities, and you can see they’re not quite right and you know – you can sort of predict sometimes what’s going to happen before it escalates into something really bad …*
>
> Researcher: *So, you’re saying you get to know them so well - you build that really good relationship with them and get to know them so well that you can tell through their body language … that there is something they’re not happy with or they are in pain.*
>
> EN: *Yes, absolutely.* (Interview, S2, pp.70,78)

In support of these comments about the importance of relationships, another EN describes how a close relationship with a resident helps identify his pain:

> The EN was telling me that she had given some pain medication to a resident about ¾ hour previously and was going to check on him. She came back and told me he was sitting in his armchair in his room and was looking better. I was aware this particular resident would probably not be able to verbalise his pain, so I asked her how she knew he needed pain relief. She said it is because she knows him so well –

> spending time with residents and consciously observing their regular actions and personality, you get to know their body language and facial expressions. This morning he somehow didn't seem himself – he ate very little breakfast, was shuffling rather than walking, and his face looked drawn and tired. She identified he had a headache by asking him where he felt pain and at the same time touching his legs, arms and head – he reacted significantly when she touched his forehead. As the EN and I were talking, we saw the resident walk along the corridor and into the lounge area. She observed he was no longer shuffling but walking normally, and his face looked more relaxed. She was very pleased with this outcome. (Field Notes, S2, p.112)

This extract confirms the benefits of a strong relationship between staff and residents. Rather than dismissing this resident's actions and demeanour as unimportant or as merely symptoms of dementia, this EN identifies that the resident is experiencing pain and also ascertains the location of the pain.

The Clinical Leader explains that the benefits of knowing a person really well also extend to recognition of emotional and spiritual needs:

> Clinical Leader: *I like that I can come in and follow things through from start to finish … I can sit there and assess them … I spend a lot of time in there so I'm picking stuff up and acting on it really quickly.*
>
> Researcher: *So you get to know the residents really well…*
>
> Clinical Leader: *Yes, definitely. I know what's not normal for that person – I know them all really well, you know …*
>
> Researcher: *So, this all points to easily picking up if something is wrong with a resident – which could be physical or emotional …*
>
> Clinical Leader: *Yes – physically, mentally, spiritually.*
> (Interview, S2, p.54)

Without the distraction of needing to provide regular physical care, the Clinical Leader is able to regularly observe and assess the needs of each resident. Her close relationship with residents enables her to not only notice physical changes they may be experiencing, but also potential emotional and spiritual issues.

The Chaplain at Site 1 speaks of the connection between relationships and personhood:

> Chaplain: *… and how do we relate is a very fine balance …*
>
> Researcher: *So what you are saying in there, I think, is that the … quality of the relationship is really important.*
>
> Chaplain: *Yes, yes. And that is an aspect of personhood which is very, very significant and often is the deepest meaning of personhood for somebody … I seek to build that within the first couple of days after they come in*. (Interview, S1, pp.1,4)

In acknowledging these close connections, as part of her spiritual care practices the Chaplain begins building relationships with residents within the first few days of their admission to the facility. Those relationships form the basis of individualised personhood care which responds to the person's specific needs and personality. It is likely that the resident gains support and security from this ongoing relationship with the Chaplain.

Relationships are also significant to the Chaplain at Site 2, albeit with somewhat deeper connotations. In line with his broad perspective on chaplaincy, he speaks of a need to regularly re-assess his approach to relationships, particularly when relating to people with late stage dementia:

> *With people with late stage dementia – boy – that gets tough – really – who are now being looked after with a palliative model of care … but what about how is it for the person, and how do we actually relate to them? How are we relating to them? It always varies … relationship is a key factor.* (Interview, S2, pp.44,47)

As an example of his style of relating to residents, the Chaplain conveys the nature of both his and a LS staff member's relationship with a particular resident:

> *So, for example, there's* [resident's name] *… - he would be transitioning into later-stage dementia, but the family just can't believe how he remembers my name for some reason. And there's another one – one of our Lifestyle people -* [name] *who he does the same with. And I reckon I know why that is – there are a number of reasons.* [Name] *finds it really amazing - it's about the way she operates a consistent kind of approach. She listens quite deeply to him – she's a Lifestyle person - and she cooks, she regularly cooks and is brilliant at getting him involved in the cooking of the scones and all sorts of little treats, and I'll often be there helping him so both of us – he and I – help each other put our gloves on and put our aprons on and it's this*

> *regular thing. And the family are amazed because – and it's a little upsetting for them because he forgets their names but remembers ours. So that's fascinating.* (Interview, S2, p.46)

The Chaplain reflects on an occasional struggle to know how to relate to people with dementia and, in fact, knowing what a specific experience feels like for that person. His descriptions of the cooking activities reveal he has discovered that consistency, listening deeply and regularly sharing experiences significantly contribute to building a meaningful relationship.

When staff are supported to maintain a positive approach to dementia care, they are enabled to build relationships with residents, thereby creating a psychosocial environment conducive to personhood preservation.

Psychosocial Environment

The psychosocial environment is the space in which the person with dementia lives, and the ability of this environment to maintain personhood is largely dependent on the approach taken by staff towards their role, and the nature of relationships they build with residents. The environment at Site 2 is successful in maintaining personhood care, largely because of the 'working from the heart' approach discussed earlier in this chapter. This approach is supported by the LS Coordinator as she speaks of the comfort and reassurance offered by the MSU environment:

> *I just think the* [MSU] *structure. Like there's always somebody there – you know – you can go to your room, but, actually, no, I feel lonely in my room, and so that's where the sense of loss comes in, and thinking about home, and all the things that I'm missing – but come into the community, there's a TV, there's good stuff happening, there's always somebody to make you feel that this is your home – this is your community.* (Interview, S2, p.62)

This calming and reassuring culture described by the LS Coordinator is confirmed in my observations:

> The culture in this MSU is relaxed and welcoming. All staff disciplines work really well together – PCAs, ENs and Lifestyle. They support each other, and the teamwork seems really strong. From what I have seen so far, the priority of all staff is attending to needs of individual residents, and there is always at least one staff member in the lounge/dining area where residents spend much of their time.
> (Field Notes, S2, p.94)

The following extract describes a calm and peaceful psychosocial environment during a group activity:

> The Lifestyle staff member was highly skilled at interacting, communicating and leading appropriate conversations and communications. The Chaplain was also effective in his role by joining in conversations and making sure all residents had appropriate amount of involvement. A bright, happy environment, with staff being sensitive to needs of all residents - inclusiveness for all. Later in the dining room, atmosphere continued to be calm, happy and peaceful … the benefits of a calm environment for people with dementia are obvious from today's observations. The staff were calm, interactive, responsive and sensitive to residents' needs. I observed laughter and happiness, respect and an appropriate level of banter. Staff worked together as a team, supported each other, and appeared to enjoy their responsibilities. (Personal Diary, S2, pp.36,37)

This diary reflection confirms a supportive psychosocial environment which is welcoming and inclusive of all residents, and where residents and staff regularly share conversation and laughter.

This discussion on the confidence of staff demonstrates how staff who feel supported are able to create a psychosocial environment which is responsive to residents' needs and creates a welcoming and supportive community. Within such an environment, care practices which meet individual needs will reinforce to the person with dementia that they are valued as persons.

7.3 Valuing the Person

A person with advanced dementia is unlikely to have the capacity to initiate the meeting of their psychological needs, therefore, interactions which show the person they are valued are based around meeting their psychological needs and, as a consequence, preserving their personhood. This discussion on valuing the person explores the themes of Psychological Needs and Personhood Interactions.

Psychological Needs

The overarching psychological need within the psychosocial environment is love which, in this context, signifies an unconditional acceptance of the person with dementia, and does not expect reward. The psychological needs, all of which are closely linked to love and are interconnected with each other, are discussed under the themes of: i) Connections, ii) Identity, and iii) Spiritual and Emotional Comfort.

Connections

Human beings are social people, therefore, a basic human need is to feel a sense of connection with others. Feelings of connectedness may be achieved through attachments to family members or community groups, and are likely to produce feelings of security and belonging, particularly during times of anxiety and uncertainty, especially for people with dementia.

Regular visits from family members are vital to the maintenance of familiar bonds and attachments. For example:

> A resident's daughter comes to sit at the table with her mother while she finishes her lunch. They sat and talked for quite a while, with daughter showing photos … after lunch, three residents have families come in to visit and family members take them away from lounge area – either back to their room or to a more private spot in small lounge room. (Field Notes, S1, pp.3,10)
>
> At the end of the corridor, a resident is sitting in a small lounge room with his wife. She waves to me – they have some afternoon tea on the table and it looks as though she is reading to him from a newspaper. (Field Notes, S1, p.38)

These two extracts illustrate the importance of family members maintaining connections with those living in residential care. Connecting bonds are maintained when a daughter sits with her mother during lunch time and discusses her photos, and when family members find ways to spend time with their relatives, such as the husband and wife sharing afternoon tea in a small lounge room.

The following extracts indicate deeper levels of connection between family members. A willingness to show public displays of emotion through hugging and holding hands expresses the pleasure these family members feel as they are connected at this moment in time, and also shows they feel comfortable to express their emotions in this environment:

> A resident's daughter walks into unit and goes up to her mother … resident throws her arms around her daughter when she sees her, and they hug for a long time. They are both very emotional - they walk together out to resident's room. (Field Notes, S2, p.73)
>
> The resident … had been brought into the room in a princess chair, and his wife sat alongside him. Because he appears to be quite drowsy it is difficult to tell how much awareness he has of the church service, but his wife seems to appreciate being there with him and frequently holds his hand. (Field Notes, S1, p.21)

The body language of the resident when she sees her daughter indicates pure joy. The bond between the two is obviously very close and the daughter's visit enables that to continue. Although the resident in the princess chair seems to be dozing, he may be aware of his wife's presence. Either way, his wife clearly draws comfort from being there with him, enabling this close bond to be maintained.

A LS staff member describes how she regularly tries to instigate connections for residents in a manner which is personally meaningful for them, even during group activities:

> Lifestyle: *I want those group activities to be specifically able to be enjoyed by a range of people, not kind of a generic 'here's a high tea and we're going to decorate the room and call it that', I want to be able to talk to them and say 'who do you barrack for?' and 'why are you here?' and 'look at the colours', and so on, and just kind of make it so that it has a meaning for each person*.
>
> Researcher: *So, you try to personalise it or tailor it to each individual as much as you can.*
>
> Lifestyle: *Yeah, yeah. Yes, because I kind of imagine if I was here I would need to feel a connection with the people who are here – with the people who are around me. I would like to have not just people caring and doing for me, but to do stuff with me and to be next to me and to sort of understand.* (Interview, S1, p.27)

The actions of this staff member help individual residents to have meaningful connections with their physical surroundings as well as other people in the group. If such interventions are not instigated, it is likely the person will feel isolated due to inabilities to see, hear or comprehend what is happening around them. Appropriate interventions reduce feelings of isolation by enabling connections.

A LS Coordinator explains how she repeatedly advocates for residents in princess chairs to be included in group settings with other residents:

> *I've always included princess chairs in all aspects of games – just because you're in a princess chair doesn't mean you have to go down the back now. You'll notice we've got* [name of resident] *… she's in a princess chair. I don't know how many times carers put her down the back, but I get her straight back out the front … she will stay there until further notice.* (Interview, S2, p.60)

Due to their size, princess chairs are challenging to fit around other furniture, therefore, they are frequently placed to the rear or side of others in the group, creating a sense of separation from other people. The LS Coordinator displays great determination to include this resident in the group in spite of the challenges of the large chair.

A group activity is being conducted outdoors on the patio by a LS staff member, and

PCAs assist residents to join the group once their individual shower routine is completed. This extract shows the willingness of this staff member to ensure the person in the wheelchair is connected to the remainder of the group:

> [Lifestyle staff] realises a resident has just been wheeled in and is sitting behind her. She invites him to come closer to the table, and there is some chair shuffling to enable his chair to fit at the table. A couple of the residents greet him as he settles at the table.
> (Field Notes, S2, p.78)

The resident is warmly welcomed to the group by the staff member and other members of the group, and, therefore, experiences connection to the community in which he lives.

Residents are enabled in various ways to experience ongoing connections, thus lessening the likelihood of feelings of insecurity and isolation to occur. The psychological need of identity is now discussed.

Identity

The categorisation of identity incorporates the need for a person to feel some identification with the uniqueness of their past and, therefore, to retain possession of a unique life story. Identity also encompasses the concept of occupation, where a person is given opportunities to use their skills and knowledge in order to continue meaningful involvement in the processes of life. In order to provide care which acknowledges a resident’s identity, an initial lifestyle assessment is undertaken soon after admission to the facility, and then made accessible to all staff members involved in the resident’s care. The LS Coordinator comments on the importance of this process:

> *We gather their history, their hobbies, their background so then that way we structure our program around that resident.* (Interview, S1, p.13)

The SM explains that one of the uses of the life history assessment is to create visual reminders of a resident’s background to act as prompts for staff to initiate conversations with the resident:

> Site Manager: *Lifestyle do a very good ‘snapshot’ of the residents which is in their rooms which allows any staff to refer to, and they can say ‘oh look, I see you used to play football, or you follow the Crows, or pick up some other interest.*
>
> Researcher: *So, is this something that is displayed in their rooms somewhere and so can be seen…*
>
> Site Manager: *Yes, seen by everybody who walks in. It’s really useful, especially with agency staff or new staff, to allow them to say ‘oh, there’s a picture of roses here, did you used to have a rose garden?’ and things like that … and the care staff have commented that that reminds them - yes, although this person can’t have a conversation with you now, this is the type of work they did, this is all the travelling they did, and so on. It’s just been really great for that.*
> (Interview, S1, p.33)

A resident’s life history is used to create conversation starters by which staff members help maintain the identity of the person with dementia. During the processes of providing care, staff are prompted by individualised photos and displays to converse with residents about specific subjects with which the resident can relate. In this way, the person’s identity is maintained when the conversation is centred on a specific person or activity, and the person feels validated when they are engaged in a meaningful conversation.

As described in the following extracts, residents are facilitated to retain their sense of identity through opportunities to share parts of their life story:

> A Lifestyle staff member is sitting at table with six residents – he is picking out items of interest from a magazine to talk about. He reads a couple of sentences, then stops to ask question or engage someone in conversation about the topic. He is reading an article about when early closing was in place for hotels.
>
> Lifestyle: [Resident’s name], *you used to work at* [name of hotel] *didn’t you?*
>
> Resident: *Yes, yes – I certainly did*.
>
> Lifestyle: *Can you remember when 6.00 closing ended – when pubs were allowed to stay open longer?*

> Resident: *Oh goodness me, yes. A lot of people were very excited by that. It was good for business – well, in some ways it was good. We sold a lot of drinks later in the evening, but of course there wasn't that rush of selling just before 6.00. They were good times.*
>
> Another resident says he remembers when 6.00 closing ended and he thought it was a bad thing, because, instead of having to leave at 6.00, he had to decide for himself when to go home and he would forget what time it was and then get into trouble with his wife for getting home late for dinner. He laughed and then said: '*She was good to me – she never really got angry with me, she put up with me coming home late a lot'.*
> (Field Notes, S2, p.74)

> The Lifestyle staff member takes a book off the shelf and sits down alongside a resident who is sitting at a table by herself. It is a book about the history of South Australia and they reminisce together for a short time. They are looking at photos of original miners' cottages and Lifestyle asks her if she remembers houses like that. The resident replies that she used to live in a house like that in Moonta where her father worked. She talks about sleeping in a small bedroom with her two sisters, and the games they used to play in the back yard. She remembers waiting for her father to come home from work, waiting at the edge of the road then running to meet him when she saw him walking up the road. This resident is truly engaged in this moment, and seems to be gaining comfort from talking about her family.
> (Field Notes, S2, p.70)

The LS staff member empowers people with dementia by creating opportunities for them to retain their own identity. Sharing stories is a powerful tool in maintaining identity, and, in sharing their life stories, these residents are enabled to reminisce about their earlier lives.

As discussed in these extracts, identity is also maintained through opportunities to participate in tasks with which residents are familiar:

> *It's about giving them a sense of belonging, trying to encourage them to be part of the community as much as they can, without making it seem like it's working – it's volunteer, and we actually do even document – like when [resident name], for example, crushes our cans, he's volunteering in our community down in [name of MSU]. It's always an invitation for them to do it, but it's really quite amazing how much enjoyment they get out of it. Umm - folding the napkins – as simple as that is – setting the tables, helping wipe the tables down, cleaning out the cupboards – opening the cupboard doors and cleaning the cupboards out, finding things that they have done at some time in their life – you know.* (Interview, S2, p.61)

> A resident is sitting at a table folding and rolling pieces of fabric. She looks content and obviously needs to be 'doing' something … the Lifestyle staff member gives napkins to resident who was folding fabric and asks her to fold them ready for lunch. She agrees, but then picks up her handbag and walks away saying: '*I'll be back soon*.' She later returns with another handbag – now has two. Is sitting down and looking through the contents of both bags … resident … is now folding napkins. (Field Notes, S2, pp.87,88)
>
> A resident enters the room – I have noticed she usually appears timid and shy. She is invited further into the room by PCA and asked if she would like to help clean out cupboards. She agrees and is led to a cupboard away from other residents and asked to help sort items in the boxes. Obviously wants to work on her own, and seems happy to do so. (Field Notes, S2, p.95)

Activities such as folding napkins and cleaning cupboards are tasks with which some residents can identify and recall from earlier times. The tasks are simple, yet important contributions to the functioning of the community. Crushing cans is an occupational activity which provides the satisfaction of helping to raised funds for the community. The resident who was rolling pieces of fabric was once a dressmaker who took great pride in her knowledge of sewing, and enjoyed working with different fabrics.

Sometimes there may be no actual value in the completion of an action, but the value is found in the sense of fulfilment for the resident, and, undoubtedly in this case, for the researcher - when the opportunity is presented. I gladly recall this personal experience:

> A resident comes to sit alongside me at the table where I am observing and taking notes. Although I can only understand a few words she is saying, she happily chats to me. A PCA comes over to me to sign a consent form, and the resident asks if she can sign her name as well. I give her some paper and a pen and she slowly and deliberately signs her name – she looks very pleased with her achievement. She occasionally walks away and then comes back to sit with me again.
> (Field Notes, S2, p.72)

This extract describes a personal experience where the resident initiates an action to express her own identity. Not only does she instigate a conversation with me, but she takes advantage of an opportunity to strengthen her sense of identity by sharing her signature. Her willingness to keep re-engaging with me appears to confirm her need to retain her identity.

As explained by the LS Coordinator, whatever the nature of the resident's contributions, the aim of these activities is to help the resident feel involved in life at that moment:

> *It is a case of individual activities - some might be painting over there – and we find out through observing, documentation, checking with people when they first come in what they like and what their dislikes are, and often it can be as simple as just giving them a newspaper – you know – and it is the best. They don't have to be in this high functioning – let's do something, there's got to be something to see at the end – it doesn't mean that. It's about in the moment – for now – trying to engage them with something that makes them feel good*.
> (Interview, S2, p.61)

This discussion on identity shows several examples of how LS staff enable residents to maintain their identity through reminiscing, sharing life stories and contributing to the functioning of their community through meaningful activities. Spiritual and emotional comfort are also classified as forms of psychological need.

Spiritual and Emotional Comfort

The concept of love is included in the categorisation of spiritual and emotional comfort because love describes the dominant care approach needed to meet all psychological needs, and, in particular, spiritual and emotional comfort. While classifying spiritual and emotional comfort as psychological needs, the equal value of physical comfort is recognised, and, in fact, physical, spiritual and emotional comfort are often interconnected. In this concluding discussion on psychological needs, however, the focus is spiritual and emotional comfort.

While discussing his role of providing spiritual and emotional support to residents, the Chaplain at Site 2 is mindful of the traditional restraint around discussing the concept of love within a care environment. He is convinced, however, that in the wide spectrum of dementia care, there is justification for using terminology around love. The Chaplain describes the depth of care sometimes needed by people with dementia, particularly those with advanced dementia:

> *There would have to be all sorts of factors that influence how they're feeling – the level they're feeling cared for and loved and so on … I hesitate to throw this one in because how do you prove the existence of love or not … but all I can say is that the importance of it cannot be underestimated … but, yeah - to be operating from love – now, this, of course, is terribly confronting to, up until very very recently, the whole history of medicine and nursing and everything else, because you're told 'don't get too close.' In fact, 'don't get close at all'. I mean that's being – that's history, isn't it … but, for me … the premise is still true that the real – the way for existential liberation is always – is always to know, to feel that you are loved, and to be able to be empowered to love.* (Interview, S2, pp.47,48)

The Chaplain highlights the contradictions between a medical model of care and the very real need by some people to show and receive love in a residential dementia care environment. In this context, love provides spiritual and emotional comfort. The Chaplain at Site 1 speaks about emotional comfort in terms of loss and grief, and also describes her comforting response to a resident who is regularly distressed:

> *To me, it's whether the person hangs on to their grief and loss and goes into depression or whether they come to life in an aged care facility, and find who they are and their place.* (Interview, S1, p.1)
>
> *And then she's forever calling out* '[Chaplain's name]' *every time she sees me. I need to get a taxi, I need to get the taxi because it's getting dark. And then I go and reassure her that we've got a meal for her, we've got a bed for her.* (Interview, S1, p.8)

Some people with dementia regularly experience a strong need to return to their family home, particularly towards the end of the day. This person just described is one such person who frequently longs for the safety and comfort of her own home. The Chaplain periodically offers emotional comfort to this person by assuring her that a meal and bed are provided for her at the facility. The long-term effects of this comfort are not known, but, as with many aspects of dementia care, emotional comfort is sufficient for this moment in time.

Conversations around comfort at both Sites 1 and 2 include these discussions on palliative care practices:

> Researcher: *Can you comment on palliative care practices here, particularly in the context of personhood care?*
>
> Site Manager: *If we are talking palliative care in the context of each person having as comfortable a death as possible, I think we do it very well. For those people who we can see are deteriorating we certainly put strategies in place that keep them comfortable … all we do really is an extension of comfort care and pain management. There's not a lot of bells and whistles and, you know ... I think we do it very well.*
> (Interview, S1, p.37)

> Lifestyle Coordinator: *Palliative care is really individualised … it's one of those things – we do the best we can … if they need it, they'll get it …how do you prepare for an end of life – you know – again, you just make it as bearable as possible for everybody …*
>
> Researcher: *And I actually think it's not much different, really, to the care you have been giving right from the day they came in the door, because it's still about 'what is right for this person, right now?'*
>
> Lifestyle Coordinator: *Yes - it's the person. And I think we do that. It doesn't have to be fluffy and shiny – that's not what it's about.*
> (Interview, S2, p.69)

These discussions focus on palliative care at the end of life stage when physical, emotional and spiritual comfort are all significant needs. The interesting points in these conversations is that, in line with the philosophy of palliative care, end of life comfort is seen as an extension of individualised care already being provided. It is clearly defined by individuality and comfort, and not about 'bells and whistles' nor needing to be 'fluffy and shiny'.

This discussion on spiritual and emotional comfort concludes with further comments from the Chaplain:

> *I can't help thinking in my own frame of reference about people living with dementia …* [who are] *facing an unknown future, and so they are in uncharted territory in lots of ways … and sometimes it is just continuing to hope, that your presence - just your mere presence – makes a difference to that person … it's important for us to keep the sacred memory of this person, to keep telling their story.*
> (Interview, S2, pp. 71,73)

This additional explanation by the Chaplain is deliberately chosen to close this discussion on spiritual and emotional care. The languages of comfort, love, spirituality and emotions are often difficult to articulate, particularly in a care environment which is still, to some extent, medicalised and, therefore, seeks measurements and results that are quantifiable. But, from the perspective of personhood preservation, this discussion indicates the value in persisting with the provision of spiritual and emotional comfort, particularly for the purpose of meeting the psychological needs of people with dementia.

Having described the culture of a psychosocial environment which is capable of meeting the psychological needs of people with dementia, this argument for the need to value the person concludes with a discussion on interactions which preserve personhood.

Personhood Interactions

Preservation of personhood is achievable through quality interactions in a safe and sound psychosocial environment. Data analysis revealed three categories of interactions which contribute to personhood preservation: i) Respect and Dignity; ii) Contentment; and iii) Inclusion. These themes are used to describe examples of personhood interactions at both sites.

Respect and Dignity

Showing respect and dignity for another person is basic to preserving their personhood. In the context of dementia care, respect is demonstrated through actions such as recognition of the individual as a person, use of their preferred name, and direct eye contact when speaking. Negotiation with the person about their preferences, along with the creation of a safe physical and emotional environment, significantly contribute to the person with dementia feeling respected.

Linked with this understanding of respect is the manner in which two new staff members interact with residents, as described by the LS Coordinator:

> *Two new ones who have come on board, extraordinarily amazing. The way that they talk to these residents – 'where do you sit for lunch?' – you know, just asking them. A simple thing – just asking them, you know. Instead of just assuming that they sit here or they sit there or putting them wherever they go, they actually ask. And you see them go down to their eye level and they are really watching and listening. They're not telling – they are actually there for the residents. It's quite amazing.* (Interview, S2, p.66)

This description of the care practices of two new staff members indicates their strong understanding of the need to show respect and dignity. They are setting up situations of equality whenever possible. Through asking residents for their preferences instead of taking control, and by bending down to the resident's eye level rather than standing over them when conversing, both help, in small ways, to eliminate an environment of 'them and us' and, instead, to encourage a feeling of 'sameness'.

Respect and dignity are strong characteristics of this interaction:

> Resident is walking into dining room using her walking frame and assisted by PCA. Resident is walking quite slowly, and PCA walks alongside at resident's pace. They are having a conversation about dogs as they are walking. PCA: '*Now where would you like to sit* [name]'? Resident: '*I'm over there by the window* (pointing to the

> table)'. PCA: '*Okay, I'll help you to your chair*'. PCA pulls out chair and helps resident get seated. PCA: '*Is it alright if I put your walker over here?*' Resident: '*Can I just get a tissue first?*' PCA helps her find a tissue. PCA: *'Is that all you need for now?*' Resident: *'That's good, thank you.'* PCA: '*Okay, your walker will be just over here. Enjoy your lunch.'* Resident: *'Thank you for your help.*' PCA: '*You are very welcome'.* (Field Notes, S1, p.7)

Here, the PCA is totally focused on the resident and the need to maintain her respect and dignity. This interaction occurs as residents are being assisted to the dining room for lunch, when, on some occasions, residents are rushed so that the meal can be served on time, thus fulfilling the needs of the organisation. But, on this occasion, the resident's needs are given priority, her choices are respected and her dignity is maintained.

In this extract, a resident's dignity is not compromised when he says that he does not like his meal:

> Meals are efficiently and quietly served … Resident: '*No, I don't like sausages.'* PCA: '*Okay, would you like a burger and some salad?*' Resident: *'Yes that would be good.'* PCA: *'Okay, I'll just be a minute.'* Another plate of food is served up and brought to resident which he seems happier with as he starts eating. (Field Notes, S2, p.84)

Rather than this person being told that he had ordered sausages, and therefore shaming him for making a wrong choice, he is immediately offered a substitute meal which is provided in a timely manner. As mentioned previously, the process of meal choices can be confusing and overwhelming for some residents, but, in this case, a policy is in place which respects the person's choice at that moment. The entire process is polite, prompt and respectful.

An EN explains how organisational routines have been adapted to incorporate choice for residents:

> *They did bring in that there's no getting them up, that when they get up of their own accord, that's when they tend to their ADLs – which I think works really well … it's not like the old days where everyone had to be showered by 8.00 and sitting up – you know, it's their home – they wander out. I know we had one man who was a publican so he was never an early riser so that – you know, they changed that – he would wander out at 10.00, they'd give him something to eat, and they found his behaviours reduced and he was much happier.*
> (Interview, S2, p.75)

The organisation demonstrates a willingness to move beyond a medical model of care, which focuses on routines, to giving residents a choice about when they wake up in the mornings. This model of care requires PCAs to be flexible in their morning schedules and to serve breakfast at various times during the morning. In this extract, the lifestyle and preferences of this resident are respected and accommodated in a dignified manner.

The need to treat residents with respect and dignity is summarised by a PCA:

> *We all want to be treated with respect and kindness, you know, and these are – you know, because they're old, you know, they've still got feelings and they've still got needs and wants, and, you know – they were mothers and fathers, they've brought up children, they've had heartache, and I think – you know – we give back what they've given us. To look after these people is just like being thankful for what they've done for us years ago. We've got to treat people with respect – you know, not degrade them because they're old – you know, they've still got hearts.* (Interview, S2, p.84)

This PCA adequately captures the recognition that a person with dementia deserves respect and kindness. Her comments describe an environment of respect and dignity, and are grounded in the belief that older people continue to have feelings, and that caring for them in a kind and respectful manner is showing gratitude for their lifetime of contributions. This is a remarkable expression of personhood preservation. It is worth noting that these words are not spoken by a corporate staff member, but by a PCA. She is a person who truly believes in kindness and respect, and, in spite of receiving a minimum rate of pay, is an expert in dementia care because she has been providing such care for many years. Indeed, this PCA is an extraordinary person.

As important indicators of personhood preservation, respect and dignity for people with dementia are acknowledged and implemented in various ways through the attitudes and interactive care practices of staff. Other indications of the preservation of personhood are observed when residents appear to be content, both physically and emotionally. Issues around the theme of contentment are now discussed.

Contentment

Contentment is subjective and difficult to accurately identify, however, in the context of personhood interactions, contentment refers to signs of relaxation, celebration and happiness. On those occasions when residents are left in front of the TV for long periods of time, it may well be that they are feeling content and relaxed, or they may be feeling isolated and abandoned. Fieldnote entries reflect my inability at times to accurately identify the differences between relaxation and abandonment:

> It is very much the same thing each time – although residents always look well cared for, they are usually just sitting around in various types of chairs, sleeping or looking bored. Sleeping is fine – they are old and frail and obviously need sleep and rest. But bored – not so good.
> (Field Notes, S1, p.26)
>
> Many of the residents are seated in the lounge area – either dozing, watching TV or staring blankly ahead … I understand that many of them would be wanting to rest at this time of day (early afternoon) … however, some of them appear restless (standing up, walking around, then sitting down again – repeatedly), one is mumbling although I can't understand what he is saying, another keeps calling out for someone to help him, while another man repeatedly tells him to 'be quiet – you're making too much noise'. (Field Notes, S1, p.46)

These extracts reflect my occasional lack of ability as a researcher to identify whether people with dementia are content or, in fact, are being ignored. In actual fact, both would have been happening at various times, but, in this discussion on contentment, it is important to note that, in these extracts there is evidence of residents appearing to be relaxed and content, perhaps even sleeping.

The following interaction seems to be grounded in relationship, and embraces the concept of contentment by including relaxation, gentleness and celebration:

> EN walks up to a resident sitting in an armchair – she has her head lowered as if she is asleep. EN kneels alongside her and speaks to her while gently touching her arm. Resident is a bit startled but lifts her head and smiles. EN gives the resident her medication and a drink and stays with resident until drink is finished – resident is fairly slow finishing drink but they are chatting to each other and EN is patient and gentle with resident. EN holds on to chair as she stands up and they both laugh about EN almost losing her balance.
> (Field Notes, S1, p.3)

This interaction is framed in contentment because the resident is clearly relaxed. The EN's approach recognises the resident's contented state, and so she bases the interaction on gentleness, appropriate touch and patience. Fittingly, the interaction concludes with laughter shared together in this relationship, and the resident was then able to resume her relaxed state.

Contentment was regularly a dominant feature of interactions at Site 2. For example, a LS staff member engages with a resident through music and dance:

> Lifestyle Support is interacting with residents who are sitting around in lounge and dining area. Music playing on CD – old time songs which are appropriate for age group of these residents. The song 'As time goes by' is playing – one resident walks around singing along with the words. She walks over to Lifestyle while still singing and he starts to dance with her. They both sing and dance for a few minutes.
> (Field Notes, S2, p.69)

This resident is experiencing a level of contentment which she expresses through singing. I have previously noticed that she sings along with music, and it seems that on this occasion, she wants to share her happiness and contentment. The preparedness of the LS staff member to dance with the resident further extends her level of contentment.

Contentment and enjoyment are obvious during a group activity where residents complete the second part of well-known sayings:

> Lifestyle: *'This one is for* (name) *because she says this.'*
> The resident answers correctly, and says: *'Have you heard me say that?'*
> Lifestyle: *'Sure have – lots of time. It's a fun thing to say.'*
> Another resident says: *'We are having some fun here, aren't we?'*
> Lifestyle: *'We certainly are!'* (Field Notes, S2, p.148)

There had already been a significant amount of laughter during this group activity, so it is quite appropriate, and significant, for this resident to declare that they were, indeed, having some fun.

On another occasion, the combined contributions of staff members and a resident create a display of contentment in the form of joking and laughter. The song currently playing on the CD is 'Cockles and Mussels', the title of which, as explained here, is the instigator of this few moments of delightful contentment:

> Lifestyle: '(Name of resident), *do you like to eat cockles and mussels?*'
> Resident: *'I'm not sure. Is that fish?'*
> Lifestyle: *'Cockles and mussels are seafood'*.
> Resident: '*Oh well, I'm sure I would then. I do like seafood.'*
> An EN walks in carrying a thermos flask. She walks up to this resident and asks him: '*Do you know what is in here* (indicating thermos flask)?'
> Resident: *'No, but I'd like to'* (laughing).
> EN: *'Here have a smell'*.
> Resident: (Laughing) *'Oh, it's not alcohol.'*
> EN: *'No, what is it?'*
> Resident: *'I think it's coffee.'*
> EN: *'You're right – it is'*.
> Resident: *'I was hoping it was alcohol. Or perhaps cockles and mussels.'* Lots of laughter. (Fieldnote, S2, p.153)

The laughter following these interactions lasts for several minutes, and for that period of time, joyous contentment and happiness dominate the entire room.

This discussion shows that indications of contentment are observed through body language, communication and engagement with music. Preservation of personhood is also supported when interactions enable a person to feel included in their community.

Inclusion

Human beings need to feel included in their community and in the overall process of life. In the context of dementia care, interactions which support inclusion are those which enable collaboration in tasks or decisions, validation of the person's reality, and facilitation to undertake tasks which would not otherwise be achievable. While conducting a group activity in which she asks questions on various topics, a LS staff member demonstrates an ability to include residents in the conversation. The following are examples:

> She directs one question to a specific resident who hasn't yet said anything: '(Name), *you know Peter Pan don't you?*' Resident replies: '*Yes, I have heard of him – that would be Wendy.'* All staff members applaud him for getting answer correct. (Field Notes, S2, p.77)
>
> Lifestyle repeats a question for a resident who is hearing impaired even though the correct answer has been given. He expresses his gratitude that she repeated it. (Field Notes, S2, p.79)
>
> Lifestyle has been noticing which residents are not participating very much, so directs questions at them, e.g. *'This one can be for* (name)'; *'This is for* (name)'; (Name) *for you'*. When they answer she responds with *'well done'* or *'good try'.* Lots of clapping, interaction, socialising. Lifestyle has direct eye contact with specific resident she is addressing. (Field Notes, S2, p.79)

These three extracts are examples of a LS staff member including specific residents in the discussion. She seems to understand their reason for minimal participation up to that point and then appropriately addresses the need, thus they are helped to feel included in the conversation.

As mentioned by a PCA, care practices which go beyond the practical tasks to include explanations and communication will ensure inclusion:

> *Explaining to them – communicating with them and telling them what you are going to do before you do it. And then they are able to help you as well, so that keeps their quality of life intact as well. Get them to join in to be part of what you're doing to them.* (Interview, S2, p.84)

This PCA explains how she consistently communicates with residents as she is caring for them, and, where possible, includes them in performing those particular tasks. The PCA's willingness to communicate in this way keeps the person with dementia involved in the process of the activity, such as showering or dressing. They are able to help where possible, to make decisions about the process, and generally be part of an interaction, rather than having an action done for them.

An example of the willingness to adapt activities to accommodate residents' needs is explained by a LS staff member. This extract is supported by a subsequent observation during the Word Game activity:

> *One resident in particular whose only activity in the whole week is at Word Games and I want to be sure that I can really work it around him … because he has a particular aspect of that that he stars in and he believes that - it sort of gives him the idea that he's still 'got it' … he's lost his hearing, he thinks he's losing his eyesight and he thinks he's going a bit mad. And he says: 'After all, I'm nearly 97'. So he's someone who is really missing that sort of opportunity to excel in something, and to be able to show that he is still able to do things … it is the only thing that he does … anything that is a one-on-one conversation we have to write on a whiteboard*. (Interview, S1, p.26)

> A resident is sitting in a wheelchair in front row holding a small whiteboard. Lifestyle regularly speaks closely into his ear – resident seems hard of hearing and Lifestyle's interactions enable him to become part of conversation. She regularly writes on his whiteboard.
> (Field Notes, S2, p.11)

This is an interesting observation. Because this staff member has previously described her desire to particularly help this resident (as described in the interview notes above), it is fascinating to observe how she manages to find the time to pay close attention to him while, at the same time, conduct this activity for a large group of people. The resident totally focuses on his whiteboard and listens intently when the staff member speaks specifically to him. Without her dedication, this resident would not be included in this group activity.

A significant contributor to personhood preservation is to feel included in the surrounding processes of life, and, as shown in the data, staff members regularly facilitate this support for residents. As previously discussed, the aged care industry is surrounded by controversies and complexities, and, under these conditions, it seems highly unlikely that care practices which result in personhood preservation can be consistently facilitated by staff members without the ongoing support of management. For this reason, it is advantageous to understand the views of management at Sites 1 and 2 on the importance of personhood. The SMs at Sites 1 and 2 respectively express their thoughts on personhood:

> *I still believe that things like the resident's well-being, respect, dignity, quality of life, holistic care – all those things – are tremendously important factors in the way we care for residents … I think it starts from the time of admission. I'm responsible for the admission, so I make sure the person I admit fits the unit, fits with other residents we've got. I mean, that's the start of personhood, because I look at them as a complete picture*. (Interview, S1, p.33)

> The Site Manager said she totally believes in, and strives to provide care which maintains personhood and places the person at the centre of care … personhood is prevalent in her mind due, to a large extent, to the experiences she went through when her grandmother was in a nursing home. Grandmother wanted to go home, was very unsettled and the Site Manager feels that staff did not take time to find out what was important to her … she feels the nursing staff didn't … look on her grandmother as a person … The Site Manager keeps this in front of

> her mind, and various personal experiences relating to her grandmother help her to remember the importance of the person.
> (Field Notes, S2, p.105)

These comments from both SMs indicate a personal dedication to the provision of personhood care as much as possible, and, as discussed previously, a supportive management style is a significant contributor to personhood preservation. The views of the SM at Site 2 describe deep personal connections to the concept of personhood, which now contribute to her inclusive management style.

Interactions which preserve personhood are presented through examples of residents experiencing dignity and respect, and by indications that they are feeling content and included in the life of their MSU community. The suggestion is made that, in order to be consistent, personhood preservation requires management support. The care as revealed in the data is, of course, provided within two institutionalised environments – large physical environments which are home to people with dementia. Aspects of these physical environments and their ability to preserve personhood are now discussed.

7.4 Homelike Environment

Within the context of this study it is not possible to comprehend the true experience of living in an institutionalised environment. However, the following reflection describes my approach to trying to understand the experience:

> So – does it feel like a home? It possibly does to some extent … if ‘home’ is about familiarity, ritual, nutrition and hydration, sleep and comfort there is a high possibility the residents feel at home in the MSU. It depends how we define ‘home’. (Personal Diary, S1, p.18)

Therefore, by looking beyond the institutionalisation of the environment to focus on aspects such as homelike features and feelings of security enable an alternative perspective into viewing this environment as home, a perspective which is now discussed.

Feeling Secure in the Home Environment

Irrespective of a person's expectations of a home, initial reactions of a living environment are usually about the physical setting and appearance. Consequently, the layout and contents of the MSU at Site 2 are described in this extract:

> This is a very large, yet pleasant, public space for sitting and dining. Windows and doors along one wall look out to a beautiful garden. The sliding door out to the garden opens automatically when approached and residents can walk out if they choose – the garden area is securely fenced, and there is a large walking area with pathways, patio, bird feeder, flowers and greenery. The room is bright and cheery. Although it is clearly an institutionalised setting with a nurses' station at one end, the room does have a welcoming feel about it. There is a very large bench in middle of room with many items on top – cupboards underneath. Top of the bench is well set out with easily accessible items for residents to engage with if they choose … this is a secure unit, but certainly does not have a closed in feel about it. It is very spacious and light with plenty of room for walking around.
> (Field Notes, S2, p.71)

This description of the MSU possibly does not do justice to the pleasant ambience and sense of freedom for residents that I notice during my first observation session in this unit, and which remains with me during my field work at this facility. Of course, when speaking of freedom for residents, this is not true freedom because this is a secure unit. However, compared to many MSUs, this environment offers relatively large walking spaces and immediate access to a large outdoor area. The LS Coordinator comments on the benefits of this level of freedom for people with dementia:

> Lifestyle Coordinator: *The big thing, too, down there* (in MSU) *is those doors how they open automatically – the doors to go outside.*
>
> Researcher: *Yes, I've watched them walk out.*
>
> Lifestyle Coordinator: *They can – when they've had enough inside, they can get up to walk outside and the doors just open. I've seen other places built, and, unless you can open a door and have enough*

> *strength to push it, you aren't ever going to get outside without supervision – but, here you can do that at your own leisure. And that sense of feeling is massive … it's empowering – choice.*
> (Interview, S2, p.63)

The freedom facilitated by the automatic door to the garden is powerful. Most of the residents in this MSU are independently mobile, therefore they are able to walk outside whenever they choose without the barrier of a heavy door, and without the need for supervision. This door is a contributing factor to a homelike environment.

Meal-times are an important feature in traditional homes, and staff go to considerable effort to create a home-like environment at lunch time:

> EN begins distributing medications – medication trolley is discreetly left in passage-way so it is not near dining tables. (Field Notes, S2, p.82)
>
> Meals are efficiently and quietly served. Food appears to be at appropriate temperature as residents begin eating straight away. Looks appetising and well served on plate. (Field Notes, S2, p.84)

Importantly, the medication trolley is not visible to residents while they are seated in the dining room, thus reducing the medicalised and institutionalised aspects of the dining room. The efficiency and calmness with which staff serve the meals and, where necessary, assist residents with eating, all contribute to the peaceful environment of a dining space.

The intimate and caring approach of a PCA is observed as she assists residents with their meal:

> The PCA serves plates to residents. She assists two of the women with their cutlery then draws up a chair and sits between the male resident and the other female resident and begins feeding them alternately. At one stage, I notice one of the women trying to feed herself, but she is not able to get any food on the fork. The PCA waits while she tries again, and then asks her if she would like some help. She laughs and says: '*I think so, my hand isn't working too good today*'. The PCA replies: '*That's no good. Let's see if we can do it together*.' She places food on fork for her, and then says: '*Shall we see how your hand is going now?*' She hands her the fork and the resident

> manages to place food in her mouth. The PCA says: '*Look at that – we are a great team, aren't we?*' The resident smiles. The PCA chats with residents while continuing to assist with their lunch. It is a pleasant, home-like meal-time which seems to be enjoyed by all residents. (Field Notes, S2, p.18)

The setting for the meal described in these field notes is the smaller dining room in the MSU, a fact which may contribute to a more relaxed and informal approach to mealtime than often seems to be the case in the larger dining room. It is possible the residents feel safer in a smaller dining room. The perception of feeling safe both physically and cognitively in one's environment is an important contributor to the concept of home. Staff offer reassurances for residents as they move to the dining room for lunch:

> A PCA is helping a resident who says: '*Who are you*?' The PCA replies: '*Hi* [name of resident], *I'm* [her name] - *here's a seat for you*.' The resident asks: '*Do my family know that I'm here*?' and the PCA replies: '*Yes they know - it's all good. You're head of the table today*.' The PCA asks: '*Can I move your walker over here?*' and the resident says: '*You can if you like.*' The PCA responds: '*Thank you*'.
> (Field Notes, S2, p.81)
>
> Another resident is being helped inside and asks: *'Now where am I? I don't really know where I am'.* Lifestyle staff replied: *'I'll tell you where you are – you are at* [name of facility] *and we are going to have some lunch'.* (Field Notes, S2, p.81)

These extracts offer insights into the minds of people with dementia as they express disorientation and confusion. Interestingly, a short time prior to these conversations taking place, both these residents appeared relaxed and totally engaged in the outdoor activity, as they did at the dining table later once they were seated. So it seems moving from one environment to another creates a sense of uncertainty for them. However, as noted in this diary extract, in spite of the second resident being unsure of his whereabouts, he appears to sense he is in a safe place with people he can trust:

> There was one resident who indicated he didn't know where he was nor what he was supposed to be doing but a staff member provided

> reassurance. He did not seem distressed by not knowing his whereabouts. Rather, he showed signs of feeling safe, confident enough to ask the question, and trusting of those around him.
> (Personal Diary, S2, p.37)

Issues around home and feelings of security in the MSU are discussed in the context of the physical environment because feeling safe in one’s home contributes to a sense of personhood preservation. Regardless of the level of awareness each resident may feel about safety and security measures, it is not unreasonable to assume they would, at some level, sense that the MSU is a safe place in which to live. Furthermore, in those times when they may feel unsafe, the reassurance that a trusted person is nearby very likely contributes to their sense of wellbeing.

This chapter has examined how aspects of organisational connectedness, confident staff, valuing the person with dementia, and a homelike environment create a positive impact on the personhood of people with dementia. Personhood is preserved as demonstrated through meaningful engagements and interactions. Configuration of personhood preservation as presented in this chapter provides evidence that, at some junctures of aged care provision, people with dementia are valued and respected. Furthermore, staff feel valued and empowered to deliver care which enables recognition of personhood to be maintained. Chapters Six and Seven are presented as parallel discussions about personhood violation and personhood preservation in residential dementia care settings. Together, they present the outcomes of the fieldwork for this research. The following chapter will draw together these findings, by discussing interpretations of the findings in conjunction with relevant literature.

Chapter Eight: Stigma, Silencing and Reconceptualisation

The Cultural Reconfiguration of Personhood Practice

This investigation into reconfiguration of personhood practice in residential dementia care finds that both personhood preservation and personhood violation continue to occur in contemporary care practices. Because a level of disregard for personhood care exists, the additional aim of this study, to argue for the positioning of personhood at the forefront of dementia care, is justified. In this way, the reconfiguration of personhood practice succeeds in diminishing personhood violation and, accordingly, maximises preservation of personhood. The previous chapters explored literature relating to the study, outlined relevant theoretical and methodological frameworks and presented findings of the study. This chapter discusses interpretations arising from the research by drawing on literature reviewed in Chapter Two, literature emerging since the review, and data from this study. The study aims are addressed in this chapter's interpretations of the research.

Most personhood violations are a result of actions or inactions of care staff. On the surface, therefore, it seems the solution to eliminating such violations is to re-educate staff on appropriate care practices. However, in most cases, staff display efficiency, dedication and compassion as they care for residents, and are, in fact, doing the best they can under somewhat difficult circumstances. The ethnographic nature of this research enabled deeper scrutiny of the culture in which staff are working, revealing that the nature of personhood care is influenced by external cultural attitudes about people with dementia. These attitudes are multi-layered in that they emanate from society's opinions and perceptions about people with dementia, and then infiltrate the culture of the aged care organisation. In turn, the organisational culture directly affects the culture of the psychosocial environment in which the person with dementia lives, thereby determining the status of their personhood. This chapter discusses these interconnecting societal and organisational cultures, and concludes with an argument for placing personhood at the forefront of dementia care. Thus, the chapter outline is: 1) Society's Cultural Shaping of Dementia Care; 2) Intersection of Personhood Care and Organisational Culture; and 3) Positioning Personhood at the Forefront of Dementia Care.

8.1 Society's Cultural Shaping of Dementia Care

Societal expectations of an aged care organisation are high. The community expects that people with dementia are well cared for and that quality dementia care is available if it should ever be personally needed. Families expect that their family member with dementia will feel safe and content living in an aged care facility, will receive a high standard of physical and psychosocial care, will receive appropriate and timely access to medical care, and will consistently experience meaningful connections and support. Those employed as care staff understand their work can be both rewarding and challenging, but expect to be valued and respected as an employee, supported as a team member, and adequately trained and resourced to undertake their role. These are all reasonable expectations, but, as this study finds, the outcomes of dementia care often fall short of society's expected standards. Yet, interestingly, it is society itself which creates a stigmatised culture around dementia care – a culture which is markedly removed from expectations, and within which it is extremely challenging to fit a framework of personhood care. Within these seemingly incompatible contexts of culture and expectations, societal influences on aged and dementia care are now discussed, commencing with how society has historically shaped the aged care industry.

The Shaping of Aged Care

As discussed in Chapter Two, the aged care system in Australia is complex, inequitable and under-resourced (Henderson et al. 2017; Hughes 2011), and, as mentioned previously, is, once again, under public scrutiny with a Royal Commission into aged care currently underway (Royal Commission 2018). Major concerns of the current aged care model are quality of care and governance, the need for increased respect for personal rights of residents and improved facilitation for social connectedness (Ibrahim 2018), concerns which, significantly, are reflected in the aims of this thesis. This doctoral research has revealed a disconnection between organisational culture and personhood needs, a point supported by Ibrahim’s (2018) suggestion that care outcomes are related to organisational characteristics such as staffing profile, financial viability, leadership and workplace culture. To better understand this ongoing struggle for aged care providers to successfully accommodate personhood needs, this discussion will explore society’s shaping of the aged care system.

In the 1950s, long-term hospital beds began to close in preparation for high technology acute care, and, as a consequence, residential aged care facilities were developed to accommodate older people from hospitals who required long-term care (Fine & Davidson 2018). Adaptation from a hospital environment has seen a medical model of care superimposed on residential aged care, with little consideration for the specific physical and cognitive needs of older people, nor an understanding of what quality of life involves for older people (Walmsley & McCormack 2016). A further consequence of this development was the transition from a mostly unpaid model of care in the family home, performed predominantly by women, to a structured and paid system. Thus the landscape of care provision was transformed from the family relationship environment to ‘care as a commodity’ (Farris & Marchetti 2017, p.116). A commodified system of residential aged care has seen the emergence of marketisation and corporatisation across the industry.

As with other countries, the marketisation of aged care is currently occurring in Australia. Marketisation in residential aged care is associated with increased ownership of RACFs by private providers, residents being viewed as consumers, and a belief that marketisation ensures quality care (Henderson et al. 2018). Organisations tend to respond to the impacts of marketisation by becoming less benevolent and more business-like in their behaviour, an approach which sees ‘care’ becoming more a commodity than a relationship (Fine & Davidson 2018). This study has shown the need for a stronger focus on the person and less on the organisation, and that more consideration seems to go into the organisation’s website content than on the needs of residents. The high cost of entering aged care, due, in part, to marketisation, is raised in this study as being a major problem for families who suddenly need to deal with excessive financial burdens in addition to their already existing health concerns (Data: Interviews, pp.73, 74). Marketisation invariably leads to inequalities in the quality of care provided (Brennan et al. 2012), and, according to Woods, Phibbs and Severinsen (2017), does not support the ability of staff to function within an ethic of care. As discussed in Chapter Two, the importance of quality interactions and relationships based on an ethic of care are fundamental to quality dementia care, with the issue of justice being closely linked to an ethic of empathic care (Waghid 2019). It is suggested, therefore, that effects of marketisation may be detrimental to the integration of personhood in dementia care.

Aged care organisations are developing into larger corporations (Goldsworthy 2019), thereby adopting corporate practices such as cost-cutting and redistributions within workforce structures. Even though not-for-profit organisations may not categorically belong to the ‘corporate’ sector, there is a strong suggestion in both for-profit and not-for-profit organisations of a general restructure of care processes. This research has demonstrated that corporate staff are frequently geographically distant from the care situation, and, in this way, corporatisation tends to remove the responsibility of assessing residents’ care needs away from care staff and, instead, gives corporate staff the authority to design care services. For this reason, Farris & Marchetti (2017) believe there is a risk that care practices are becoming less personalised and less sensitive to the changing and individualised needs of people with dementia.

My research has shown that a number of corporate decisions are negatively affecting staffing and operational performances at both sites. A corporate mandate that the personalised community newsletter at Site 1 will be replaced with a mass-produced corporate circular to which individuals can make only minimal contributions; a directive that care plans are now to be structured in a way that prioritises diagnoses and ‘behaviours’ and focuses less on the person; and new rules about storage of documentation which makes residents’ life histories less accessible are all indicative of the decreasing amount of autonomy at the facility. The organisational requirement of staff to attend meetings at head office yet not be replaced on site results in the psychosocial needs of people with dementia being ignored for that period of time. The decision to substantially reduce staffing hours in order to cut costs has serious consequences for residents and staff. Not only is there a significant impact on care delivery, but, as noted by Killett et al. (2014), the unique culture of each facility is ignored.

This discussion on the shaping of aged care through the societal trends of marketisation and corporatisation indicates a significant disconnection between an organisation’s culture and its delivery of personhood care for people with dementia. The findings of this study demonstrate that questions must be raised in a contradictory situation where, in spite of espoused values, an aged care organisation’s leading focus becomes ‘market and commercial considerations’ (Fine & Davidson 2018, p.512) rather than personhood care. Alongside the trends of marketisation and corporatisation, society’s opinions and perceptions about dementia, which largely stigmatise and devalue, have also had a negative impact on dementia care, and will now be explored.

Under-Valuing and Stigma

Residential dementia care is positioned within a wider society which, to a large degree, misunderstands, devalues and stigmatises people with dementia. This study has discussed widespread criticism of derogatory language such as ‘zombies’, the ‘living dead’ (Behuniak 2011), and ‘no longer there’ (Johnstone 2013) in reference to people with dementia. Research institutes, governments and other public bodies make dramatic statements about dementia as a ‘tsunami’ and an ‘epidemic’ (McDonald 2019), while dementia is often referred to as a ‘second childhood’ or a ‘social death’ (Gerritsen, Oyebode & Gove 2018), all examples of language which catastrophises a diagnosis of dementia (Reed, Carson & Gibb 2017). Discourse of this type facilitates perceptions of a person with dementia as ‘other’, thus setting them apart as separate and different to other members of society (McParland, Kelly & Innes 2017). As a consequence of these negative discourses, society tends to associate dementia with fear and stigma, and people with dementia are widely considered to be deprived of life and as having lost their personhood (Macdonald 2018). Although these societal views are not representative of the facts about dementia, there is, nevertheless, 'an entrenched stigma associated with aged care' (Walmsley & McCormack 2016) which has a significant impact on the culture of residential dementia care. If society perceives that people with dementia have lost their personhood (MacDonald 2018); are a financial burden to the community (Macdonald, Mears & Naderbagi 2019); are characterised by 'challenging behaviours', a term used to label actions of those who are agitated and confused (McDonald 2019, p.61); and are of less value than others and, therefore, considered as 'other' (Biggs, Haapala & Carr 2019), it is reasonable to assume that this supposed entitlement to devalue people with dementia, referred to as 'dementiaism' (Brooker 2004, p.217; Reed, Carson & Gibb 2017, p.696), exists at some level in residential dementia care.

Evidence in this research has found care practices which result in devaluing or 'othering', yet many of these approaches have been condemned in the literature review. This research finds that devaluing occurs when people with dementia are spoken to, or spoken about in a dismissive or derogatory manner (Nowell, Thornton & Simpson 2011; Reed, Lane & Hirst 2016); when it is deemed satisfactory to deprive people with dementia of social interaction for long periods of time (Hunter, Keady et al. 2016; Kaufmann & Engel 2016; Moyle et al. 2015); at those times when it is considered too expensive to have sufficient staff available to meet residents' needs, particularly during times of urgent need (Edvardsson, Fetherstonhaugh & Nay

2010; Henderson et al. 2017; Killett et al. 2016; Talbot & Brewer 2016); when residents are denied appropriate nutrition because of organisational policies (Milte et al. 2017); when residents are expected to comply with the organisation's needs rather than their own personal needs (Edvardsson, Fetherstonhaugh & Nay 2010; Hirst, Lane & Reed 2013; Killett et al. 2016; Moyle et al. 2015); and when people with dementia are ignored as they attempt to express a need or engage in social interaction (Moyle et al. 2015). Many dementia care practices are, in fact, controlling and paternalistic in nature, a form of personhood violation which is internalised by people with dementia (Reed, Carson & Gibb 2017). Paternalism is manifested in this study when velcro bibs are automatically placed around necks at meal-times, when residents are condescendingly told they need to wait before a request is granted, and when a person with dementia, whose wife is living in the same building, is prohibited from visiting his wife and is not provided with appropriate emotional support to address his distress. This study clearly shows that, in spite of considerable evidence supporting personhood preservation, organisations continue to use societal stigmas around ageing and dementia as justification for enforcing practices which result in violation of personhood.

Under-Valuing Leads to Under-Resourcing

As stated previously, society holds high expectations of residential dementia care. Nevertheless, this discussion has shown that societal culture continues to under-value people with dementia, and, in fact, this societal culture permeates the culture of aged care organisations. Thus, the need to transform societal culture continues to be relevant, particularly when the issue of resourcing for the aged care sector is considered.

As revealed in this study, aged care providers receive subsidies and benefits from the Australian Government, and also receive income from residents in payment for services provided (McDonald 2019). The level of governmental funding is frequently cited as a problematic issue in quality care provision, with aged care providers regularly advocating for extra Government funding (Leading Aged Services Australia 2018), while the Government periodically increases or decreases aged care funding as it sees appropriate (ABC 2018). As noted by Joenperä (2017), the funding system is a difficult area for aged care providers to navigate, often further complicated by changes in government policy regarding funding entitlements.

The aged care system and governmental policies are mentioned in this study as stimulating the recent organisational cost-cutting exercises. A manager speaks of the stress and anxiety caused by the ‘massive’ roster reviews, describing the emotional impact on herself and staff of the need to reduce staff hours. The manager expresses her gratitude that most of the staff have been understanding about the need to reduce their hours, however, she is clearly concerned about the financial implications for staff members, particularly in light of their low pay rate. Although not necessarily understood by those on higher rates of pay, she explains that even a reduction of half an hour can make the difference between buying ‘a loaf of bread and two litres of milk’. The manager describes the pay rate for PCAs as ‘horrendous’, and recognises that, even for many of those from a double income household, their total family earnings are barely sufficient (Data: Interviews, pp. 71, 72).

My research has clearly demonstrated the apparent disregard and unaccountability by society, governments and organisations regarding the emotional and financial effects of choosing to cut costs at the lower end of the wages bracket. It is these same staff members who now face an overwhelming workload as they are expected to complete the same amount of work in less time and while receiving less pay. These staff members are undervalued, and, indeed, the residents for whom they care are also undervalued as they now experience a reduction in the quality of their care. A genuine understanding of dementia care would inform organisational decision-makers that a directive for staff to work faster is not appropriate. The physical pace of older people cannot be accelerated nor the anxiety levels of people with dementia be reduced in order to accommodate organisational needs. This situation highlights the fact that undervaluing does indeed result in under-resourcing, a situation which, apparently, is acceptable and, somehow, justified.

Although the matter of insufficient funding was raised in this study, it is beyond the scope of this thesis to analyse or comment on the adequacy of income streams for aged care providers. However, it is clearly the role of this thesis to question whether society’s stigma and devaluing of people with dementia has an impact on the level of funding for dementia care, or, furthermore, an impact on the conditions placed on how funding must be spent. Obviously, many significant costs are involved in the operation of aged care organisations, however, it is paramount to question how much of the allocated funding, along with fees paid by residents, is assigned to areas other than provision of personhood care and maintenance of a skilled workforce which is appropriately resourced to deliver such care. With this study adding support to the growing evidence that personhood violation in residential dementia care continues to occur, there is justification for questioning the conditions and processes for allocation of funds by governments and, equally, the distribution of organisational funds. As has been discussed, negative positioning of people with dementia continues to exist in society, a cultural practice which destabilises the security and rights of those with dementia, and places them, and those who advocate on their behalf, at an unfair advantage in the competition for governmental resources (McDonald 2019). In light of this study, it is clear that the response to such questions emanate from societal stigma, and are further impacted by the trends of marketisation and corporatisation.

Although not discounting the accountability expected of each staff member, individualised explanations of personhood violation often distract attention from systemic injustices existing within the aged care system, such as stigmas, staff shortages, inadequate training and low wages, mostly due to chronic under-resourcing (Walmsley & McCormack 2016; Woods, Phibbs & Severinsen 2017). The following discussion explores the personal impacts of under-resourcing, largely instigated by stigma and corporatisation, as these impacts intersect with the personhood needs of a person with dementia.

8.2 Intersection of Personhood Care and Organisational Culture

The impacts of marketisation in the aged care industry and societal stigmas about dementia have been described, and this discussion now locates those impacts within the organisational culture. This study shows that organisational structures are, at times, able to successfully diminish the effects of these societal impacts, most noticeably when people with dementia are treated with respect, rather than stigmatised, and when staff appear confident and well supported in their roles. On the other hand, this study also shows that when the organisational culture has succumbed to the impacts of marketisation and societal stigma, staff are not feeling supported by the organisation, and are, in fact, working under very stressful conditions. The impacts on care practices when personhood care intersects with a conflicting organisational culture are now discussed.

The Psychosocial Environment

As discussed in Chapter Five, the psychosocial environment refers to the social and emotional space in which the person with dementia lives. The nature and characteristics of daily experiences within this environment dictate whether personhood is predominantly preserved or violated. The attitude and mindset of staff play a major role in determining the personhood culture and, to some extent, the deciding factors are linked to the current emotional and physical states of staff members as they function within their workplace environment.

The contrasts between the workplace environments of Sites 1 and 2 are clearly evident in the data. Following extensive roster cuts, the staff at Site 1 are experiencing heavier workloads, stressed because they are under-resourced to perform their work to a satisfactory standard, and facing job insecurity. There is a strong sense that they have been abandoned by the organisation, and the need to survive each day and to retain their job is a personal priority. They are, therefore, emotionally and physically exhausted. On the other hand, staff at Site 2 interact and connect frequently with people with dementia, are well supported by a strong management structure and each other, and create a positive living and working environment. There are some underlying management and staffing issues and an emerging sense that organisational change is imminent, but, for the most part, there is a sense of strong communication, teamwork and commitment to quality care practices. Staff at Site 2 usually appear calm, in strong relationships with residents, and, when challenges arise, show confidence in their ability to manage the situation.

As discussed in Chapter Seven, the philosophy of ‘working from the heart’, as expressed by a PCA when describing her attitude to caring for people with dementia, is embraced by many staff members at Site 2 who are willing to engage in personhood care beyond the responsibilities of their job description. By contrasting the workplaces of these two sites, this study has shown that when staff feel supported and work in a stable environment, they feel confident and well-resourced to provide quality personhood care.

To a lesser extent, the physical space also frames the nature of personhood care. The layout of the MSU at Site 2 encourages care which focuses on individual needs and interests. A large number of lifestyle resources, such as household items and art, craft and reading materials are easily accessible for residents to access if they wish. Staff are regularly available to facilitate music, reading and reminiscence interventions and to engage in conversation and assistance with ambulating. Residents are able to freely walk outside to an attractive garden with seating, pathways and an abundance of plants. This environment at Site 2 focuses on preserving personhood through interactions which are almost understated in appearance, yet are comprised of respectful openness to each person’s preferences (Carr, Hicks-Moore & Montgomery 2011). Residents are frequently included in conversations, invited to go out to the garden, offered refreshments, and given choice and freedom about their inclusion in group activities. This environment is a welcoming space for those seeking companionship, either as a participant in an activity or an observer from one of the many comfortable seating areas. In contrast, the physical environment at Site 1 looks dismal and uninviting. The décor is rather dreary, there is only a limited walking area, no easy access to outside and, in fact, no windows in the lounge area from which to see outside. For the most part, those living in this space seem to reflect their physical environment, in that they regularly appear disheartened and abandoned. Only on rare occasions is there meaningful communication or interaction within this environment.

Interventions which effectively address psychosocial needs help to reduce anxiety, enhance remaining abilities and deliver opportunities for interaction and social connection (Johnson & Narayanasamy 2016), and are, therefore, an important component in preserving personhood (Milte et al. 2016). A culture of consistently incorporating psychosocial care into daily practices exists at Site 2, and purposeful interactive behaviour with others (Hunter, Keady et al. 2016) is a strong feature of daily care. This study demonstrates such care when staff help a resident fold items from the ironing basket, invite a resident’s input during a group activity, calmly walk with a resident who is feeling anxious and patiently help a resident to slowly eat a meal. While the culture at Site 1 is, in the main, less inclined to incorporate psychosocial interventions in daily care practices, staff do periodically provide emotional support through compassionate interactions. This study has demonstrated these interactions through a PCA’s respectful manner while assisting a person with dementia to walk to the dining room, an EN’s gentle approach as medication is administered to a person who seems quite drowsy, and the chaplain’s practice of personally speaking to each resident when entering and leaving a musical activity and church service. Psychosocial actions such as these engender emotional and social support within the psychosocial environment, and acknowledge the person beyond the diagnosis of dementia (Johnston & Narayanasamy 2016). On the other hand, the person is not acknowledged or supported when their needs are ignored, delayed or, in fact, silenced.

Silenced Voices and Needs

Dementia care approaches such as person-centred care have enhanced personhood preservation (Edvardsson, Fetherstonhaugh & Nay 2010), however this study shows the ongoing presence of a seemingly entrenched culture which continues to justify and excuse care practices resulting in personhood violations. A significant consequence of personhood violation is that the voices and needs of people with dementia are silenced and, therefore, ignored. As noted in Chapter Two, this silencing is inconsistent with an ethic of care, which, according to Waghid (2019), is concerned with issues such as responsibility and justice.

This research shows that people with dementia at Site 1 consistently have their psychosocial needs ignored, and their voices and other attempts at communication are frequently deferred for attention at a later time or not heard at all. The psychosocial environment at Site 1 appears to not welcome expressions of need from people with dementia, but, rather, encourages silence and compliance so that tasks and routines can be completed.

My research demonstrates that silencing and disengagement are the consequences of a recently introduced policy to counteract roster cuts. Because there are now insufficient staff in the mornings to attend to all residents, a decision is made on a daily basis about which residents are left in bed for the day, meaning that the personhood of those left in bed is violated. This violation is worsened because previously allocated time for LS staff to visit residents in their rooms has now been withdrawn. Therefore, it is highly unlikely that a person temporarily or permanently confined to bed will receive any social interaction other than with staff who are focused on completion of tasks rather than psychosocial needs. Rather than social isolation, interventions which offer regular social interaction, attachment and inclusion are essential for the wellbeing of a person with dementia (Kaufmann & Engel 2016), and, the more advanced the dementia, the more urgent the need for ‘person-work’ (Fazio et al. 2018, p.S12). Leaving a person with dementia in bed for the day when they would otherwise be participating in the life of the community is a practice which silences voices and overlooks needs for inclusion and social interaction.

People with dementia at Site 1 frequently appear disengaged, ignored and, quite often, abandoned, even when they have been assisted out of their room and into the lounge area. The regular routine of leaving people with dementia seated in a rather dismal lounge area with only a television for stimulation is depressing and negligent. On those occasions when staff do provide personhood care involving music and singing, many of the residents respond by singing, smiling and interacting with staff members and the music. However, these opportunities are infrequent, and the normal procedure is to leave residents in front of the television with minimal social interaction for considerable periods of time (Mjørud et al. 2017). Psychosocial outcomes such as demeanour and mood of people with dementia are well recognised features by which quality of care can be judged (Beerens et al. 2018), and this study frequently demonstrates that the demeanour and mood of these people indicates discontent, confusion and emotional isolation. These findings support the literature which documents that people living in residential dementia care frequently spend up to 40% of the day disengaged from activity and interactions (Jao et al. 2018), have a low number of social connections (Mitchell et al. 2016), and spend long periods of time alone (Casey et al. 2014). Whatever the reason, ignoring opportunities for meaningful interactions are instances of missed care.

Missed Care Becomes Silenced Needs

People living in residential dementia care are reliant on staff to meet many of their physical and psychosocial needs. The allocation of enough time to meet these needs is critical, however, direct care staff report they regularly have insufficient time to complete tasks, resulting in occurrences of missed care (Knopp-Sihota et al. 2015). Such occurrences are often random, and incorporate care which is inadequate, infrequent or missed entirely (Henderson et al. 2017). The ambiguity of the term ‘missed’ in this context raises concerns about the priority given to the specific task in question. It is possible that what is not done is regarded as unnecessary rather than missed, particularly if the overlooked care is not recorded in the resident’s care plan (Henderson et al. 2017). Any need which is not effectively addressed in a timely manner can be interpreted as silencing the need and, in effect, silencing the voice of the person with the need.

My research has shown responses to toileting needs delayed for considerable periods of times, nutritional needs not adequately met when residents become restless during meal-times, and psychosocial needs ignored when staffing levels are inadequate. Spending time talking with residents is a basic psychosocial care practice, yet it is the form of care most often missed (Knopp-Sihota et al. 2015), and the most commonly identified reason for missed care in residential dementia care is lack of staff (Henderson et al. 2017). Priority is given to tasks defined as medically orientated or related to resident safety rather than psychosocial care practices such as social and emotional care. This discussion has shown that personhood care is frequently not prioritised in dementia care, highlighting, therefore, the need to reverse standard values and practices, as discussed in the following section.

8.3 Positioning Personhood at the Forefront of Dementia Care

Having investigated the reconfiguration of personhood practice in residential dementia care, the remaining aim of this study is to argue for the consideration of personhood to be a priority in dementia care practice. My research has demonstrated that, when their personhood is consistently preserved, people with dementia are more engaged with their surroundings, appear more relaxed and self-assured, and, through their actions and communications, indicate they enjoy a caring and secure relationship with staff. These findings supported the literature where personhood is described as 'recognition of the worth and uniqueness' of each person (Hirst, Lane & Reed 2013, p.76). Preservation of personhood occurs through 'intentional caring attitudes and actions' (Carr, Hicks-Moore & Montgomery 2011, p.405); the fulfilment of needs such as comfort, attachment, inclusion, occupation and identity (Kaufmann & Engel 2016); good quality individualised care (Milte et al. 2016); the meeting of emotional and spiritual needs (Powers & Watson 2011; Reed, Lane & Hirst 2016); and quality resident-staff relationships (Perkins et al. 2015). Therefore, the value in preserving personhood has been established and interactions fundamental to personhood care are suggested.

Nonetheless, as evidenced in this study, personhood care is periodically ignored, therefore, this closing discussion focuses on areas of concern which, if appropriately addressed, will significantly contribute to prioritisation of personhood care. Specifically, the following discussion addresses major barriers to personhood care as identified in my research: societal and organisational stigma leading to undervaluing of people with dementia; and insufficient support and resourcing of staff.

Reconceptualisations of People with Dementia

The process of positioning personhood at the forefront of dementia care begins with restructuring dementia ‘from a medical and/or ageing issue to a political and social issue’ (McDonald 2019, p.74). The biomedical model of dementia has traditionally focused on medical treatments and possible cures, yet these fall short of portraying the complete story of a person with dementia. A focus only on neuropathology reduces the situation to a person with a brain condition, thereby dismissing appropriate access to psychological and social support (Gerritsen, Oyebode & Gove 2018). The medical focus is the dominating cultural understanding of dementia as portrayed by media, politics and the arts, and, therefore, is entrenched in societal and, perhaps, organisational cultures.

Rather than a bodily phenomenon, dementia is a social experience, therefore the focus for dementia care must be social engagement, relationships and appropriate oversight of dementia-related symptoms. Biomedicine is challenged by dementia, in that it cannot address its moral and social expressions. The medical model looks to treat a person with dementia as an individual, but dementia is an experience shared with family and staff, therefore, along with the person with dementia, they should also be a focus of care and support. The quality of life for the person with dementia depends on family and staff, not on the medical profession (Macdonald 2018). Thus, effective and consistent social support is a responsibility of residential dementia care policies.

In this discussion on reconceptualising dementia care, acknowledgement of personhood care within organisational policies is highly relevant, and, in fact, given the findings of this study, is worthy of further exploration. It is necessary to question how the person with dementia is imagined and understood by the organisation, and what characteristics and needs of the person inform organisational policy and practice (Macdonald 2018). My study has demonstrated several indications of organisational disconnection and misunderstanding, including calls from staff members for a greater corporate understanding of dementia care, a need for the 'powers-that-be' to understand the needs of older people, and the need for care staff to feel supported and appreciated by corporate staff. These findings of disconnection and misunderstanding are reflected in recent media reports, indicating they are widespread across the aged care industry (for example, ABC 2019; Bendigo Advertiser 2019; News 2019; Nine News 2018; SBS News 2019; The Guardian 2019). It must be noted that the gravity of violations in these media reports does not reflect the findings of this study, however, any level of personhood violation emanates from disconnections, misunderstandings or undervaluing of people with dementia. It is likely, therefore, that, without any other frame of reference, corporate staff adopt society's stigmatised views of dementia, which, at times of economic difficulties, and as demonstrated in this study, lead to actions which exhibit undervaluing and misunderstandings of the needs of people with dementia.

An important step towards connection and understanding is to ensure that corporate staff and management view dementia within a personhood framework. Such a framework understands that dementia incurs a level of vulnerability, but accepts that vulnerability is a legitimate life experience for many people. Those who are vulnerable, and, in fact, every human being, benefits from living in a society which provides care as needed. Rather than perceiving dementia as a cruel, feared and denigrated disease, and a financial 'burden', a personhood framework values vulnerability and care as fundamental characteristics of life (Macdonald, Mears & Naderbagi 2019). Consequently, within this framework, dementia care is normalised. From this perspective, the value of the person is acknowledged and ‘living with dementia’ focuses on quality of life rather than symptoms of dementia (Gerritsen, Oyebode & Gove 2018, p.601). Thus, in order to achieve connection and understanding of dementia care, those responsible for dementia care budgets and policies must be conversant with viewing dementia care within a personhood framework. As discussed below, alongside the need for realistic budgets and policies, is the need to reconceptualise current trends relating to staff and staffing levels.

Reconceptualisations of Staff and Staffing Issues

This study has discussed devaluing aspects of working in aged care, and the demeaning issues of demanding working conditions, low levels of remuneration and the systemic stigma of working in aged care (Walmsley & McCormack 2016). My research has confirmed the existence of demanding working conditions and low pay rates. This study has also confirmed that appropriate levels of support and resourcing of staff have significant impacts on the nature of personhood care, and, at those times when staffing levels are inadequate, personhood violation occurs more frequently. Therefore, the stigma and undervaluing of dementia care discussed above are also apparent in issues concerning care staff, leaving no doubt that reconceptualisations of working conditions and personhood of staff are warranted.

In Australia, devaluing of aged care work is deeply entrenched in historical and cultural contexts. Traditionally, the role of caring has been performed in the home by women, therefore, care work is associated with unpaid women’s work. Hence, the rewards of care staff are emotionally framed in the concepts of care, self-sacrifice and love (Palmer & Eveline 2012). This gendering of aged care work strengthens the justification of low-waged and low-skilled work, thereby reinforcing cultural norms that devalue care work (Ravenswood & Markey 2018). Likewise, inaccessible training for care staff justifies poor remuneration (Walmsley & McCormack 2016). Palmer and Eveline (2012) suggest that, in order to overcome the dichotomy of high quality care provided by unskilled care staff, aged care organisations periodically engage in the 'love, not money discourse' (p.270) which constructs care staff as gaining emotional reward from care work, and, therefore, being prepared to choose low pay. Within this construction, therefore, justification for low wages is sound (Palmer & Eveline 2012). This study has shown, once again, that under-valuing leads to under-resourcing.

Personhood discourse rarely focuses on the personhood of staff, yet, despite being expected to provide person-centred care to residents, the unskilled status of care staff means they are generally undervalued, and the issue of their personhood is seldom given consideration (Kadri et al. 2018). Nonetheless, as indicated in this study, personhood care for people with dementia must, by definition, include personhood support for staff. The most valuable assets in aged care organisations are the staff who actually provide the care, and management and workplace practices need to reflect the value of care staff members, along with indications that their work and contributions are valued by the organisation (Cooke 2018). Indeed, staff members are persons too, therefore, it is important hear their voices.

Unsilencing the Voices: Prioritisation of Personhood Care

This discussion on positioning personhood at the forefront of dementia care has argued for reconceptualisations of people with dementia and of staff members, so that societal and organisational stigmas can be transformed to cultures of value and respect for both cohorts. It seems appropriate, therefore, in these concluding comments, for my research to allow the voices of these two groups of people to be unsilenced.

This doctoral research shows that staff members know their residents really well, and, to a large degree, are able to understand and articulate their needs, so, when given the opportunity, are able to act as a voice for themselves as well as for the residents. Through enacting the principles of personhood care, that is, valuing, respecting and listening to each person, this study validates the needs of people with dementia and staff members. The following discussions incorporate paraphrased excerpts from the data specifically expressing the needs of people with dementia and staff members, and are written in the first person to unsilence their voices.

In Our Voices: The Needs of People with Dementia

As people living in residential dementia care, we need our environment to be welcoming and accepting, and a place where we feel we belong. Staff within our community need to offer companionship, protection, and a safe place in which our needs can be expressed, heard and addressed. Consistency in staffing provides familiarity, relaxation and security. We need staff to spend time sitting, walking and listening to us as well as helping with showering, dressing and eating. We need staff who are calm, interactive, responsive and sensitive to our needs and who can provide emotional support.

The need to contribute to the community is important for some of us, as are the needs to reminisce and share life stories, and to be given choices about what time to get out of bed in the morning. It is important we are treated with respect and kindness, not degraded because of our age or dementia, and to be acknowledged as a person who has made contributions to our families and to society. We regularly need access to resources or people who help make life pleasant and meaningful, and we need to have genuine choice about our food rather than feeling rushed to state our preferences when we are unable to hear or comprehend the menu choice. We need to be understood as individual persons who still feel emotions and still have a heart, and for staff to be patient with us and realise that we can't move or think as quickly as we once could.

In particular, we need staff to know that we often feel lonely, scared, confused or sad, and can become agitated when needing reassurance. We cannot predict when these feelings may overwhelm us, so we often need extra reassurance after hours or on weekends, as well as on standard working days. We are doing the best we can even though there are many things we do not understand about the life we are now living.

In Our Voices: The Needs of Staff Members

As carers, chaplains and lifestyle staff working in residential dementia care, many of us love our job and have a genuine compassion for people with dementia. Building relationships with them so we can provide the care they need is so rewarding and helps us to better understand what it might be like to live with dementia. Feeling supported by management and by each other is important, particularly when feeling overwhelmed by work pressures or during stressful situations.

The work is quite hard physically and emotionally, especially when people with dementia become tired, frustrated or aggressive. This seems to happen more frequently after hours when less staff are on the floor, and, on occasions, poses safety risks for residents and staff. Even during the day it seems as though there are not enough staff on the floor, and we sometimes struggle to attend to residents when they need it. We know they need us to spend more time with them, especially to talk with them and support them, and it can get very upsetting for us when we feel we are not doing our job properly. We often feel physically and emotionally drained at the end of a shift.

We need to feel respected and supported by the organisation, but we doubt that many people understand what caring for people with dementia is really like. We know our residents really well, and it is hard not being able to provide all the care we know they need. The emotional drain of dealing with death on a regular basis is hard, but there is no acknowledgement or support for our sadness and grief. The work in a dementia unit is under-rated and we are not paid enough for what we do, but most of us regard the residents as family and we are more than happy to love and care for them to the best of our ability. We are expected to provide person-centred care, but, as staff members, we rarely feel as though we are valued and respected as persons.

Positioning Personhood at the Forefront of Dementia Care

The similarities between personhood and person-centred have been well documented in this thesis. Person-centred care has become associated with best practice dementia care (Edvardsson, Fetherstonhaugh & Nay 2010), and has emerged as the ‘buzzword’ of industries tasked with caring for those with dementia (Macdonald 2018). It is fair to say, then, that person-centred care programs are currently leading the way in dementia care practice. Person-centred care has certainly delivered improvements to dementia care, however, my research demonstrates that, as a complete model of care, it may contain inadequacies. The findings of this study suggest that person-centred care is not sustainable in the current aged care climate of low budgets and insufficient staff. These findings are supported by Macdonald (2018) who suggests that the person-centred care model has become commonplace, and not truly achieving the goals for which it was intended. Instead of placing the person at the centre of their own care practices, it has, instead, become a ‘technique’ which is ‘part of the carer toolkit’, separated from the lived experience of the person with dementia (2018, p.294). My study shows that, in spite of an organisation-wide person-centred care focus, personhood violation continues to occur, and that the priorities of an organisational culture can be such that, somehow, a financial crisis justifies the implementation of personhood violations.

This study demonstrates that the concept of personhood is an effective and enduring framework of care. The culture of personhood care is deeply grounded in the value and respect of each person, and, therefore, as shown in the study findings, requires significant cultural transformations at societal, governmental and organisational levels. Once these transformations are in place in societal and governmental spaces, an organisational culture, based on personhood principles, will prioritise the needs of residents and staff equally alongside other competing priorities. Of course, cultural change often occurs over a long period of time, therefore, the process must be accelerated with individuals and organisations leading the way for society and governments to change. Whatever may be the pathway to change, no longer should the need to cut costs automatically result in cuts to care staff, and, by definition, resident care, and alternatives must be considered. This study has clearly demonstrated the need for implementation of cultural changes which position personhood at the forefront of dementia care.

Unsilenced Voices Justify Reconfiguration of Personhood Practice

Personalised voices from this study have highlighted aspects of personhood care which are needed by people with dementia and staff members. These voices are well supported in the literature and send clear messages to aged care organisations. Organisational culture must implement policies which ensure adequate staffing levels at all times (Edvardsson, Fetherstonhaugh & Nay 2010; Henderson et al. 2017; Killett et al. 2016), continuity in staffing to enable relationship building (Hunter, Keady et al. 2016; Kaufmann & Engel 2016; Moyle et al. 2015), an appropriate skill mix to facilitate emotional, spiritual and social care (Carr, Hicks-Moore & Montgomery 2011; Perkins et al. 2015; Powers & Watson 2011; Reed, Lane & Hirst 2016), preserve personhood of people with dementia (Hirst, Lane & Reed 2013; Milte et al. 2016; Milte et al. 2017; Nowell, Thornton & Simpson 2011), and maintain personhood of staff (Talbot & Brewer 2016; Walmsley & McCormack 2016). Residential aged care facilities are, essentially, small communities which are both homes and workplaces to people who are vulnerable, marginalised, undervalued and misunderstood by society. On the other hand, they are also environments of compassion, acceptance, strong relationships and support. Aged care facilities can be seen as ‘barometers of values and practices’ (Armstrong 2018, p.74) from which the rest of society can understand and learn about human rights and social justice.

This chapter has addressed the aims of this doctoral study which are to investigate the reconfiguration of personhood practice in residential dementia care, and to argue for the positioning of personhood at the forefront of dementia care. Following evidence of both personhood violation and personhood preservation in the data, this chapter has discussed cultural elements which impact the nature of personhood care practices in the psychosocial environment. While each psychosocial environment has its own culture, it is the external societal and organisational cultures which largely determine the nature of personhood care. This discussion has shown that entrenched cultures of stigma and devaluing of people with dementia inform and justify an organisation’s reluctance to adequately resource dementia care. Competing organisational demands, many resulting from market and commercial interests, take financial priority over the unseen and unacknowledged challenges of the psychosocial environment. Reconceptualisations of people with dementia and the staff who care for them are suggested as a fundamental means of reframing the dementia care culture. Building on these reconceptualisations, this chapter concludes by unsilencing the voices of people with dementia and staff members as a means of establishing a firm argument for the positioning of personhood at the forefront of dementia care. Thus, a reconfiguration of personhood practice in residential dementia care is presented. The following discussion concludes this thesis with an overview of this research, study limitations and recommendations for future research.

Conclusion:

A Reconfiguration of Dementia Care Culture

This doctoral thesis reaches its conclusion having established that personhood principles must be the benchmark for dementia care practices. Voices emerging from my research methods are powerful reminders that reconfiguration of personhood practice requires a ‘more proactive and integrated approach’ which acknowledges that those with dementia ‘are still people’, and, just as importantly, ‘staff are persons too’. Within this personhood framework, societal and organisational reconceptualisations of dementia will lead to a culture which values people with dementia, and, consequently, a culture which demands adequate resourcing for residential dementia care. In presenting concluding thoughts, this discussion begins with a personal perspective, followed by discussions on existing culture, the significance and contributions of the study, recommendations for future practice, and a reconfiguration of dementia care culture.

Personal Perspective

The need to better understand why there are inconsistencies and discriminations across the aged care industry, and why poor care practices exist at all, sparked this investigation into the ethos and cultures influencing dementia care practices. It was not difficult to choose the concept of personhood as the benchmark for care. On occasions when value, respect and dignity were not accorded to my parents and parents-in-law while living in aged care, I personally felt, along with them, the belittling and inferior treatment of them as persons. Because I knew them so well, I could often sense another small fragment of their ‘personhood’ disintegrate through humiliation and disrespect. Yet, for the most part, I felt powerless to change the situation. After all, the various care staff, managements and aged care organisations assumed the position of power, thereby silencing and marginalising. Ultimately, concerns about imbalances of power became the motivation for undertaking this doctoral study. Now, at the completion of the study, reasons for those imbalances are clarified and insights have been gained into approaches for working towards an inclusive culture which accepts and respects people with dementia. The following discussions highlight the role of this research in moving dementia care from the existing culture to a reconfigured socially inclusive culture.

An Overview of the Existing Culture

A striking feature of this doctoral study was the compassion and dedication displayed by staff as they provided care. The close relationships with residents and a genuine desire to preserve personhood were clearly evident in the cultures at both Sites 1 and 2. The contrasting outcomes between the two sites highlighted the influence of organisational culture on the ability of staff to provide personhood care. Specifically, where staff were not respected and supported, and staffing levels were drastically reduced, staff were significantly restricted in their ability and desire to provide personhood care. However, even outside of the roster review circumstances, staff members expressed frustrations about inadequate recognition, support and resourcing by the organisation. On the other hand, staff were grateful for management support at both sites. The ability of management to absorb organisational pressures was noted, and, to some extent, staff were able to find strength and resilience in the trust and support provided by management teams.

The organisational culture presented much confusion and distress for staff. Having felt inspired and motivated by the recent person-centred care training program, the experiences of roster cuts now left staff feeling abandoned and overwhelmed. They were experiencing the inner conflict of no longer being able to meet many of the residents' psychosocial needs and, at the same time, were experiencing heavier workloads as well as facing either a reduction in their hours or losing their jobs altogether. There was a strong sense that the organisation had disconnected itself from the very staff, who, in fact, were responsible for providing the core business of the organisation. The organisational culture was demanding and unrealistic in its expectations of staff, and demonstrated misunderstandings and insensitivities regarding the needs of residents and staff. This study has shown, therefore, that organisational cultures must change by incorporating policy changes which take responsibility for preserving the personhood of residents and staff. Personhood care must share balanced prioritisation with competing responsibilities, and not be an easy target of surrender when budgets need to be tightened.

Significance of the Study

This study is highly relevant and significant in the current climate of Australian aged care. As the Royal Commission into Aged Care continues in 2019, social and media interest in the industry is currently high. Media reports concerning safety, quality and systemic issues in aged care are frequently presented, with staff and family members highlighting challenging working conditions and negligent care practices. Because the findings of this study directly relate to these issues, this study speaks to Royal Commission hearings and media reports that describe instances of personhood violation. Significantly, this study also speaks to those who have historically raised concerns about residential care conditions, people living in residential dementia care and their families, staff members, aged care providers, and society in general. Although issues currently being raised in the public arena are not named ‘personhood violations’, this study identifies them as such. In recent months, the media has reported several alleged violations to residents including overuse use of chemical and physical restraints, physical abuses, sexual assaults, inappropriate use of medications, and limited psychological support. These allegations all indicate violations of personhood.

Contributions of the Study

This research makes an original contribution to knowledge by identifying that societal and organisational cultures are major barriers to personhood care, and, consequently, argues for a positioning of personhood at the forefront of dementia care. The study distinguishes between ‘personhood’ and ‘person-centred care’ by naming personhood as the foundation of person-centred care. Thus personhood is established as the basis for care practices on which appropriate models of care may be developed, and dementia care is located within a cultural framework of value, respect and dignity for people with dementia.

The study is based on Kitwood’s conceptual framework of personhood and dementia care. Although established more than twenty years ago, Kitwood’s framework continues to strongly influence dementia care around the world, and is responsible for considerable improvements in care practices. An integrative literature review undertaken during this study resulted in sixteen articles being selected for review, and Kitwood’s work had influenced twelve of those articles. Therefore, as indicated by the strong presence of Kitwood’s work in the literature, the theoretical framework for this study was strong and relevant to the topic of personhood.

This doctoral study has filled a gap in the literature by locating personhood at the forefront of dementia care. Most of the literature based on Kitwood's work promotes person-centred care as the standard to be achieved in dementia care. However, as discussed in this study, the persistence of person-centred care programs has not successfully achieved sustainability of equitable and respectful care practices. This thesis takes the alternative view that personhood is the foundation of person-centred care and, therefore, must be the underlying philosophy of all approaches to dementia care. An important component of care is dismissed when personhood is overlooked as the basis for care practices. By its very definition, personhood provides a clear understanding of why individualised dementia care must be provided for each person. This is the point of difference between personhood and person-centred care. Progams focused on person-centred care aim to place the person with dementia at the centre of their care provision, a goal which is certainly valuable and beneficial. However, with this approach, the focus is on the details of the program, such as time restraints, finances, resources and parameters, and is, quite often, not sustainable because it is not sufficiently grounded in a philosphy of care. On the other hand, personhood, as presented in this study, provides a theoretical and philosophical foundation which requires an understanding of why people with dementia are to be valued and respected. It does, in fact, require a change in existing cultural thinking and discourse about ageing and dementia.

Therefore, this study has reversed the trend of the dementia care literature, by positioning personhood at the forefront of dementia care, rather than submitting to the current trend of focusing on person-centred care. Furthermore, by investigating organisational cultures of personhood, this study recognises the impossibility of merging personhood culture with societal and organisational cultures that stigmatise and devalue. They are, in fact, opposing cultures, yet many attempts to create dementia care programs have been built on this conflicting basis. Therefore, the need for a reversal in the current societal and organisational cultures of dementia is noted in the study. Changing any cultural perspective is, of course, a major and long-term undertaking, but this study clearly articulates the need to do so, and, indeed, contributes to the literature which already supports this move. Building on the evidence in this study, the responsibility of reversing those cultures which marginalise and discriminate against people with dementia must be taken both individually and socially in order to cultivate momentum towards a societal culture of personhood.

Study Limitations

It may be argued that my personal and professional relationships with people with dementia have the potential to create bias in this study. Indeed, I have openly declared the frustrations of being a family member to people living in dementia care. However, just as those personal experiences offered insights for my chaplaincy role, my overall experiences have provided insights that allowed this study to proceed in an informed and rational manner. An acknowledged familiarity with dementia care environments led me to be particularly attentive to the potential for bias, and, therefore, to be actively reflexive during the research process.

Another possible limitation is the restriction of data collection to two aged care facilities, thereby raising the possibility that results are not transferable to other RACFs. However, significant insight into the provision of dementia care at each site is provided through observations of a total of thirty five people with dementia, and ten interviews with staff members from various disciplines. All staff interviewed had significant experience in the dementia care environment. Adding further depth to the data is the fact that both facilities contrasted each other in physical layout, staffing levels, styles of interactions, and staff attitudes and disposition. It is reasonable, therefore, to assume that results of this study are transferable to other dementia care environments.

Recommendations from the Study

In conjunction with societal changes, organisations must take responsibility for adopting changes which ensure they consistently provide personhood care for residents. This study has identified that disconnections between the organisational culture and the necessities of dementia care are significant barriers to personhood preservation, evidenced, in particular, through the organisation's non-recognition of the critical need for sufficient and available staff. These barriers must be addressed to transform violating care practices into those that preserve personhood. Recommendations to effect such changes are now discussed:

Recommendation 1: Organisational Connectedness

Organisations must connect with the needs of people with dementia and the needs of staff caring for them. There must be a requirement for those making financial and policy decisions to understand the essentials of dementia care and the subjectivity of people with dementia. The experience of life is different for every person with dementia, but some lived experiences include a slower pace of mobility, hearing and visual impairments, a slower rate of comprehension, heightened confusion and anxiety, and the need for regular social interaction, and physical and emotional support. As discussed in this study, organisations must accommodate the psychological needs of people with dementia, and facilitate interactions which preserve personhood. Addressing these needs takes time and specialised skills, and the organisation must understand these needs and allocate resources appropriately.

Recommendation 2: Sufficient Staffing Levels

A significant contributor to personhood violation in this study was the unavailability of sufficient staff to provide adequate care. Organisations must review their staffing levels to ensure dementia care environments are sufficiently staffed to provide acceptable levels of physical, emotional and social care at all times. Effective spiritual care must also be accessible on a regular basis. Staff providing these forms of care must be adequately skilled in their area of expertise, and, in particular, be proficient in the skills required to manage risky situations within a personhood framework, and according to their particular area of discipline. In this context of sufficient staff levels, the importance of continuity of staff must be considered in order to provide familiarity for people with dementia, and to facilitate relationship building between staff and residents.

Recommendation 3: Personhood of Staff

This study has found that disrespect for the personhood of staff significantly contributes to personhood violation of people with dementia. Staff are not able to sustain personhood care if they, in turn, are not feeling supported and respected. It is the responsibity of organisations, therefore, to acknowledge the personhood of staff at all levels, and to appropriately resource and support them to provide a level of care consistent with an organisation which espouses personhood values. The stigma experienced by care staff has been well noted in this study, particularly in relation to low pay and inaccessibility to appropriate training. Organisations must take responsibility for providing free and accessible training on a regular basis in order to keep staff updated with developments in their particular area of expertise. Apart from the need to employ skilled staff, provision of training is an acknowledgement of the personhood of staff members. Likewise, appropriate mental health support must be available to staff, particularly those needing emotional assistance such as loss and grief support. Although rates of pay are an external industrial issue, organisations are obviously able to increase pay rates if they choose. Such a decision would increase the status of staff, show respect for their personhood, and more accurately reflect improved skill levels received from training. This would be a valuable step towards changing societal culture around dementia care.

Recommendation 4: Removal of barriers to psychosocial care

Barriers to psychosocial care for people with dementia were identified in this study. The psychosocial environment must be supported to provide adequate emotional, social and spiritual care. Staff who are skilled in these specific areas must be allocated time to effectively meet these needs and, concurrently, be realistically resourced to provide such care. The importance of appropriate physical care is imperative, but effective psychosocial and mental health care are equally needed. In many ways, each type of care complements and enhances the others.

This doctoral research's original contribution to knowledge has addressed the impossibilities of integrating personhood culture with current societal and organisational cultures which marginalise and discriminate through expressions of ageism and dementiaism. By positioning personhood at the forefront of dementia care, a philosophical model of care has been proposed which is consistent and sustainable. Strategies have been suggested for reversing stigmatising cultures which oppose the culture of personhood. With the contributons of this study, it is appropriate to move to a new and inclusive culture of care.

A Reconfigured Culture

This research has clearly shown that societal and organisational cultures must overcome the stigmas associated with ageing and dementia by reconceptualising images of people with dementia, and of staff who work in dementia care. Valuing and respecting people with dementia will help to reverse the trend of under-resourcing in dementia care, and result in a more balanced and equitable focus on budgeting within organisations. Language about dementia must change from a ‘tragedy’ and ‘medical’ discourse to a debate about social and political responsibilities. Individual and organisational efforts to reframe dementia discourse in the public space will begin to erase stigma and, therefore, create momentum for more accurate conversations and knowledge about dementia, and working conditions for staff.

A reconfiguration of dementia care practices will give urgent consideration to staffing issues. As previously stated, in order to ensure consistent provision of personhood care, staffing levels must be increased, and care staff provided with sufficient training and resources to perform their roles. Reframing of the care staff culture to professional status will ensure training is accessible and appropriate pay rates will better reflect the increased skills and responsibilities of the role. Removal of the hierarchical nature of aged care organisations will facilitate connections within organisations, and enable care staff to share their expertise about dementia care and, therefore, contribute to decision-making.

The scope of cultural changes arising from this study is significant, and, in some ways, overwhelming. However, change is possible through the actions and convictions of individuals. At a personal level, as an active voice for the implementation of standardised personhood preservation in dementia care, future projects based on the findings of this research will include: various publications; conference presentations; and consultations and workshops undertaken with staff, organisations and the general public.

Every person is entitled to appropriate care and support, but not all people, including some of those with dementia, are necessarily able to effectively articulate their needs, nor access their rights. Within a framework of social and political discourse, it is possible to be an active voice for, and with, people with dementia, thus unsilencing their voices and, potentially, spreading even wider those original seeds of concern.

This doctoral research supports a body of literature calling for changes in dementia care practices. The research identifies that opposing views on dementia care exist between personhood culture and societal culture, thereby rendering societal and organisational views to be significant barriers to the consistent and sustainable integration of personhood and dementia care practices. My research calls for a reversal of stigmatisation in societal and organisational cultures, thereby paving the way for a reconfiguration of personhood practice in residential dementia care.

APPENDIX 1: Summary of Literature Reviewed

Author, Year, Location	Aim	Sample Size	Methods	Major Findings	Limitations	Significance to Study
Carr, Hicks-Moore & Montgomery (2011) Canada	To understand the meaning of spiritual care for persons with moderate to severe dementia, their families and health care workers	29	Qualitative: hermeneutic phenomenology	Main theme: Spiritual care involves the promotion of personhood through intentional caring attitudes and actions. Sub-themes: Paying attention to 'the little things' that matter; Giving and receiving in the context of a relationship; Barriers to spiritual care	Two participants indicated no religious affiliation, with the remainder identifying as Christian. A different perspective on spiritual care may have resulted from a broader range of religious or non-religious links	Research on individualised spiritual care, a care practice which maintains personhood
Edvardsson, Fetherstonhaugh & Nay (2010) Australia	To describe the content of PCC as expressed by people with dementia, family members and staff	67	Qualitative: focus groups and interviews	Main theme: The core category of PCC is promoting a continuation of self and normality. Sub-themes: Knowing the person; Welcoming family; Providing meaningful activities; Being in a personalised environment; Experiencing flexibility and continuity	The study represented experiences from a limited sample in selected settings	Explored individualised aspects of PCC of importance to people with dementia
Henderson et al. (2017) Australia	To explore the frequency and causes of missed care in RAC in three Australian states	922	Quantitative and Qualitative: cross-sectional survey	All care tasks are missed at least part of the time. Most frequent missed activities: Responding to call bells; Toileting residents within five minutes of request; Ambulating with residents. Most common identified reasons: Lack of staff; Unexpected rise in patient volume or acuity; Lack of assistive and clerical staff	The sample was drawn from ANMF members only, therefore the sample is small compared to the total number of staff working in aged care. The survey tool was developed for use in hospitals, therefore may not account sufficiently for RAC social and behavioural aspects	Personhood and quality of care are adversely affected when care tasks are missed or ignored

Hirst, Lane & Reed (2013) Canada	To examine the construct of personhood of older adults within nursing homes	37	Qualitative: ethnography	Main themes: Acknowledgement of personhood; Personhood behaviours. Sub-themes: Valuing and devaluing behaviours	Staff member participation limited to nursing and care staff	Parallel interests of constructing and maintaining personhood in RAC
Hunter, Keady et al. (2016) UK	To develop a substantive grounded theory of staff psychosocial intervention use with residents with dementia in LTC	67	Qualitative: grounded theory	Main theme: Becoming a person again. Sub-themes: Balancing the influences; Individualising status; Striving to make the most of time; Interpreting care	Most of the data were collected from staff. The authors acknowledged that obtaining more data from residents with dementia may have altered the overall conceptualisation	Psychosocial interventions are an important factor when providing personhood care
Kaufmann & Engel (2016) Germany	To examine Kitwood's model of psychological needs and wellbeing in dementia, and to differentiate and elaborate on this model	19	Qualitative: interviews	Themes: Comfort; Attachment; Inclusion; Occupation; Identity; Agency	Because the participants were all living in the same special care unit, the findings cannot be generalised	Parallel framework to Kitwood's personhood theories
Killett et al. (2016) UK	To investigate the relationship between care home culture and residents' experiences of care	11 care homes	Qualitative: comparative case study	Elements of organisational culture that facilitate positive care: Shared purpose in providing the best possible care; Management able to mediate external pressure to avoid negative impact on care; Staff are empowered to take responsibility for resident wellbeing; Openness to change for the benefit of residents; A sense of community between all involved in the	Although a large number of care homes were studied, they were all situated within the UK, therefore results may not be transferable to cultures in other countries	Organisational culture has a significant impact on the ability of staff to maintain personhood

				care home; Person-centred activity and engagement are integral to care work; Use of the care home environment to the benefit of residents		
Milte et al. (2016) Australia	To describe the meaning of quality residential care from the perspective of people with dementia and their family members	41	Qualitative: interviews and focus groups	Themes: Good quality care supports personhood; Good quality care maintains connections with family; Supportive physical environment	Although the perspective of family members is valuable, they do not possess the lived experiences of people with dementia and are not fully aware of the nature of all interactions	This study identified that supporting personhood is the foundation of quality care
Milte et al. (2017) Australia	To describe the food and dining experiences of people with dementia in nursing homes	19	Qualitative: interviews and focus groups	Themes: We know what we want, just ask us; Our wants are not always heard; The tipping point – when consideration of choice and individual preference stops; A tricky balance between health and quality of life	This study does not take into consideration the dining needs of multicultural groups in Australia	The recognition of individual needs and preferences is a core component of personhood care
Moyle et al. (2015) Australia	To understand the perceptions of QOL of older people living with dementia in LTC, the influences on their QOL and strategies to improve QOL	12	Qualitative: interviews	Themes: QOL as maintaining independence; Having something to do; The importance of social interaction	The small number of participants is a limitation, as is the qualitative nature of the research, which does not allow the data to be generalised	This study highlights the personal views of people living with dementia on influences and strategies affecting their QOL
Nowell, Thornton & Simpson (2011) UK	To understand personhood by exploring the subjective experiences of those living with dementia	7	Qualitative: interviews	Themes: Working out the system and adapting in order to survive it – the 'peoplehood' of the system; Using past and future roles and experiences to manage the present – the	The transferability of these results is weakened by the relatively small sample size	Personhood is explored through the subjective experiences of people with dementia

				transient nature of personhood; Being both an individual and a member of a group – the conflict of a dual role		
Perkins et al. (2015) New Zealand	To investigate the views of residents of dementia units, families and staff on what is important or meaningful for them	18	Qualitative: interviews	Themes: The importance of relationships; The retention of identity; Changes and losses due to the progression of dementia	Misinterpretation of the gestures, body language, and speech of people with dementia is possible, and audio recording limits an independent review of non-verbal responses	Relationships, spiritual care and maintaining identity are identifies in this study
Powers & Watson (2011) USA	a) To obtain an understanding of residents' spiritual practices and preferences b) To examine family member and staff perceptions of spiritual support for residents c) To analyse institutional approaches to assessing and meeting residents' spiritual needs	83	Mixed method. Qualitative: observations and interviews. Quantitative: survey and interviews	Themes: a) Rituals; lifting spirits; spiritual concerns such as faith, doubt, disillusionment; need for someone to talk to b) Need for spiritual connectedness, need to nurture the spirit c) Personhood and the ethics of dementia care, spiritual and religious coping, meeting spiritual care needs, overcoming fear and stigmatisation, accommodating diversity, maximising resources	For the most part, the concept of spirituality is limited to religion and religious rituals	The study identifies various components of spiritual care, including its close connections to personhood
Reed, Lane & Hirst (2016) Canada	To demonstrate that the spirit can survive, and that personhood can be nourished in people with dementia	1	Qualitative: case study	Individualised spiritual care comprised: Respecting the needs of the client; Facilitating life story telling; Attending to emotions; Dignifying the client in undignified	The transferability of these results is weakened by the very small sample size	Although based on a single case study, the study highlights the importance of individualised spiritual care and personhood care

				situations; Family support; Appropriate touch; Presence; Religious rituals		
Talbot & Brewer (2016) UK	To provide an in-depth understanding of the experiences of staff caring for people with dementia in RAC	8	Qualitative: interviews	Themes: Psychological wellbeing of the care assistant; Barriers to effective dementia care; The dementia reality; Organisational issues	The transferability of these results is weakened by a relatively small sample size	The quality of personhood care is largely dependent on the wellbeing of staff and the extent of organisational support
Walmsley & McCormack (2016) Australia	To seek subjective interpretations of the lived experience of health professionals; to understand both the positive and negative impacts of their experiences on their work, their personal lives, their beliefs about past and future dementia care and their sense of wellbeing	7	Qualitative: interviews	Overarching theme: Honouring stigmatised self. Sub-themes: Systemic stigma; Invalidated; Self-respect; Moral integrity and growth	As a qualitative study, this study aimed to explore the subjective interpretation of the lived experience of these health professionals. As such, detailed insights were sought on the experiences of a purposive sample rather than generalise findings to all people in a similar situation	To maintain moral and professional integrity, staff need a high level of resilience and self-respect to overcome systemic stigma. Poor remuneration and training contribute to stigma which, ultimately, impacts on quality of care delivered to people with dementia

FINAL APPROVAL NOTICE

Project No.: **6757**

Project Title: An Ethnographic Account of how Personhood is Considered, Practiced and Experienced in Residential Aged Care

Principal Researcher: Ms Jenny Slape

Email: slap0005@flinders.edu.au

Approval Date: 6 February 2015

Ethics Approval Expiry Date: **31 December 2018**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). 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.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **6 February** (approval anniversary date) for the duration of the ethics approval using the annual / final report pro forma available from Annual / Final Reports SBREC web page.*Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **6 February 2016** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- change of project title;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Rae

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday, Wednesday
Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday
Email: human.researchethics@flinders.edu.au
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CRICOS Provider No. 00114A

Dear Sir/Madam

This letter is to introduce Jenny Slape who is a PhD student in the School of Nursing & Midwifery at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

Jenny is undertaking research leading to the production of a thesis on the subject of “How Personhood is Considered, Practiced and Experienced in Residential Aged Care”.

She would like to invite you to assist with this project through her observations of personhood care during your interactions with residents. You are also invited to consent to an informal interview which would take no more than an hour, and would be held at a mutually agreed time and place.

Participation is voluntary, and you would, of course, be entirely free to discontinue your participation at any time or to decline to answer particular questions. Be assured that any information provided will be treated in the strictest confidence and you would not be identifiable in the resulting thesis.

Since an audio tape recording will be made of the interview, consent forms seeking your approval will be provided. At no stage will your name or identity be revealed and, because Jenny will be undertaking the transcription of the interview herself, the recording will not be made available to any other person.

You can register your interest in this research by completing your contact details on the tear off sheet attached to the Information Sheet. An envelope and nominated secure box will be supplied for return of the tear off sheets.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8201 3483, or e-mail ann.harrington@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely

Assoc. Professor Ann Harrington
School of Nursing & Midwifery
Faculty of Medicine, Nursing and Health Sciences

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6757). 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

ABN 65 524 596 200 CRICOS Provider No. 00114A

inspiring achievement

Ms Jenny Slape
School of Nursing & Midwifery
Faculty of Health Sciences
GPO Box 2100
Adelaide SA 5001

Email: slap0005@flinders.edu.au

CRICOS Provider No. 00114A

INFORMATION SHEET

Title: ‘How is Personhood Considered, Practiced and Experienced in Residential Aged Care?

Researcher:
Ms Jenny Slape
School of Nursing and Midwifery
Flinders University

Supervisors:
Assoc Professor Ann Harrington
School of Nursing and Midwifery
Flinders University
Phone: 8201 3483

Dr Anita De Bellis
School of Nursing and Midwifery
Flinders University
Phone: 8201 3441

This study is part of the research being undertaken by Jenny Slape, a PhD candidate in the School of Nursing & Midwifery at Flinders University. It focuses on how personhood is considered, practiced and experienced in residential aged care.

Personhood care places the focus of a particular task or situation on the welfare and needs of the person, rather than on the specific activity or the needs of the organisation. The acknowledgement of personhood status significantly contributes to wellbeing, relationship building, spirituality, quality of life and job satisfaction, thus creating better care outcomes for residents, and work environment for staff.

The study aims to:

- Identify the extent to which personhood principles are taken into consideration during the development of regulatory, funding and policy decisions
- Identify the extent to which personhood principles are practiced and experienced in the delivery of aged care

What will I be asked to do?
The researcher is seeking to accompany participants for brief observations of activities in relation to personhood practices. The researcher may record observations in field notes. Additionally, you are invited to agree to attend an informal one-on-one interview with the researcher who will ask you a few questions about your views on personhood practices in aged care facilities.

The interview will be held at a mutually convenient time and place, take around 30-60 minutes, and will be recorded using a digital voice recorder.

What benefit will I gain from being involved in this research?
This is an opportunity for you to share your feelings about the quality of care you provide for residents. The sharing of your experiences will greatly assist this research in exploring how personhood is considered and practiced in residential aged care. It is anticipated that outcomes of this research will be used to advocate for greater consideration of personhood practices in future regulations and policy decisions.

Will I be identifiable by being involved in this study?
Your name is not recorded during the observation period or interview and you will not be identified in any way. The transcribed file will be stored on a password protected computer which only the researcher can access.

Are there any risks or discomforts if I am involved?
The researcher does not anticipate any risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?
Participation in both the observation and interview components are voluntary. During the interview you may answer ‘no comment’ or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences.

You can express interest in participation of this study by completing the tear off sheet accompanying this Information Sheet. If you would like to participate, please detach the tear off sheet and fill in your contact details. Place the form in the envelope provided, and deposit in the secure return box at this facility.

How will I receive feedback?
If you indicate you would like to have access to the findings, feedback may be provided directly to you. Feedback will also be available indirectly through any future publications of this study.

Thank you for taking the time to read this information sheet and we hope that you will accept this invitation to be involved.

This research project has been approved by Flinders University Social and Behavioural Research Ethics Committee (Project number 6757). 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.

TEAR OFF REPLY SHEET

Research Title:

How is Personhood Considered, Practiced and Experienced in Residential Aged Care?

If you would like to participate in this research or just wish to speak with the researcher, please complete the form below:

Name:
…………………………………………………………………………………………

Site:
…………………………………………………………………………………………

Job Title:
…………………………………………………………………………………………

Contact phone number and/or email address: ……………………………………………

………………………………………………………………………………………….

Tear off the two front sheets and keep for your information.

Place this sheet in the addressed envelope provided and drop it in the specially marked box provided at this facility.

The researcher will collect the forms regularly and contact you to make an appointment at a time that is suitable for both parties.

Thank you for your interest.

Flinders
UNIVERSITY

How Personhood is Considered, Practiced and Experienced in Residential Aged Care

Consent Form: Staff Observation

I hereby give my consent to Jenny Slape, a research student in the School of Nursing & Midwifery at Flinders University, whose signature appears below, to record my work activities and interactions as part of a study of my professional role.

I give permission for the use of this data, and other information which I have agreed may be obtained or requested, in the writing up of the study, subject to the following conditions:

I understand what will be involved and that my participation in this study is voluntary, and I understand that I may withdraw from the study at any time without consequence. I understand that this research is not related in any way to my employment or job performance.

SIGNATURES

Participant………………………………………………………..Date……………………..

Researcher……………………………………………………….Date……………………..

How Personhood is Considered, Practiced and Experienced in Residential Aged Care

Consent Form: Interview

I ………………………………………………………………………………………..

being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction and Information Sheet for the research project on Personhood Considerations, Practices and Experiences in Residential Aged Care.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to the audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:

   I may not directly benefit from taking part in this research.

   I am free to withdraw from the project at any time and am free to decline to answer particular questions.

   While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.

   I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Participant's signature……………………………………………Date…………………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's Name……………………………………………………………………………

Researcher's signature……………………………………………Date…………………………

SEMI-STRUCTURED INTERVIEW GUIDE

Research Title: An Ethnographic Account of how Personhood is Considered, Practiced and Experienced in Residential Aged Care

Tell me your ideas about personhood and caring for the ‘person’, and how you feel about residents receiving care which is based on personhood practices.

Do you feel you have the time, resources and training to provide personhood care?

Do you feel it is the culture of this facility to focus on personhood care?

Do you have the support of your team members and management to provide personhood care?

From your perspective, do you think the residents would feel they receive personhood care most of the time?

Why/why not?

Do you feel personhood principles are applied to staff members at this facility?

Do you feel personhood principles are applied to aged care staff throughout the wider industry?

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