

# **Chapter 1: Introduction**

## **1.1. Introduction to the study**

This chapter presents the background and context of research into the lived experience of older people living in residential aged care facilities (RACFs). The challenge of investigating this phenomenon revolves around understanding the complex nature of the health system and aged care industry in Australia in which older people are linked when they require health care, particularly residential aged care services. This study also explores experiences of ageing, as well as how the relationships of care in RACFs are conceptualised by a group of older people. In exploring the experiences of these older people, it is anticipated that rich information surrounding the reality of RACF life may emerge. This in turn may inform an understanding of older persons' perceptions of RACF life, Quality of Life (QoL) and care needs. There is limited literature relating to the Australian experience of living in a RACF and this thesis draws on what is known about RACF life in Australia and some relevant overseas literature to explicate the issues of interest.

This chapter first presents a brief description of the background of health systems and aged care service delivery challenges. Next, the Australian context is outlined, including the history of aged care service delivery and the challenges of providing services that meet the needs of our ageing population. The significance, purpose, aims and objectives of the study are then explained within the context of the research topic. Following this, a brief explanation of the chosen methodology, which draws on a framework proposed by van Manen (1990, 1997) and the philosophical framework of phenomenology, is provided. Consistent with this approach, my own personal profile as the researcher is included to inform the reader of the motivation and the position I have taken within the study. Lastly, an overview of the organisation of the entire thesis is provided.

## **1.2. Background to the study**

### **1.2.1. An introduction to health systems and aged care**

The delivery of health services comprises one of the largest and most important sectors in the world economy, encompassing a combination of resources, organisations, financing and management systems (Mills & Ranson, 2004, p. 515). While this characterisation could be applied unilaterally, each country's health system varies greatly and is the product of a complex and dynamic range of processes. Efficiency and equity variables are constrained by different internal systems and funding wherein providers and policy workers in all sectors experiment with, redesign and seek to improve services (Zigante, Costa-Font & Cooper, 2012). From a global perspective, the dynamics of health care have had to respond to a rising demand for health care services. This is due to increased numbers of consumers and an increased demand for aged care services, combined with community expectation for high-quality services (Ansell, Davey & Vu, 2012, p. 10; Cook & Halsaw, 2011, pp. 1, 5; Commonwealth of Australia (CoA), 2007, p. 9; Schultz & Monin, 2012, p. 178).

Fernández and Forder (2010, p. 714) identify the current objective of global health policy as an attempt to blend equity and efficiency in the provision of health care services for all people. These authors suggest that reform of aged care systems across developed countries has sought to expand the coverage of the services provided, and has defined increasingly universal levels of state support. As such, government decisions have been subject to the influence of political and economic structures within an international spectrum. While these reforms are commendable, they are heavily reliant on reacting to the economic pressures of ageing, rather than considering ageing as a positive event, or considering the perspectives of older people themselves. This position is supported by Henningsen and McAlister (2011, p. 89), who recognise the need to change attitudes towards ageing by improving understanding of, and attention to, the needs of older adults through more proactive—rather than reactive—policy recommendations within the health system. This premise is consistent with the results from a 2011 workshop convened by the International

Association of Gerontology and Geriatrics (Tolson et al., 2011) for international researchers of aged care facility care. This group stressed the importance of developing a global response to the development of sustainable strategies to enhance acceptable outcomes for aged care by considering older peoples' preferences (Tolson et al., 2011, pp. 184–185).

The provision of health care services for older people has traditionally been grounded in policy creation based on the premise of older people as a 'problem' or 'burden' to society, a drain on the economy and social welfare services. However, more recently, through radical reform of social service systems, aged care services have been encouraged to draw on a social justice concept. This is clearly preferable to the 'deficit' model of care (Kalache, Barretto & Keller, 2005, p. 38; Schultz & Monin, 2012, pp. 178–179; Young & McGrath, 2011, p. 369). Newacheck and Benjamin (2004, p. 142), Grbich (2004, p. 156) and Faunce (2007, p. 223) have all reported on concerns regarding public spending on the care of older people, citing diminished public spending on other deserving groups, the subsidisation of health services, the financial burden shouldered by future generations and overall financial security as the aged population rises. Carp (2000, p. 92) sees the depletion of retirement funds, capital stock and economic growth as reducing the opportunities for universal access to health services and aged care facilities. Health and social protection, according to Podneiks (2006, p. 64), are dependent on these resources, and this author claims that when the care of older people is subsidised by government, ageist attitudes can emerge. It is important to note here that while there are economic costs in providing aged care services, only a small proportion of older people reside in a RACF at any one time and/or receive community support and care.

In western societies, it has been suggested that the status of older people has declined, especially after colonial times, where ideologies of equality, secularism and the free market undercut elders' status (Palmore, Branch & Harris, 2005, p. 171). Since World War Two, retirement from the workforce, availability of pensions and public health care, bereavement, longevity and loss of roles have rendered older adults more dependent than in the past. This, in turn, has resulted in feelings of isolation,

inferiority and of being undervalued (Jopp & Schmitt, 2010, p. 167; Podneiks, 2006, p. 61). Carp (2000, p. 94) suggests that views regarding economically dependent older people underpin policy creation, and contribute to issues of intergenerational inequity and the sometimes negative reactions of taxpayers who provide the funds for care of older people. Similarly, in the United States of America (USA), Cochran et al. (2012, p. 235) comment that societies' reaction to welfare subsidies makes welfare more difficult to obtain, with newer government policies tightening assistance and eligibility.

Further, reactionary economic rationalist policies, based on the 'problem' of increased older residential aged care provision, have resulted in the growth of community aged care policies orientated towards deinstitutionalisation and increasing pressure on informal carers, rather than qualified health professionals to care for older people (Schultz & Monin, 2012, p. 195). At the moral-political level, this promotes the devolution of responsibility for aged care from governments to families (Glucksmann 2006, p. 61). However, Bokel (2007) and the Productivity Commission (2005) suggest that increasing numbers of older people, changes in traditional family structures and work patterns in developed countries see fewer children able to care for older parents in their home, placing greater stress on community services, but also increasing demands for places in RACFs.

Research into global principles of aged care has identified three common principles at a global level: 1) older residential care should be situated within a continuum of services that are accessible on the basis of need; 2) there should be an explicit focus on quality of care in long-term care facilities; and 3) QoL should be the primary objective (Gibson, Carter, Helmes & Edberg, 2010, p. 1,074). The Organisation for Economic Co-operation and Development (OECD) (2005) further reports that while initiatives based on global objectives are being implemented, many other issues affecting residential aged care remain unaddressed. These include inadequate accommodation and lack of privacy; depression and inadequate pain management; functional problems and decline; inappropriate use of chemical or physical restraints; poor social relationships; increased demand on limited social and medical resources;

fragmented care; and a lack of trained aged care professionals., From an international perspective, this suggests that health and service providers have the responsibility to reject sub-optimal care models, which emphasise aged care facility management perspectives based on health care interventions, safety and outcomes based on regulations (Diekelmann, 2002, p. 14; Wan, Breen, Zhang & Unruh, 2010, p. 6). The preferred model of aged care services should be based on quality of care that include more extensive psychosocial and cultural components based on the experiences of older people (Chapelhow, Crouch, Fisher & Walsh, 2005, p. 43).

At an Australian level, similar problems within aged care service provision exist. While reports indicate compliance with accreditation standards, the regulatory framework is complex and fragmented (Productivity Commission, 2009, p. 19), and there are numerous documented areas where health and personal care is substandard, such as medication errors and the under- or overprescribing of medications (Foundation for Effective Marketing and Governance, 2011). A number of consumer groups and researchers also identify other care issues for frail older persons in RACFs including pressure ulcers (Lewin et al., 2003, p. 57; Pemberton & Hampton, 2011, p. 27), dental care, gastroenteritis, malnutrition and dehydration (Banks, Bauer, Graves & Ash, 2010, p. 897; Ullrich, McCutcheon & Parker, 2011, p. 1,339; Wylie & Nebauer, 2011, pp. 32–33), neglect, fall risk, pain management, palliative care, ethical and abuse issues (Aged Care Crisis, 2010a, 2010b). While it is outside the scope of this study to discuss all of these QoL and life issues (Santamaria et al., 2009, p. 22), they may well be flagged by the participants in their narratives.

Staff retention continues to be a major area of concern in aged care (Seblega et al., 2010) and in Australia (Productivity Commission, 2011a, p. 351). This ultimately has an impact on the continuity of care for older persons (Ball, Ford & Smith, 2005, pp. 41–44). Daly, Speedy and Jackson (2004, pp. 18, 82), in their assessment of leadership policy in the nursing industry, suggest that one of the major issues affecting RACFs is the retention of qualified nursing home staff. The industry suffers from a lack of perceived rewards and relatively low pay rates, approximately 25% less for nursing home staff compared to hospital-based nurses (Hogan, 2004, p. 223).

According to the Productivity Commission (2008, p. 66), increasing aged care workforce sustainability is a major challenge. Concerns have been voiced by the Australian Nursing Federation (2013) in relation to the federal government sanctioning unqualified care staff to work with high dependency persons in RACFs. In their examination of the ways in which Australian aged care sector employers justify and sustain low pay levels, Palmer and Eveline's (2012) feminist study found that aged care employers actively reproduce a familial logic of care. This familial logic presents paid aged care work as unskilled and natural for women, and therefore not deserving of higher pay. This suggests that although care in RACFs is care-centred, it needs to be recognised as valuable work and appropriately remunerated. The disposition of care, as opposed to the provision of care, is often grounded in emotional investment in caring, where women undertake 'natural' roles as carers and are expected to provide emotional support to others (Gatrell, 2008, p. 12; Gattuso & Bevan, 2000, p. 898). Often women carers go beyond their duties to provide the care required. It will be interesting to discover whether the participants in this study identify staffing issues as factors that affect their experience in a RACF.

The literature suggests that daily life in a RACF is dominated by non-meaningful activities such as sitting, sleeping and being alone, which gives rise to older people experiencing loneliness and helplessness (Brownie & Horstmanshof, 2012, p. 778; Harper Ice, 2002; Tuckett, 2007, p. 120). Psychological wellbeing is affected by negative experiences of transition to a RACF (Jilek, 2006, p. 11), changes in relationships, including those older people in remote RACFs (Parmenter & Cruickshank, 2010, p. 62), along with associated feelings of social isolation, despair and loneliness, resulting from loss of autonomy and independence (Fay & Owen, 2012, p. 35). Lack of control is often associated with vulnerability and older people en masse are rendered dependent and helpless. In their phenomenological study into older persons' experiences of striving to receive care on their own terms in RACFs, Anderberg & Berglund (2010, pp. 65–66) found that older people attempted to hide their vulnerability, protecting their composure to effect limited control over care needs.

Kane et al. (2003, p. 241) suggest that health-related QoL is only a subset of QoL, where independence, autonomy and privacy comprise significant elements of wellbeing in a RACF. Again, it is outside the scope of this study to investigate all these issues. However, some documented problems are highlighted to indicate the nature of institutionalisation.

While these concerns exist, social and economic indicators underpin the demand for reformed aged care policy in Australia. According to the Productivity Commission's inquiry into aged care in Australia, one of the future challenges for Australia's aged care system is to respond to demands arising from a significant increase in the number of older people (Productivity Commission, 2011, p. xxii). Additional drivers of demand for aged care in Australia, determined by extensive consultation with all stakeholders, including user groups, include: catering for a diverse population needing aged care services, including those living in remote areas as well as older persons requiring appropriate cultural and linguistic services; a demand for better options, choice and control over living arrangements and care; the decline of informal carers; access to information, community care and technology enabling older persons to remain at home longer; and the cost of services and user financial capacity (Productivity Commission, 2008, p. 63; Productivity Commission, 2011, p. 37). Importantly, policy needs to address the more humanistic elements of RACF life, such as QoL and wellbeing, which constitute significant elements indicating the performance or success of such policy directives. This all has implications for funding, and is discussed later in the chapter.

Against this background, this study seeks to understand the experiences of living in RACFs from the older persons' perspective. This study introduces the essential components of the Australian system and the basis from which service delivery of aged care services takes place. The discussions relating to the history of care provision and implications of an ageing population, burden of disease and financial policy challenges as they compare to other countries, provide a background from which to understand how RACFs operate within this complex system.

### 1.2.2. Context of aged care in Australia

Since 1901, Australia has been an independent nation with a federal system of government with origins in the British system of government and law (Sandford 2007, p. 19), with the Constitution giving the federal government parliamentary powers in specified fields such as health services provision (Forrester & Griffiths, 2008, pp. 26–27). Two levels of government in Australia have overlapping responsibilities in this field. The Commonwealth Government has a leadership role in policymaking, particularly with respect to national issues like public health, research and national information management, as well as registration of health professionals. The states and territories are primarily responsible for the delivery and management of public health services and for maintaining direct relationships with most health care providers (Hally, 2009, pp. 31–33). Despite the growth of government funding (Harris & Benson, 2006, p. 9), and numerous Acts providing for expansion of the industry, incorporating hostels (Rosewarne, 2001, p. 119) and capital costs (Braithwaite, Makkai, & Braithwaite, 2007, p. 22), Ryan and Willits (2007, pp. 907–908), found that family members and other informal carers were traditionally expected to continue as the primary, and sometimes sole, source of care for older people.

Before the introduction of the *Aged Care Act 1997*, which saw the emergence of RACFs, hostels and nursing homes were funded and regulated as separate entities (Australian Institute of Health and Welfare (AIHW), 2012e, p. 4). Hostels provided low care options for older persons with less intensive needs (Palmer & Short, 2000, p. 298) requiring some supervision, health care services and personal care assistance (Wacker & Roberto, 2010, p. 139). Activities of daily living would include bathing, toileting, eating, dressing, mobility and communication with others, such as medical personnel. Other support options consist of assistance with medication, recreational therapy and rehabilitation support. Nursing homes provided higher level care, including all low-level care services plus 24 hour nursing care, access to specialised services, more extensive support with ADLs (allocation for daily life) and additional levels of personal care services (AIHW, 2008). The main difference between these two types of accommodation was the level of care (AIHW, 2012d; Bigby, 2003, p.

177). Holmes and Ramirez (2003, pp. 175–176), (Gelfand, 2006, pp. 4–5) and Crisp and Taylor (2008, p. 13) all note that older people residing in the RACFs will generally have greater co-morbidities, increased cognitive deficits and more limited physical and psychosocial functioning and will therefore need access to 24 hour care. It is this latter category of older people that is of interest in this study.

In 1985, the Commonwealth Government introduced regional geriatric assessment teams (now known as aged care assessment teams (ACAT) to assess and provide for the health of older people, underpinned by the principle of supporting as many people to remain in their own homes as possible by providing community-based and home support services (Cape & Gibson, 1994, 378–379). In 1986, the Commonwealth announced a comprehensive strategy of reform of older residential care to counter emergent problems. Policy changes included: monitoring adverse outcomes for older people; introducing a funding system for uniform nursing home staffing standards; and establishing 31 outcomes of minimum compliance standards of care (Department of Health and Ageing (DHA), 2008c). By 1987, the Commonwealth took over regulations governing nursing homes, and new outcome standards were adopted with the aim of promoting quality of care and QoL. This replaced a focus on input standards of care and regulations that focused on the physical environment of nursing homes (Australian Bureau of Statistics (ABS), 1989, p. 230; Braithwaite, Makkai & Braithwaite, 2007, pp. 35–36). The *Nursing Homes and Hostel Review 1986* was also introduced to provide for the development and expansion of the Aged Care Assessment Program (ACAP), including the recommendation that ACATs be given the delegation for recommendations for admission to nursing homes (Commonwealth of Australia (CoA), 2006, p. 2).

All levels of government in Australia, plus consumers and the non-government sector, have some role in funding, administering, or providing care for older people (DHA, 2007). There are many complex issues involved with service delivery in the Australian health care system, such as a confusing maze of administrative and funding systems (Keleher, 2008, p. 33). Within these structures formal services are coordinated and funded by government, while informal care is provided by family and

friends. Willis, Reynolds and Keleher (2009, p. 92) propose that, in conjunction with older residential care, the Australian government's policy since the 1970s has been centred on providing community services to enable older people to stay in the community. Clark and McCann (2009, p. 88) suggest that while this approach is consistent with a conservative political view that places primary responsibility for caring on families, the demand for older residential aged care places remains significant.

Concerns relating to an ageing residential aged care system, including infrastructure quality and care in RACFs, have contributed to the restructuring of the older residential aged care system. The restructure was undertaken in October 1997 (Gibson, Rowland, Braun & Angus, 2002, pp. 1–2), and legislated through the *Aged Care Act 1997*. This Act replaced the *National Health Act 1953* and the *Aged or Disabled Persons Care Act 1954*, and currently provides the regulatory basis for Australia's aged care industry. Mackenzie (2003, p. 328) and Vasunilashorn, Steinman, Liebig and Pynoos (2012, p. 5) suggest that, consistent with the objectives of the *Aged Care Act 1997*, most high care facilities in Australia support an 'ageing-in-place' principle, which fosters a mixed occupant profile. This was one of many changes and its premise was to enable older people have access to higher levels of care within the same facility as their needs change. The Act, along with various other regulatory instruments, also formalised compliance monitoring and assessment against standards, as well as funding arrangements for RACFs (DHA, 2008c). Further structural reform of the aged care system has been proposed, largely informed by the inquiry into aged care through *Caring for Older Australians* (Productivity Commission, 2011), so that legislation can address future challenges in aged care service delivery to meet needs. To further inform the background of the reality of RACF life for older people, a more detailed analysis of the current framework is provided in Chapter Two.

### **1.2.3. Older persons: demographics**

For the purposes of this research, relevant agencies such as the ABS, AIHW and the Productivity Commission, use the age 65 and over to refer to older Australians, with some specific reference to those aged 85 and over. Historically, there has been a significant reliance on the age 65 as an acceptable chronological criterion for the ageing process, mainly due to it traditionally being the age of retirement and receipt of health care benefits. However, Millar (2009, p. 4) has suggested that ageing is too complex to be defined only by the length of time since birth. In assessing ageing, there has been a shift from dependence on chronological age to consideration of those elements that see older persons contributing to society and benefiting themselves and others, such as physiological health, psychological wellbeing, socio-economic factors and the ability to participate and function in desirable activities (referred to as 'functional age'). Ryff (in Poon & Cohen-Mansfield, 2011, p. xvi) suggests that the pathways for wellbeing in the very late stages of ageing have moved from a focus on basic needs such as nutrition, to the importance of cognitive vitality, social relationships, spiritual and religious connections and leisure activities. Further, they suggest that these are only some areas of wellbeing that can only be experienced at the end-of-life. To assess the effects of an ageing society, most of the following discussion relates to the age of 65 as contained in most statistics.

An ageing population is a significant phenomenon affecting most countries, resulting in considerable impacts on the health, social, and economic sectors, and requiring, according to the World Economic Forum (2011), governments to provide efficient provision of health care (Beard et al., 2011, p. 7). It is important to understand that an ageing population and an increase in life expectancy itself is not problematic in itself, rather it is the demands on the health and social system, including residential aged care, which need to be addressed through policy. This includes demand for aged care services and older residential care for older persons who require care, a population that is expected to quadruple between 2010 and 2050 (World Health Organization (WHO), 2012). According to data provided by the WHO and the United Nations (UN), the proportion of the world's population aged 60 and over will double from

11% to 22% within 50 years from 2000 (WHO, 2012b), and reach 2 billion persons (UN, 2012). Older persons aged 80 plus will increase to 400 million by 2050, a significant increase from 14 million since the middle of the twentieth century (WHO, 2012c, p. 10). The number of persons over 100 will increase even more rapidly from approximately 343,000 in 2012 to 3.2 million in 2050 (UN, 2012). It is predicted that from 2015, older population growth will continue to occur essentially in developing countries. This growth in older persons will maintain pressure on governments and the broader community to fund appropriate levels of care for the ageing population. Combined with the decline in the number of workers relative to dependent older people (Weiner, 2009, p. 12), governments face increased pressure to fund aged care. However, Cubit & Meyer (2011, pp. 583, 586) see the challenge as one promoting active and healthy ageing. This is in response to the dominance of policies underpinned by a deficit model, where older people are seen as a burden and as passive recipients of care (Minogue, 2008, p. 218).

The DHA (CoA, 2012), in response to the findings of the reform package *Living Longer. Living Better*, reported that Australia has one of the fastest ageing populations compared to other developed nations, especially in the sector of persons over 85 years (CoA, 2012, p. 8). As such, the aged care system will continue to experience high demands to meet the health and welfare needs of older people, older residential aged care and the resources required to support the system, including workforce and delivery of services (CoA, 2012, p. 8).

According to the ABS (2010) the proportion of people aged 65 years and over, between the period of 30 June 1990 to 30 June 2010, increased to 13.6% (an increase of 2.5%), while the proportion of the population aged under 15 years decreased by 3.1%, with the remaining population increasing marginally by 6% (ABS, 2010). It is reported that in the next two decades from 2010, the number of people aged 65 and over is projected to rise by 91%, and the number aged 85 and over will more than double (AIHW, 2012, p. 46). According to the CoA (2012, p. 8). An increase in life expectancy is the major driver for continued growth in the proportion of older persons. As the greatest users of health and aged care services, this ultimately places

escalating demands on funding and service delivery. The statistics indicate that older persons will live longer, suggesting that demands on the health care system will increase in response to these changing demographics.

LaPierre and Hughes (2009, p. 204) state that population ageing is generally viewed in pessimistic terms. However, they contend that the convention of old age beginning at age 65 is being challenged by empirical reality, as there has been an increasing active life expectancy among older adults. As such, definitions of age have been categorised as 'young-old', 'middle-old', 'old-old' and 'oldest-old'. Millar (2009, p. 4) suggests that the concept of functional age provides a more rational basis for care management than chronological age. Current data in Australia shows that people aged over 65 have a longer life expectancy and are generally healthier than the previous generation (AIHW, 2010, p. 318). The ABS (2012) has reported that, based on current mortality rates, life expectancy for Australians has improved over the last 10 years. Therefore, the challenge for Australia is to provide appropriate services for supporting and caring for the ageing population, whether through policy improvements in home services, residential care, or combinations of services to meet health care and lifestyle needs.

#### **1.2.4. Burden of disease and disability**

Increased life expectancy and increases in medical successes have contributed to significant growth in the numbers of people living with a chronic illness (Larsen, 2013, p. 8). There has been a shift in the assessment of ageing in literature and policymaking, from a decline and loss paradigm, which focuses on ill health and disease, to one that promotes a successful ageing agenda, using a preventative discourse model (Minichiello & Coulson, 2005, p. xiii). Living longer leads to greater vulnerability to accidents and disease events (Larsen, 2013, p. 8), with the majority of Australian older persons tending to have one or more chronic health problems (Byrne & Neville, 2010, p. 23). The AIHW has reported that older Australians in general have good mental and physical health, with nearly half of those aged 65–74 having five or more long-term physical health conditions, increasing to 70% of those aged 85

and over (AIHW, 2012, pp. 82–83). A proportion of those aged over 65 years will have co-morbidities, simultaneously experiencing depression, frailty, difficulty in understanding things and related social issues (AIHW, 2010, p. 320). While the incidence of chronic conditions is ever increasing, the WHO (2006, p. 17) has reported that Australians can expect to experience good health for most of their lives and an improved health status can be enjoyed, due to a greater focus on prevention of illness and improvements in medical progress.

The loss of health and wellbeing due to morbidity, disability and non-fatal events is referred to as the ‘burden of disease’ (ABS, 2010b). Cancer has been a consistent contributor to the total burden of disease in Australia: in 2003, it surpassed cardiovascular disease as the largest cause of burden, from 18% to 19% of the total causes. According to Begg et al. (2007), Australians aged 65–74 in 2003 comprised 6.8% of the population and experienced 16.3% of total burden of disease. Those aged 75 years and over comprised 6% of the population and experienced 25.4% of the total burden of disease, with cancer and cardiovascular diseases accounting for 53% of this burden. For those persons aged 65–74 years, cancer was the largest underlying cause of death for both males and females in 2010. However, heart disease was the largest cause of death in those persons aged 75 and over, for both males and females (ABS, 2010c; ABS, 2012). It is expected that there will be a steady increase in cancer as a burden of disease, a decrease in cardiovascular disease (AIHW, 2012, p. 117) and a steady growth in burden from dementia-related conditions (ABS, 2012).

While cancer and heart disease were the largest causes of death for males and females in 2010, death rates for females caused by dementia and Alzheimer’s disease increased by six times since 1979 (AIWH, 2012, p. 93). Coronary heart disease, once a leading cause of death, has decreased by 72% and 69% for males and females respectively between the years 1979 and 2010.

Similarly, disability appears to be increasing. An increase of 70% is expected in the number of older persons experiencing a disability (ABS, 2009b). Disability increases with age and statistics show that 40% of people aged between 65 and 69, and 90% of

those over 90 years experienced disabilities (ABS, 2009b). The National Disability Insurance Scheme (NDIS) was suggested by the Productivity Commission in its 2011 *Disability Care and Support* report as a way to foster active participation in society of those with a disability (Productivity Commission, 2011b, p. 3). The inquiry estimated an increase in persons with a disability to increase by over two thirds in 2099. As such, the current economic response and informal care options will be insufficient to cope with the increase, and RACFs will become an important source of accommodation and care for those in need.

These figures suggest important implications for patterns of health, disease and disability, and services to provide for morbidities. Globally, as suggested by Goldstein (2009, p. 7), this places a high dependency burden on governments to face these challenges and support an ever-increasing ageing population. Begg et al. (2007) suggest that the economic costs with respect to appropriate funding and delivery of services are expected to be considerable. Further, it is expected that the demands will be more evident initially in the home and community care sectors, followed by the residential aged care sector. It is again noted that the policy driver is related to the conceptualisation of older people as a whole or ‘the older population’, who are perceived as being highly dependent, encumbering the government with massive problems. This represents a paradox: the reality is that, even while the statistics indicate significant illness and dependency prospects, there are many older people who live very healthy and productive lives, with little justification for this deficit model of thinking.

### **1.2.5. Challenges and funding**

It is difficult to compare health status and quality of services across countries due to the diverse and complex nature of funding, health care arrangements and data recording systems (AIWH, 2012, p. 37). In Australia and internationally, there has been a focus on improving the safety and quality of health care, including that of the older population. It is important to discuss the funding of health and residential care as it directly influences the level of care for older Australians, which is a key focus of

the aims of this study. Accordingly, the OECD has actively commissioned the *Health Care Quality Indicators* project across member countries to measure and compare quality of the delivery of health care (AIHW, 2012, p. 41). In recognition of ageing populations and the challenge of addressing health care issues at an international scale, it is envisaged that the project would represent the main disease and client groups and work towards improving the 'important preventive, curative and caring interventions for these groups', in terms of guiding future health care advances and funding allocations (OECD, 2006, p. 9). This creates challenges for governments in fiscal management, policymaking and the delivery of health care services. As such, issues such as rising costs, health market dynamics, poor practice, lifting the level of investment in prevention, technological advancements, medical error, accountability issues, and inequality and uncertainty of access to quality services, have become a community concern, with an ever-increasing economic burden on health care spending (OECD, 2006, p. 10; Reinhardt, Hussey & Anderson, 2004, p. 11). International political and economic issues relating to aged care, as proposed by Hogan (2004, p. 92) and Weiner (2009, p. 12), depend on the accumulation of capital, the high cost of community level and home care, user payments for a larger proportion of care, separation of care and nursing costs, a greater use of insurance schemes and alternative ageing-in-place programmes. As well as highlighting the challenges of responding to an increasing ageing population, other challenges of providing access to health care in remote areas, including cultural diversity issues and knowledge transition in policymaking, have been raised by the WHO (2002, p. 20, 2007, p. 75, 2012d, p. 56).

In Australia, the Commonwealth Government has the primary task of funding the health system, although the responsibilities are also divided between state and federal government budgets (Briggs, Courtney, Cormack, Smith & Sadler, 2004, p. 4). The government pays for older residential and community aged care through non-specific tax revenue subsidising the provision of aged care services, where access to the system is based on an assessment of care needs and the cost to users is very low (Wacker & Roberto, 2010, pp. 138–139).

The Australian government has committed additional funds for health care and aged care over time, and provided 69.1% of the total health expenditure in the most recent budget assessment for the year 2010–2011, an increase of 1.4% over the last ten years (AIHW, 2012h). Expenditure on health care was estimated at \$130.3 billion, totalling 9.3% of total gross domestic product (GDP). This represented an increase from \$122.5 billion in 2009–2010, and \$77.5 in the year 2000–2001. The AIHW (2012h) has reported that the increase in expenditure is largely due to demand on the volume of health goods and services, rather than cost. The government funds approximately 70% of all older residential care services, representing a payment of \$51,400 for each person in an older residential care facility, and is an increase of 9.6% from 2010–2011. Long-term care costs are certain to increase with the ageing population (WHO, 2009, p. 12). However, the increasing complexity of medical treatment and technology contributes to increasing health care costs (OECD, 2006, p. 12; WHO, 2009, p. 9). It is clear that the issue of funding for aged care services is a significant agenda item for the government and the success of the implementation of the subsidies and supplements affects the experience and wellbeing of older persons in older RACFs.

Literature on the economics of aged care revolves around the global influences on funding of health care services. This is directly associated with the escalating costs of care and associated economic pressures (McMurray & Clendon, 2011, p. 394). Internationally, aged care is funded by five principle methods across different countries. They are: state funded, non-means tested and universal entitlement; a social insurance model where the state acts as an insurer; a partnership of cost sharing between the state and those older people requiring care; a limited liability model that caps an individual's ability to obtain help with care costs; and a savings-based model where older people contribute to an earmarked savings pool, such as a pension scheme (Wanless et al., 2006, p. 221).

Internationally, most developed countries are experiencing a demographic shift resulting from increased longevity, with a corresponding larger older population and a relatively smaller working population, placing pressure on publicly funded health and

social services, including health care and older residential aged care (Taylor, 2011, p. 3). As suggested by Stabile and Greenblatt (2010, p. 21), a radical overhaul of health care systems is inevitable, including strategies such as how to provide universal health care for an ageing population not met solely by tax contributions. According to the discussion above, it appears there is a push towards long-term health insurance. According to Bloom and Canning (2008, p. 17), this will result in reducing publicly funded services to a basic minimum, conflicting with many social welfare models. It also sets different generations against each other if working age people are net producers and older people are net consumers of social goods and services. However, according to Christensen, Doblhammer, Rau and Vaupel (2009, pp. 1,204–1,205), longevity can enable older people to continue being workers, volunteers, consumers and carers for longer, assimilating a life course approach to care provision. Stauner (2008, p. 206) suggests that this requires policy reform in pension systems, health insurance and flexible working structures to allow older workers and those with caring responsibilities to continue working.

### **1.3. Purpose and aims of the study**

The purposes of this study are to explore the lived experiences of older people in high care RACFs, to gain insights into how they perceive their daily lives and their perception of the quality of care and life. This purpose was accompanied by four specific aims:

1. to investigate the impact that living in a RACF has on the older person's care and experience
2. to assess those elements of RACF life which made a difference to the older person
3. to understand the older person's QoL issues, such as, but not limited to, independence, dignity, autonomy, communication, relationships with staff and explore their perceptions of their QoL
4. to explore the overall perception of RACF life and how care might be improved, from the participants' perspectives.

To address these aims, an exploration of aged care facility life, including exploring the personal, social and economic factors that contribute to older persons' experiences of aged care facility life, is undertaken in Chapter Two, as a background to this study. These aims underpin potential recommendations that may contribute to a more positive experience for older people living in RACFs. In the time since the works of Goffman (1961) found unfavourable experiences of institutional life by older people living in aged care, literature has reported on many facets of aged care life. The more relevant contemporary findings are discussed in Chapter Two, to outline what is currently known about RACF life. From a social approach, health systems have continuously been reviewed by introducing new policies addressing, among other issues, standards through accreditation requirements and funding policies aimed at increasing the QoL, rights and autonomy of older people. While this study does not attempt to provide an assessment of QoL for these older persons, it is referred to as part of the aims of the study as contributing to their experiences.

This study explores the lived experience of older people in high care aged care facilities to reach an understanding of what this life is like for them. As the aims of the study specifically needed to address the construct of the experience under investigation, a phenomenological approach was required. Phenomenology provides the construct for understanding the nature of reality and epistemology: the framework used is proposed by van Manen (1990, 1997) as it reflects the philosophical assumptions of phenomenology. This approach will assist in addressing the aims of the study.

#### **1.4. Significance of the study**

The significance of this study is embedded in the aim of achieving a greater depth of understanding of the lives of older people in high care older RACFs. There is little known about how older people actually experience life in high care older RACFs in Australia; it is an under-researched area with most studies concentrating on staff and carers' perspectives, or on particular issues of aged care facility life. It is vitally important that the experiences of older people in RACFs are explored and this

specific issue relates back to the aims of this study. There is limited research in this area and, as such, the voice of older people remains silent. This study will add to what is known about aged care facility life as perceived by those who live in them. It will also reflect on the health care system and older residential aged care as it currently operates under regulations and policy within Australia. The experience of the participants will provide an indication of how this system affects their lives and their perceptions of reality. It is anticipated that the findings will contribute to policy makers' and health care providers' understanding of the reality of those older persons living in an aged care facility. Essentially, this will be done by addressing the aims of this study through: gaining insight into aged care facility life as it affects the participants, identifying what elements make a difference and ascertaining perceptions of care and if they consider care can be improved.

Literature regarding what it is like to live in an aged care facility is limited and represents an under-researched area globally (Cooney, Murphy and O'Shea, 2009, p. 1,029). Therefore, this study aims to 'fill a gap' in the research by exploring older peoples' perceptions of life in high care aged care facilities from an Australian perspective. A range of research studies have explored some aspects of older residential aged care. These include: anxiety over admission to an aged care facility (Thein, D'Souza & Sheehan, 2011); staffing characteristics affecting living conditions and safety (Castle & Anderson, 2011; Castle & Engberg, 2007); physical environment and how this affects safety and autonomy (Marquardt & Schmiege, 2009; Moore et al., 2011); meaningful activities contributing to a positive experience (Takeuchi, Hatano & Yamasaki, 2011); dependency and dignity (Edwards, Courtney & O'Reilly, 2003a; Kane et al., 2005); positive experiences with food and nutrition (Cahill & Diaz-Ponce, 2011); and wellbeing through significant relationships (Robison, Shugrue, Reed, Thompson, Smith & Gruman, 2011).

This study is also significant as it seeks to gain more knowledge regarding principles of independence, dignity, decision making and wellbeing as they relate to participants' lives. This information may inform policy and practice regarding the expectations and grievances of older people. In describing older peoples' life

experience in a RACF, the study may highlight important elements of how RACFs are provided and affect their lives. This is significant given the limited amount of research into aged care facility life, and the results of this study will add to the literature in Australia and globally.

As previously discussed, both the dependency level and the length of stay of older people in aged care facilities have significantly increased (AIHW, 2010). According to McVey (2011, pp. 5–6), rapid growth in the older Australian population will lead to an even greater demand for older residential aged care by people who have profound disabilities and complex medical conditions requiring complex management and care in aged care facilities. It has been suggested by the OECD (2005) that there may also be a shortfall of quality care within older RACFs, consisting of various degrees of reduced social and physical wellbeing. This study is significant as it acknowledges those issues and will discuss care issues for older people and the importance of wellbeing in the form of relationships and meaningful activities. This study also recognises that the overall experience of wellbeing for older persons is multifaceted and will investigate the more humanistic side of older persons' lives.

There has also been much literature relating to concepts of ageing and models of care, and these perceptions by the community and policy makers ultimately affect older peoples' insights into their lives and themselves. This study is also significant as it will highlight the influence such discourses have on the aged care system, which ultimately influences how older people are conceptualised, treated and subjected to the effects of institutional life.

## **1.5. Introduction to the methodology and philosophical framework**

This study adopts a phenomenological methodology, based on the Utrecht school of phenomenology as advanced by van Manen (1990, 1997), and was chosen to explore the lived experience of older persons in high care facilities as it was appropriate to situate this study within a qualitative research framework. This approach is suited to examining a phenomenon that is a single kind of human experience, rather than a

social process, structure or culture (Cohen, Kahn & Steeves, 2000, p. 8). According to van Manen (1990, p. 42), the nature of the given forms of lived experience can be uncovered by a phenomenological research question. This required turning to a phenomenon that seriously interests the researcher. Formulating the question for this study required asking what it was like to be an older person in a RACF. Part of this process required formulating the phenomenological question that would represent the personal world of the participants. In this way, I as researcher would become aware of their experience, a reality as understood by participants. My research question evolved into ‘What is the lived experience of older people in high care RACFs using phenomenological investigation’.

The method adopted required investigating the experience (van Manen, 1990, p. 62). This qualitative study gathered data using semi-structured individual interviews with older people residing in high care aged care facilities. A purposive sampling method was used to select participants who could provide ‘information-rich’ data and describe their experiences in detail. The 18 participants were aged care facility older persons who were 65 plus years of age, had lived at a residential aged care facility for three months or more and were physically able to participate in an in depth interview. In undertaking the research, all ethical research requirements were fulfilled.

One of the main strengths of this study is that by using a phenomenological approach, it allowed description and interpretation of the perceptions of participants through narratives that uncovered the lived experience, while also allowing my own pre-understandings to be embedded in the study. This approach, as endorsed by Heidegger (1962), allows my reflections to be inherent in the process while still retaining honesty and trustworthiness. Recognising the relationship between the researcher and the researched provides a valid conceptual approach (Gerber & Moyle, 2004, p. 36). The methodology required reflection on essential themes and describing the phenomena through writing allowed its essential structures to emerge (van Manen, 1997, pp. 32, 64). It was not an objective of this research to prove whether a certain experience actually happened in exactly the way it was described, but whether it was plausible and true to the older person as it was lived, and this was possible through

phenomenology. According to Perry (2009, p. 129), this methodology allows rich textual descriptions of the experiencing of selected phenomena, and this was evident in this study. The methodology required a strong commitment to the research question throughout the process and this continuous orientation towards the subject ensured a rigorous decision trail (Koch, 1994; van Manen, 1990, p. 151). Consistent with this approach, the research context was fair and balanced as interpretation moved from parts of the text to the whole in many stages (Annells, 1996).

An overarching investigative framework was required to provide direction for this study. Denzin and Lincoln (2003a, p. 33) have described the ‘net’ that contains the researchers’ own epistemological, ontological and methodological praxis as a ‘paradigm’ or interpretive framework. In this study, an interpretive paradigm was used, incorporating a relativist ontology (authentic reconstructions of reality which stands in contrast to the modernist notion of a single reality) assuming multiple realities and a subjectivist epistemology (where the researcher and respondent ‘co-create understandings’). For the purposes of this study, the nature of the health care setting and the term of residency, socio-demographic status and care relationships of the participants were identified, all of which contribute to the multifaceted nature of their experiences of the phenomenon of aged care facility life.

As the main objective of this research is to investigate the experiences of older people living in RACFs, the theoretical philosophy chosen for this study is phenomenology. Phenomenology has evolved through many schools of thought, most notably the philosophies of Husserl (1859–1938) and Heidegger (1889–1976), which underpin the notions of mind, matter and being. Phenomenology has also been described as an optimal philosophical framework for health research, as it prioritises human experiences (Polit & Taranto Beck, 2014, p. 271). This interpretative study respects the existential tradition where the viewpoint of the researcher assumes an intrinsic part in investigation and interpretation.

Chapter Two provides a comprehensive validation and justification for adopting a phenomenological philosophical framework. Chapter Three investigates a phenomenology of practice, drawing on the work of van Manen.

## **1.6. A personal profile of the researcher**

Value-free research is a subject of debate. Its implementation could result in the loss of some types of knowledge about human experience, such as meaning-making (Lavery, 2003, pp. 21–22). The relationship between the knower and the known is very real and is inherent in a subjectivist epistemology. As I was conceptualising an approach to this research topic, I rejected a positivist approach that assumes objects have meaning within themselves, with reality viewed as being external to the researcher and subject. This study is based on the belief that human beings construct meaning in phenomena while experiencing interactions. Polkinghorne (1983, p. 42) saw research as a human activity in which the researcher as knower is central to the study, and Denzin and Lincoln (2003a, p. 33) viewed the investigator as a passionate participant who interacts with the subject of the research. Therefore, this study has embraced the process of interpretation and interaction between the investigator and research participants, resulting in a meaning-making activity where the understandings of the researcher cannot be bracketed or suspended. So, while I have taken care to faithfully represent the experiences of the participants, these views have been described and interpreted through my own eyes. I have taken seriously the issues of reliability and validity through the examination of rigour, trustworthiness, credibility and authenticity, and these issues are discussed in Chapter Three. This in turn comprises an informed interpretation of the older persons' lived experience. So, consistent with a phenomenological based methodology, it is important that my perspective is presented.

My desire to embark on this doctorate in health services management arose because of a combination of working in a service-oriented profession for many years in both the public and private arenas, part-time employment in aged care and my personal situation of caring for older people, infirm family members. As a full-time

professional employee of many years, I was keen to develop a deeper understanding of how service provision originated and evolved to produce these systems. I have experience in both state and local government in the profession of town planning, and while this is not aligned to health services, it provided a general framework to understand how and why services are provided, allowed the development of critical thinking skills about global influences upon decisions of government, allowed me to consider issues of sustainability, legibility and comprehensiveness in decision making, and provided a deeper appreciation of social involvement, or otherwise, in the assessment of conditions affecting the community.

The desire to pursue a research qualification in health services management was further fuelled by my experiences of being involved, both formally and informally, with the care of older people persons for well over two decades. Caring for two highly dependent older relatives, while working both full- and part-time, was an eye opener and raised many questions in my mind in relation to the health system and the need for more effective responses to caring for older people at home. In some respects, from my perspective, the government's push to encourage older people to stay in their own home with community care was not entirely successful, as resources were limited and the assistance provided was minimal. Further, my experience was of older people who refused outside care, a difficult situation to manage. One relative expressly refused to go into an aged care facility as to them it represented an early death. Without a professional health care background I could provide only minimal care. So, despite the ACAT agreeing that home care was possible, I found the experience very challenging as their physical and dementia-related illnesses were very severe. In effect, the stress and pressure on me as a family carer was a silent consequence of these policies and it was duly accepted as a duty rather than a choice. However, that was over a decade ago, and home and community assistance has come a long way in providing greater assistance to families caring for elders.

From an employment perspective, my later experience of working as a personal care assistant in a high care aged care facility for five years provided an appreciation of the aged care health system at ground level. I found that the experience of working in

aged care was both positive and negative, the former reflected in the inherent caring role of the position and the highly appreciative response of the older persons. This study was largely driven by my experiences of the more negative aspects of caring, mainly staff and management inefficiencies and the less-than-responsive nature of the health care system in addressing some of the fundamental problems in aged care. These included older persons' disillusionment with care, the apathy of some staff and the lack of a quality end-of-life for many older persons. It appeared that the lived experiences of older people in older residential care were something of an afterthought in the daily operations of facilities. The nature of life reflected disillusionment, a sense of helplessness and hopelessness and a significant lack of independence and respect. Further, I was astonished at the lack of qualifications of some staff and an apparent lack of motivation to equip themselves properly with ongoing professional knowledge or greater experience in providing care for elders. This study was driven by my need to make sense of the situation within which older people, rendered vulnerable and dependent by the system, live and it was clear that to achieve this, the opinions, needs and desires of the older people themselves needed to be heard.

With regard to the health system in general, and due to my personal experience of the general situation of older persons in aged care facilities, I brought some pre-understandings into this study. Firstly, government policies continue to endorse care at home with community-based care options as a support. While this may be cost effective, problems such as carer strain and isolation of older people still remain. Secondly, global health care systems, as they relate to aged care, are under continuing pressure due to an increasing older population, and this has serious ramifications for care options. Thirdly, there are economic and political constraints that govern aged care provision, and I believe that aged care requires a comprehensive analysis of options and funding alternatives, including investments by the user population, to provide certainty for older persons rather than adopting different responses based on changes in government. Lastly, there needs to be a review of the qualifications and attitudes of staff in aged care facilities to ensure they are equipped to provide quality care for older people.

## **1.7. Organisation of the thesis**

The first chapter of this thesis introduces the research topic and the background of the study. This includes a snapshot of health systems and aged care service provision within their dynamic constructs from global and Australian perspectives. To further inform the study question, the history of aged care in Australia, and the challenges presented by the ageing population and burden of disease are presented. This is followed by a discussion relating to a major issue underpinning care services; that of Australia's funding system, and how other countries differ in their economic policies funding aged care. The purpose and aims of the study are outlined, along with the significance of the study. The methodology chosen to explore this topic, along with a brief overview of the theoretical framework that underpins this study, is then discussed. My personal profile is included to contextualise my pre-understandings.

Chapter Two presents the search strategy used to provide a critical review of the existing literature. Next, a detailed discussion and analysis of the literature as background to the current aged care system is presented, outlining how current policy is implemented within the system. Current challenges and reform are detailed, all of which provides the most recent conditions for older persons residing in RACFs. Next, a context of conceptualisation of ageing and relationships of care are discussed, providing a background for understanding how older people are perceived within society. Elements of QoL as identified in the literature and by participatory research with older persons are discussed to inform perceptions of RACF life. Finally, the philosophical framework of phenomenology is introduced and discussed to demonstrate its significance to understanding lived experience for this study.

Chapter Three outlines and justifies the methodology and methods used in this research, and it describes the use of a phenomenological approach, drawing on the work of van Manen (1984, 1990, 1997) to explore the phenomena of the lived experience of older persons in RACFs. This approach is consistent with the ontological assumptions on which this study is based; that is, that reality is as it is

experienced. The study parameters are discussed next, including the location, inclusion and exclusion criteria and recruitment. Data collection and analysis are then presented. Ethical considerations regarding participant risks, rigour and trustworthiness are also discussed to demonstrate accuracy and truthfulness in the decision trail, and to demonstrate coherence between intention and outcome, consistent with the processes for undertaking this research. Lastly the limitations of phenomenological research activities are presented.

Chapter Four presents the results of the study based on an analysis of the interview data. The structural thematic analysis is presented to allow the participants' voices to be heard in relation to the life they live in the RACF. Participant quotations are used to develop themes that emerged during data analysis. While this study has used the term 'aged care facility', the older persons used the term 'nursing home' frequently and this is reflected in the participant quotes. This chapter describes three themes reflecting the reality of RACF life. The themes are: 1) 'You can't do exactly what you want to do': loss of self and control; 2) 'If you haven't got that sort of contact, it would be difficult': valuing important relationships; and 3) 'You make the best of it': resigned acceptance.

Chapter Five presents and discusses the major conclusions of the study. The findings, as discussed in Chapter Four, are expanded upon and organised into three major conclusions reflecting essential themes regarding the participants' experiences of aged care facility life. The conclusions are: 1) A lack of meaningful participation in decision making; 2) Importance of enduring and meaningful relationships; and 3) Resigned acceptance. Next, a summary of how phenomenology informs the conclusions is given. The limitations of the study are discussed followed by an outline of the outcomes for practice and policy in the context of the mediating or constraining factors of lived experience for the participants and suggestions for further research are detailed to build upon the important lived experiences of the participants.

## **1.8. Conclusion**

This chapter has presented the study topic and outlined the background to health systems and aged care service provision; the Australian history and context of care, population ageing and burden of disease; the specific challenges faced by Australia in addressing funding, and how it compares in a global context; the aims and purpose and significance of this interpretive phenomenological study; methodology and philosophical framework of phenomenology; a personal profile; and finally, a summary of the chapters in this thesis. The next chapter presents a comprehensive literature review to underpin and inform the study as it relates to investigating lived experience of older people in RACFs.

## **Chapter 2: Literature Review**

### **2.1. Introduction**

This chapter is divided into two major sections: the first critically reviews the literature in relation to the aged care system in Australia and the factors that may affect the experience of older people living in RACFs. The second section discusses phenomenology, which is used as both a theoretical framework and methodology for this study. The first section introduces and discusses constructs that affect ageing and aged care in Australia, and critiques the economic and regulatory context in which these services operate. Residential aged care in Australia is discussed with a particular focus on the demand for care and the regulatory framework in which older person care exists. This context is defined by socio-cultural determinants of ageing and within aged care services, which contribute to the foundations for understanding the lived experience of older persons who participated in this study. While there is significant literature from overseas relating to the lived experience of aged care facility life, there is very little published material in Australia, so international literature is also presented to provide a global perspective in which to locate this study. This chapter discusses recent research findings relating to residents' perspectives and dimensions of aged care facility life, including details of the issues surrounding quality of care as they relate to QoL, frameworks, regulations and socio-cultural factors relevant to the participants. The second section of this chapter presents and justifies the use of phenomenology as a theoretical framework. This theory is discussed in relation to understanding the experiences of others, in this instance, in aged care facility life.

This chapter provides a critical literature review relevant to the aged care system and the experiences of those who interact with this system. This chapter identifies issues relating to aged care services, forming the basis to analyse and interpret the findings, and identify how this study addresses gaps in the literature.

## **2.2. Search strategy**

The approach to the literature review has been to focus upon a comprehensive overview of key areas of the literature concerning residential aged care, to describe phenomenology as a theoretical construct, and to provide a description of the regulatory framework governing residential aged care in Australia. It comprises a literature review of primary, secondary and ‘grey’ literature, which is research that is either unpublished or has been published in a non-commercial form, such as government reports, theses, newsletters and bulletins, as well as ABS data. Literature was sourced regarding the international and Australian experience of living in an aged care facility. Database searches included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and other online databases such as JSTOR (journal storage), Gale, Springer, SAGE Premier, Taylor and Francis, and Wiley Online Library. These were supplemented with a library search for relevant studies, bibliographies of journal articles and web-based information retrieval tool searches of the Google®, Google Books® and Google Scholar® databases. Search terms used, both individually and collectively, included: aged care facility, RACF, nursing home, aged care, high care elderly, lived experience, health system, government, phenomenology, QoL, quality of care, wellbeing, transition, relationships, dying, behaviour, independence, dignity and death.

The next section discusses various elements of aged care services in Australia, as they interrelate with governmental, political, social and historical issues.

## **2.3. Australia’s aged care system**

### **2.3.1. Introduction**

The aim of this research is to explore the lived experiences of people who reside in aged care facilities. It is hoped that the findings may contribute to policy initiatives to support the provision of high-quality aged care services in Australia. Australia’s aged care sector is part of an overarching health system that receives ongoing government funding for the provision of services for older persons (AIHW, 2011a). Some of the

service supports older people who are considered likely to have functional and cognitive impairment, making them vulnerable to multiple problems when facing illness or disability and who are unable to care for themselves (Koch, Hunter & Nair, 2009, p. 164). Australia, like most developed nations, currently faces multiple challenges in providing high-quality care in RACFs especially with an undisputed increase in demand for aged care health care services looming (Irvine & Kroeger, 2010, p. 41). Henderson and Caplan (2008, p. 90) in their research into cost efficiency of community care and nursing home provision in Australia, and Healy (2011, p. 77), assessed the regulation of the health care industry in Australia. They found that the current multiplicity, rigidity and divided responsibilities of service provision resulted in an unsatisfactory aged care system that did not address issues of unmet client expectation, increasingly complex care needs and a diminishing workforce of paid and unpaid carers. It is in this context of an increasingly aged population in Australia, who should expect high-quality care, that this study is conducted.

In Australia, the Commonwealth Government has the majority of power over aged care funding and policy direction, which flows through to the state and territory implementation of services, with local government having a minor community-based role (Taylor, Foster & Fleming, 2008). These factional political and financial responsibilities affect the provision of health services in general and, in turn, aged care services (Gupta & Harding, 2007a, p. 9; Lagergren, 2007, p. 292). The proliferation of governmental departments and non-government agencies has resulted in complicated structures and processes, duplicity and fragmentation of effort. However, despite attempts to rectify the shared framework these problems persist (Chi, Mehta & Howe, 2001, p. 115). This has implications for the quality of care provided, as well as creating associated challenges for older people to achieve a high level of wellbeing in their everyday lives.

The UN principles for older persons are to support independence, care participation, self-fulfilment and dignity (UN, 1991); and the *Aged Care Principles 1997* (DHA, 2012g), recognise and support the human rights of older people. In their discussion article exploring the effects of institutional life on older persons' sense of self-

fulfilment, Brownie and Horstmanshof (2012, pp. 779, 873) found that opportunities for older persons in RACFs to exercise their basic human rights of autonomy, social support reciprocity, personal control of their life, and sense of identity and self-esteem were constrained by their living environment and the capacity of staff to deliver safe and appropriate care. While governments indicate a commitment to providing effective, quality health services to an ever-increasing older population, the impact of regulatory controls and budgetary constraints surrounding the operation of residential aged care hinders positive outcomes for older persons. Most studies that have made recommendations for policy are undertaken in a health service environment or have a professional perspective, and the opportunity to maximise understanding of the issues could be enhanced with evidence from those who experience life in a RACF (Perry et al., 2011, p. 2,140).

Nay and Garrett (2009, p. ix) are part of a growing number of researchers who advocate the rejection of a negative view of the older population as a 'burden' on society. Rather, they wish to promote ageing as being successful. Successful, or active, ageing is multidimensional and promotes active participation in society to maximise physical and mental wellbeing of older people. This is as compared to the traditional approach in aged care, which emphasises a deficit or dependency model, concentrating on the disengagement of older people from social roles because of their diminishing capabilities (Kendig & Browning, 2010, p. 460; Nay & Garrett, 2009, p. 84). Historically, this new approach was reflected in the work of Rowe and Kahn (1997), in the USA, in which these authors asserted that successful ageing is about moving forward and embracing positive biological, social and psychological attributes of older people to replace disability, disease and chronological age as the focus (Rowe & Kahn, 1997, pp. 433–445). Others suggest that successful ageing is deeply embedded in individual consciousness, whereby human understanding involves the awareness of ourselves as growing old in the social world within which we live (Kendig & Browning, 2010, pp. 459–460).

Changes to approach in understanding ageing are reflected in policy makers and service providers' endeavours to adopt a more humanistic, person-centred model of

care, in place of the traditional archetypical medical model, which promotes efficiency through the procedural and practical dominance of health professionals (Buys & Millar, 2012, p. 104; Edwards et al., 2003b, p. 33; Wilkinson, Meyer & Cotter, 2009, p. 27). While new ageing policies appear more closely aligned with challenging ageism and promoting autonomy and social inclusion, they are somewhat limited to reliance on the financial independence of older people, ignoring social inequalities and personal preferences of older people. The delivery of a psychosocial, person-centred care approach, involving the delivery of a respectful model of care, has been lauded as improving QoL for older people in care homes. However, it has also been criticised as consumer-based, as it provides for more choices and options for service providers, rather than focusing on individual preferences (O'Dwyer, 2013, pp. 234–235).

This still suggests a lack of understanding of a successful ageing that would promote personal ageing identity (Biggs, 2012, p. 98). Improving older peoples' health is a major policy agenda of the Australian government and, over time, it has attempted to respond to demands for care while promoting healthy ageing in accordance with the intention of this model (AIHW, 2012c). The aged care sector has undergone changes in approaches in providing care over the last decades. Using appraisals and re-evaluations the aim has been to maximise the quality of care for older people and use limited resources efficiently, albeit with some variations in the quality of services (Productivity Commission, 2011a, p. xxii). For example, in recent years it has become apparent that RACFs have an increasing responsibility for providing high-quality sub-acute end-of-life dementia care. This should preferably be within the framework of advance care planning (Jeong, Higgins & McMillan, 2011b, p. 165) given that up to 80% of people currently living in aged care facilities have some form of cognitive impairment or dementia (Robinson & See, 2010, p. 1). Based on an extensive review of the shortcomings and challenges of the aged care system, the Productivity Commission has recommended a comprehensive overhaul of the aged care system to facilitate greater levels of choice, innovation and responsiveness, while ensuring equity of access to care (Ansell, Davey & Vu, 2012, p. 13). A more humanistic approach to caring for older people requires a greater understanding of their

experiences (Streubert, 2011, p. 4), an aim critical to this phenomenological study. This study will contribute to this body of knowledge by exploring the perspectives of people who live in a RACF.

The following discussion focuses on the aged care regulatory environment within which older person care is located, essentially highlighting the evolution of aged care options for older persons in Australia and how the *Aged Care Act 1997* has operated to create the current environment in RACFs. The change in emphasis to more community-based care, as opposed to institutional care, is a significant change for aged care in recent years, and the funding and quality improvement models promoting this initiative are presented. Further, the challenges of the current system are offered with the most recent response from the government, addressing deficiencies in the system.

### **2.3.2. Background to Australian aged care policy**

#### ***2.3.2.1. Introduction***

A brief summary of the evolution of aged care has been discussed in Chapter One. This section provides a critical review of the current system, in the context of reforms during the 1980s and 1990s. These reforms sought to curb escalating public expenditure on aged care, provider administration and management issues and the demands placed on the system by an increasing ageing population, as well as the introduction of performance monitoring of Australian nursing homes (Productivity Commission, 2011a, p. 14; Spencer, 2005, p. 193). The Federal Government's *Structural Reform Package*, which included the *Aged Care Act 1997*, delivered a new policy framework for aged care in Australia. This package included the concept of 'ageing-in-place', as the goal of the reforms. Important policy changes leading up to and surrounding this legislation, according to Palmer and Short (2000, p. 298), were the emphasis on hostel accommodation rather than nursing home residential care, a shift in emphasis from residential aged care to home-based care, and the introduction of the *Aged Care Act 1997*, which resulted in an integrated residential care system. Implications of these policy shifts included challenges such as only highly dependent

older persons receiving nursing home admission, while those with significant needs were placed in hostels, offering limited support and services. Further, the shift in emphasis from residential aged care to home-based care, with the introduction of community care packages in 1991–1992, placed stress on informal care. Access to nursing homes and hostels was based on a means tested, user pays policy and was subject to the requirements of a quality assurance framework including certification and accreditation (Rosewarne, 2001, p. 118). This was based on funding tied to documentation and evaluation of standards, rather than personal needs assessment.

The 1997 package of reforms also introduced a single funding instrument, the Residential Classification Scale (RCS), which aimed to improve the quality of care in nursing homes, monitor and report on provider compliance with regulatory frameworks, focus on continuous improvements and enhance access to care. These reforms also recognised the high cost of caring for older people and promoted sustainable economic management of the aged care sector, mainly due to a greater user cost contribution towards accommodation (Gray, 2001, pp. 8, 9). The *Act* also made available a better complaints resolution process and certification of residential services to guarantee suitable levels of security, privacy and accessibility (DHA, 2012i).

There are three main service areas within the aged care sector: residential care, community care and flexible care services, with many residential care programmes and services offered under the *Aged Care Act 1997*, *Home and Community Care Act* and *Aged Care Principles* (AIHW, 2012e, p. 2). Residential services are mainly provided in the non-government sector, with about half being operated by religious and charitable organisations, as well as for-profit providers (Rowlands, 2008, p. 243). Both public and non-government (mostly religious and charitable) sector organisations provide community care services. The philosophies that govern the aged care sector are set out more fully in *Aged Care Principles* and the objectives of the *Aged Care Act 1997* (Section 2.1), and are summarised as follows:

Objectives set out in the Aged Care Act 1997 and Aged Care Principles:

- provide funding for quality of care and provision of appropriate care
- promote a high-quality of care and accommodation for the recipients of aged care services that meets the needs of individuals
- protect the health and wellbeing of the recipients of aged care services
- ensure that aged care services are targeted towards the people with the greatest needs for those services
- facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstances or geographic location
- provide respite for families, and others, who care for older people
- encourage services that are diverse, flexible and responsive to individual needs
- help those recipients to enjoy the same rights as all other people in Australia
- plan effectively for the delivery of aged care services
- promote ageing-in-place through the linking of care and support services to the places where older people prefer to live.

Objectives of the Home and Community Care (HACC) Act 1985:

- ensure access to HACC among all groups within the target population
- ensure that, within available resources, priority is directed to persons within the target population most in need of HACC
- provide services that are equitably between regions and responsive to regional differences
- ensure delivery of services in a cost effective manner
- promote an integrated and coordinated approach between the delivery of HACC and related health and welfare programs

(including residential care) (Aged Care Act, 1997; Productivity Commission, 2011a, p. 16).

It is evident from these principles that the focus of the reforms was to provide timely and appropriate quality services that would be received on an equitable basis.

DHA manages the supply of residential care places and the number of packages offered under the community aged care program (DHA, 2011). The government subsidises residential care in a range of accommodation options for older people who are unable to continue living independently in their own homes. Access to residential care in Australia is subject to ACAT assessment, and the availability of residential placements, while the payment of fees is appropriate to older persons' financial circumstances. The profile of people in RACFs is increasing in complexity, with shorter lengths of stay. Most residents will require care until they die (DHA, 2011). The Community Aged Care Packages (CACPs) provide a community alternative for frail older people who have complex care needs but are able to live in their own home with assistance. They cover such services as personal care, transport, domestic assistance (housework and shopping) and/or social support. Flexible care caters for those older persons who may require a different approach than that provided through mainstream residential and community care programmes. They include programmes such as extended aged care at home (EACH) and extended aged care at home dementia (EACHD) packages, transition care, multi-purpose service places and innovative care (DHA, 2012f).

Alzheimer's Australia (2010a, p. 15) estimate the demand for high and low care residential places will exceed the places available by at least 255,000 places by 2050. This is concerning as increasing pressure on these services may create challenges to the quality of care and the QoL of older people if there is not a corresponding increase in funding. Therefore, this study is timely as it will provide insight into how a group of people who reside in a residential care facility currently experience life.

### ***2.3.2.2. RACFs and ageing-in-place***

The majority of care provided in Australia to older people is within community care and RACFs. RACFs today comprise both low- and high-level care, which basically equate to the types of services offered by hostels and nursing homes in the past. The number of persons in aged care facilities in Australia is growing, with an increase in the number of places from 175,500 at 30 June 2008 (AIHW, 2010b) to 182,300 at 30 June 2011 (AIHW, 2012b); this represents a growth of 0.96%. Of that number, 3.8% of the residents were aged below 65 years; and 56.8% were aged over 85 years at 30 June 2011, compared with 55% as at 30 June 2009 (AIHW, 2011b, AIHW, 2012b).

There were 2,760 RACFs in Australia as at 30 June 2011, a decrease from 2,872 at 30 June 2007 (AIHWf, 2012), of which 60.6% were operated by not-for-profit (NFP) organisations including charitable, community-based and religious entities, with government facilities comprising 10.7% and privately run facilities making up 48.7% of the total number (AIHW, 2012b). The decrease in the number of RACFs reflects the trend towards consolidation of facilities, an increase in average size of complexes and an increase in the number of beds per facility.

NFP aged care services play an increasingly important social and political role in Australia and have grown enormously in terms of assets and system complexity (Sankaran, Cartwright, Kelly, Shaw & Soar, 2010, p. 2). As such, they constitute an important component of the ‘social capital’ of Australia due to their prominence in the health and welfare sectors, especially aged care. However, there is a high degree of government involvement in directing and regulating the operation of both services and facility providers, as well as setting the charges for such services (Productivity Commission, 2011a, p. 9). While NFP organisations—such as religious, charitable and community-based organisations—have the largest share of residential aged care beds, private facility operators are also becoming significant players in the aged care market, increasing their percentage of the market marginally between 30 June 2007 and 30 June 2011.

DHA (2009) states that accommodation in both low and high care facilities must provide (at no additional charge) services relating to: maintenance of buildings and grounds, accommodation, furnishings, bedding, cleaning services, general laundry, toiletries (bath towels, face washers, soap and toilet paper), meals and refreshments, social activities and provision of staff on call to provide emergency help. Additionally, in high care facilities, older persons must be provided with other items, including: goods to help them remain mobile e.g. crutches and walkers; goods to assist with toilet and incontinence management and more basic toiletries such as tissues, toothpaste, denture cleaning preparations, shampoo, conditioner and talcum powder.

In relation to personal care, older persons must receive assistance with the activities of daily living, such as: bathing and grooming, using the toilet, eating, dressing and mobility; maintaining continence or managing incontinence; communicating with other people; emotional support; treatments and procedures (such as assistance with taking medication); recreational activities; rehabilitation support; assistance in obtaining health practitioner services and access to specific therapy services; and support for people with memory loss or confusion. In addition, older persons in high care must be provided with additional nursing services and equipment, such as: items to assist with mobility, continence aids, basic medical and pharmaceutical supplies and equipment, assistance with medications, provision of therapy services and short-term oxygen.

The constitutional reforms enabled RACFs to put into practice the ageing-in-place policy. The policy enabled older persons to remain at home for as long as possible with community support services, enter a facility at a low care level and, as their level of care requirements increased, to remain in the same facility and be given a higher level of care (DHA, 2002b, p. 4). The policy also requires that staff are adequately trained to cope with transition of high care needs and for facilities to be thoroughly equipped to support older people needing varying degrees of care, including nursing, therefore negating the need for the older person to relocate to a separate high care facility as their care needs change (DHA, 2009). An important indicator, which shows

the extent to which ageing-in-place has been implemented and embraced, is the shifting dependency profile of older persons in RACF since the reforms (Gibson et al., 2002, p. 3) with a rise in dependency in the residential aged care sector as a whole. Since 1997, the proportion of high dependency older persons in RACFs has increased (Andrews-Hall, Howe & Robinson, 2007, pp. 613–614). Figures released for the length of stay in RACFs, according to the AIHW (2012f, p. 39) indicate length of stays up until 2011. For continuing permanent residents, data indicate that 38% stayed less than one year (with 4% moving back into the community), 44% stayed between one to five years and 18% stayed more than five years. Women stayed longer than men and most residents (91%) left due to death.

A greater proportion of older people are dying in RACFs, rather than moving back into the community or dying in hospital (Gelfand, 2006, p. 17). According to Robinson & See (2010, p. 1), the resident population is rapidly moving to higher levels of dependency with an associated increase in care needs. This may indicate that RACFs are more equipped, and that staff are better trained to care for those older persons who are reaching the end of their lives. Consistent with the longer stays in RACFs, and increasing dependency, are the growing number of older persons classified as needing high level care under the *Aged Care Funding Instrument*. Han, Madison and Chandler (2005, pp. 9–10) in their review of skills mix and funding post-1997 reforms, found that competition between hostels and nursing homes, along with the resulting problem of using qualified registered nurses in hostels, created friction in the industry.

The policy indicates that older persons should be able to receive continuity of appropriate care in RACFs; to form relationships with staff and residents due to the resident population changing more slowly; to benefit from exposure of other residents; to benefit from more highly trained staff and to receive the full range of care needs; to enjoy improved facilities; and benefit from care management plans (DHA, 2002b, pp. 3–4). Many Australian RACFs tend to accommodate those who require a combination of low and high level care, as there has been a substantial trend towards 'ageing-in-place' in the Australian residential aged care system (AIHW,

2012f) where providers are able to receive financial benefits from the federal government by putting in place ageing-in-place principles and services (DHA, 2002b, p. 6).

The practicalities of the ageing-in-place reforms to those who reside in RACFs have been the subject of debate (Rosewarne, 2001, p. 119). Service providers face many challenges including adapting the physical environment, coping with variable subsidies and accommodation fees based on the changing needs of the residents and employing appropriate numbers and skills mix of staff. Similarly, other issues exist with older persons, who require greater levels of care but who live in ‘hostel’ type facilities, and while not being compelled to move to a higher care facility may be unable to receive the required level of care. Older persons may have moved into hostels for social reasons. However, the emphasis on this type of environment reduces the importance of meeting the health care needs of older people (Angus & Nay, 2003, p. 131). According to Angus and Nay (2003, pp. 130–131), the objective of catering for the needs of older people just using a social model of care is questionable, as the reforms have failed to address the health care needs of the older person adequately. For example, trained registered nurses should play a role in institutional management to provide professional assessment, care and documentation required under the reforms. The DHA (2012c, pp. 32–33) has reported that ageing-in-place is not available in all circumstances. It is dependent on the capacity of each facility to provide for increased care requirements with respect to the physical environment and adequate staffing provision. As such, between 2011 and 2012, 54% of all operational residential care places that were allocated to meet low care needs were also used for high care. This has wide-ranging implications for policy with increasing age and frailty dictating the demand for residential places (De Bellis, 2010, p. 102). Simultaneously, the continuing policy commitment is to provide community care, enabling aged persons to stay in their own homes for as long as possible (Alzheimer’s Australia, 2010a, p. iv).

### ***2.3.2.3. Community care and ageing-in-place***

The current aged care policy in Australia strives to reflect the notion of self-determination and it presumes that older people will remain in the community for as long as possible, enjoying independent living with appropriate support services, only relocating to a care facility if absolutely necessary; this is consistent with the ageing-in-place objectives (Gray & Heinsch, 2009, p. 108). This philosophy accepts that the home provides continuity of an older person's living environment, maintenance of independence in the community and social inclusion (Barrett, Hale & Gauld, 2012, p. 361). However, the reforms that enable older persons to remain in their own home are challenged by economic considerations. Some researchers believe they are becoming increasingly financially unviable for governments (Angus & Nay, 2003, p. 130). Currently there are a number of community care packages options, such as ACAP, HACC, CACP, EACH and EACHD. The latter three programmes are designed to support older persons to remain at home even when they are eligible for residential care (DHA, 2011, p. 7). The objectives of the ageing-in-place policy, while laudable, can potentially overburden family caregivers if the level and availability of the support is not sufficient to meet the needs of older persons with declining health. This means that families are often left to address the shortfall in care (Rowland, 2012, pp. 195, 201).

So, while there are schemes such as Carer Allowance and Carer Payment, these incentives are not likely to encourage people to leave paid employment to care for an elderly family member. In reality, much of the care provided by families is unpaid work, and this has been recognised an issue for working families who care for an older relative (Yeandle, Kröger & Cass, 2012, p. 437). DHA (2012d) has reported that the funding for carer support is \$214 million for 2012–2013. However, only a small percentage of carers receive these benefits as most are receiving other forms of benefits or they are ineligible due to means tested criteria (Ganley, 2009, p. 35). Carer's associations have continuously fought for carers' interests, including income support and associated services, as well as reimbursement for the costs of providing care. Greater recognition of the value of community care and carer's involvement in

supporting older people is one of the challenges for governments, to better achieve the objective of enabling older people to live at home (Bruen, 2005, pp. 130–131). This view is supported by the Productivity Commission, who state that the role of informal carers is not only vital to those they care for, but also for the successful operation of the aged care system overall (Productivity Commission, 2011a, p. 325). In response to this trend, Henningsen and McAlister (2011, p. 20) suggest there is a need for aged care to be better integrated into the overarching health care system due to the significant pressure of supporting an ageing population and the current reliance on non-government-based care.

Another issue that affects family care-giving is that carers such as spouses or siblings are themselves older and possibly frail, limiting their ability to continue to provide care (OECD, 2011, p. 127). Research by Glucksmann (2006, p. 61) into sociological approaches to rights to care, contends that even in societies where care is formally articulated, it is also provided within a gendered and familial context. Moreover, the changing dynamics of families such as decreasing family size, the geographical dispersion of families, and the tendency for women to be more highly educated and work outside the home, makes caring for an older relative even more difficult (Moody, 2006, p. 7).

Ageing-in-place thus carries with it particular challenges, especially where older people with complex needs remain in the community despite increased dependency and reduced capacities (Findlay, 2003, pp. 467–468; Gray & Heinsch, 2009, p. 109). A consequence of these challenges to ageing-in-place and community care programmes has seen an increased number of older people entering residential aged care requiring a higher level of care, rather than low care (AIHW, 2012e, p. 49).

An Australian study by Richardson and Bartlett (2009, pp. 28, 30), investigating ageing-in-place policies, structural characteristics and dependency levels in 2009 through comparative analysis of accreditation reports, found that there was a causal relationship between the policies and a significant increase in the number of high dependency residents, as RACFs were adapting to provide for high care needs. This

trend was seen to have far reaching implications as the dependency needs of older people are likely to continue to increase in RACFs, leading to a reduced number of low care places available. This will place more pressure on family and community carers to support older persons in the community until they require high level care. Henderson and Caplan (2008, p. 88) found that while the reality of timely and equitable care for older Australians living in the community is difficult to achieve, older people prefer to stay in their own homes, increasing pressure on family and community carers to provide care.

Problems are also evident, according to Crombie, Disler and Threlkeld (2009, pp. 42–43), with achieving successful ageing-in-place in rural and remote areas, due to an increasing ageing population, partly due to the baby-boomer tree/sea change population cohort (Ryan, 2007, p. 92) and a lack of infrastructure to cater for older persons' health needs, residential care cost pressures associated with distance and isolation, and the inequitable distribution of the health workforce (DHA, 2012c, p. 157). There are significant inequalities in health service and long-term care provision in remote areas (Vines, 2011). There has been little change in the proportion of aged care places and community care packages allocated to outer regional (8.6%), remote (1.1%) and very remote (0.3%) areas over the last decade (AIHW, 2009, p. 6; AIHW, 2012f, p. 12). Consequently, poorer health outcomes are experienced by persons living in regional, rural and remote areas as opposed to urban areas (DHA, 2012c, p. 157). With significant ageing, the problems of remoteness and lifestyle habits, combined with particular risk factors such as mental health needs, combine to create higher health risk levels for rural and remote people, especially older persons. Appropriate aged care accommodation in remote areas is often unavailable, particularly for those older persons who have more or different care needs such as those persons from different cultural backgrounds, those with dementia-related illness and Indigenous people (Crombie, Disler & Threlkeld, 2009, p. 47). Flexible models of care are provided under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. The services funded under this program provide culturally appropriate residential and community aged care for Indigenous people, mainly in rural and remote areas close to Indigenous communities (AIHW, 2012f, p. 5). This

scheme, which clearly strives to meet the needs of Indigenous people, may also contribute to the fragmentation of aged care services, as it operates outside the *Aged Care Act 1997* (AIHW, 2009, p. viii).

### **2.3.3. Aged care funding models in Australia**

As discussed, the *Aged Care Act 1997* transformed aged care needs assessments by replacing the Resident Classification Instrument (RCI), designed to be used in nursing homes, and the Personal Care Assessment Instrument (PCAI), used in hostels, with the RCS, introduced at the same time as the amalgamation of hostels and nursing homes into one system of care on 1 October 1997 (AIHW, 2012f, p. 76). The introduction of the single assessment model and funding system aimed to measure resident dependency whether high or low care, and create a system where residential facilities received equal levels of funding for residents with similar needs (Gibson et al., 2002, p. 2; Richardson & Bartlett, 2009, p. 28). However, this assessment framework continues to be based on a 'deficit' view of ageing people, which contributes to perceptions that those who require care are a 'burden'. However ageing associated demands are a natural part of life and should not be considered as part of a deficit model. A social justice model should incorporate a range of resources for older people and the difference between this approach and the deficit view should be appreciated, along with their tensions and differences.

Since that time there has been considerable dissatisfaction expressed by service providers of the administrative and documentation requirements of the RCS, which resulted in a comprehensive review of this model in 2002 (DHA, 2006). There was also public reaction and criticism regarding the financial and regulatory changes made in relation to residential aged care services and the lack of community consultation in developing this model (Borowski, Encel & Ozanne, 1997, p. 178; Palmer & Short, 2000, p. 298). This included contribution by users of entry payments equivalent to the cost of their own home. However, this was changed to involve a greater daily cost, enforcing a variegated user pays principle in current policies. As a result of the *Nursing Homes and Hostel Review 1986*, ACATs were given delegation in 1994 to

determine eligibility for admission to nursing homes, so that older persons would benefit from the most appropriate care services based on RCS categories, and to prevent premature approval for aged care (CoA, 2006, pp. 1, 2).

In March 2008, the new Aged Care Funding Instrument (ACFI), which superseded the RCS, was implemented as a part of the Government's *Securing the future of Aged Care for Australians package*, with the aim of streamlining funding arrangements for core and complex care needs, reducing documentation and achieving greater collaboration between aged care staff and department review officers (Andrews-Hall, Howe & Robinson, 2007, pp. 620–621; DHA, 2012a, p. 5). According to the most recent version of the user guide for the ACFI (issued in February 2013), ACFI's objective is to focus on the main areas that distinguish day-to-day, high frequency care needs for residents as a basis for measuring the average cost of care and allocating funding accordingly (DHA, 2013, p. 1). It is intended that ACFI provides satisfactory precision to evaluate an overall care profile, using 12 questions about assessed care needs (contained in three care subsidy categories), that determines appropriate funding. The three components of residential care subsidies are:

1. Activities of Daily Living basic subsidy (ADLs) comprising;
  - nutrition
  - mobility
  - personal hygiene
  - toileting
  - continence.
2. Behaviour supplement comprising;
  - cognitive skills
  - wandering
  - verbal behaviour
  - physical behaviour
  - depression.
3. Complex Health care supplement comprising;
  - medication

- complex health care procedure (DHA, 2007).

Each of the 12 domains has four ratings, which determine the amount of payments (A, B, C or D) and two diagnostic sections. Assessments and checklists, as part of an appraisal pack, are undertaken by an approved ACFI appraiser who submits the ACFI Application for Classification. The care facilities must retain historical information for future audit and accountability purposes (DHA, 2013, pp. 2–5).

Aged care homes charge a range of fees, although a resident may not be required to pay all of them. These fees can include a basic daily care fee for living expenses like meals, laundry, heating/cooling, and nursing and personal care, as well as an accommodation fee in the form of an accommodation bond or accommodation charge (DHA, 2007). Accommodation bonds are imposed on residents in high care if their assets exceed \$43,000. An older person in a RACF is classified as ‘high care’ under the ACIF if they have medium or high care needs in activities of daily living; or high behaviour needs, or medium or high complex health care needs (DHA, 2013).

DHA (2013, p. 1) has reported that while the ACFI covers necessary care needs areas through the 12 questions, it is not intended to be an inclusive assessment package. In effect, a broader range of care issues need to be considered and these cannot be accommodated in a single funding instrument. Criticism of the ACFI has been levelled regarding the volume of paperwork that nursing staff are required to undertake, which may include: continence records; behaviour charts; depression in dementia assessments; providing information to other care workers responsible for conducting appraisals, adding to the cost without commensurate benefits (DHA, 2012e; Productivity Commission, 2011, p. 128). In their research into nurses’ documentation practices and computer-based technology in 13 Australian nursing homes, Yu, Qui and Crooks (2006, p. 570) found that such tasks have led to increasing concerns by nursing and care staff, a decrease in job satisfaction and was a leading cause of workforce attrition in the RACF. Many of these concerns relate to the tension between trying to maintain care levels while trying to save costs. Thomas

(2008), as a member of the ACFI reference group, has similarly stated that the ACFI is not a:

comprehensive assessment that drives care planning or a tool that prescribes the provision of therapy and it is definitely not designed to monitor the quality of care provided (Thomas, 2008, p. 23).

The Productivity Commission has also reported that concerns were expressed by user groups about the discrepancy between the ACFI, which allocates funding in response to dependence levels, and the accreditation standards that encourage independence (Productivity Commission, 2011, pp. 115–116).

These sentiments are endorsed by the Australian Nurses Federation who, in their submission to the Productivity Commission inquiry, found that it was difficult to score a resident to reflect their ‘true’ care needs as the ACFI assessment does not permit some areas of care to be captured (Thomas & Chaperon, 2010, p. 16). In other areas of concern, the Australian Nurses Federation found that the instrument did not specify the type of nursing that should be provided or the qualification of the person administering the care. Nor does it recognise the substantial time spent by staff supporting and managing partners/family or the various roles of staff involved in the delivery of residential aged care, including enrolled nurses, assistants in nursing, nursing assistants and personal care workers and allied health professionals. The ACFI fails to recognise the need for interdisciplinary consultation and management of people living in residential aged care settings, or the complex care needs documentation required. Further, it does not acknowledge differential funding levels for the numbers and qualification levels of staff required to provide complex care, particularly during end-of-life, or in caring for those with behaviour challenges (Thomas & Chaperon, 2010, pp. 15–16). All these issues are directly related to the experience of older persons in RACFs and affect their wellbeing. It is important to understand how aged care needs are assessed and funded in the context for this study, as the lived experience of people living in RACF will be influenced by the policy and regulatory environment.

According to the Productivity Commission report, the provision of aged care services is not financially viable and the low financial returns for services make it difficult to modernise buildings (Productivity Commission, 2011, p. 123). Even with the requirement to fund capital upgrades with accommodation bonds (DHA, 2012e), providers are unable to cover depreciation and new investment costs (Productivity Commission, 2011, p. 124), especially at a time when consumer demand is growing for high care facilities in line with the ageing-in-place policies (Ansell, Davey & Vu, 2012, p. 12). Alzheimer's Australia reiterated the need to address primary and acute care for people with dementia as well as concerns relating to inadequate subsidies to provide high-quality residential care (Alzheimer's Australia, 2010b, p. 14).

In February 2013, the Commonwealth will introduce into parliament major amendments to the *Aged Care Act 1997*, which will provide a legislative foundation for the *Living Longer. Living Better* aged care reform package (CoA, 2012). These changes to the *Aged Care Act 1997* will form a significant part of the legislative amendment process over the next two years (DHA, 2012b) and will include changes such as greater choice of care, fairer means testing and improved governance and administration (CoA, 2012, pp. 4, 20, 24, 36). The reform package aims to change the way residential aged care is financed and delivered, including a budget of \$3.7 billion over five years, of which \$660.3 million is to be spent on the development of more RACFs in areas of greatest need. The aim is to embed consumer-directed care principles into mainstream aged care program delivery, and to ensure the sustainability of aged care facilities in regional, rural and remote areas (AIHW, 2012f, p. 3). It also proposes to remove the distinction between high and low care in RACFs, to recalibrate the residential aged care funding model to reduce the rate of growth in care subsidies, and to create a new agency to accredit and monitor RACFs.

While outside the scope of this study to review many countries' long-term care systems, it is interesting to note that funding schemes differ in international approaches. Unlike Australia, long-term care subsidies in Sweden are mainly paid for out of taxation by municipalities (80% of total cost) with a cost-sharing component of 16% by government and the remaining 4% paid by private persons, following a social

democratic model (Lagergren, 2007, p. 283). In their study into private and public older residential aged care in Sweden, Stolt, Blomqvist and Winblad (2011, p. 565–567) indicated that quality in public aged care facilities tends to remain constant independent of competitive pressure from private providers and private care, with a focus on customer service rather than policy reform. Health care in the United Kingdom (UK) is funded by the National Health System (NHS) through a redistributive tax-funded scheme and is free at the point of delivery (Wittenberg & Malley, 2007, pp. 29–30). Care home places are available through a means tests model which is outside the scope of the NHS. A reform model, *The Green Paper*, details a user pays system along with government subsidies of one third of the total cost, with an associated non-mandatory private insurance scheme and local authority organised community care programmes (Department of Health, 2009). Park and Werner (2011, p. 783) see market competition dominated by profit incentives also affecting aged care facility services and thereby the quality of care. Long-term care funding is complex and is currently undergoing a period of re-development through the *Dilnot Commission and the Fairer Care Funding July 2011* report, whereby the main focus is to ascertain the level of State subsidies (Commission on Funding of Care and Support, 2011). This proposes preventative care reforms recommending new partnerships between the individual and state, capping individual contributions, high means test threshold and a corresponding focus on insurance schemes. There has been a significant shift over the last 25 years whereby more than 75% of care homes are now in the for profit, private sector. In the USA, where approximately 67% of the budget is spent on people 65 plus years of age (Patel & Rushefsky, 2006, p. 120), long-term older residential aged care is funded by the government through Medicaid. Medicaid is the largest source of funding for medical and health-related services and for people with limited income. It is funded through general taxation and is a means tested welfare based system. While approaches are different, it appears that most countries face ongoing funding reform to address the increasing complexity of provision of health care and long-term care services.

#### 2.3.4. Accreditation

According to the DHA (2008d), quality standards provide a key regulatory link between funding and quality of care and QoL in aged care homes. These are assessed on the basis of four accreditation standards (together with 44 indicators and expected outcomes), which are set out in the *Quality of Care Principles 1997* under the Act, with the objectives of the principles to be provided in a way that meets the Accreditation and Residential Care Standards (ARCS). This established a mandatory national system for assessing quality of care through four standards and 44 expected outcomes (Richardson & Bartlett, 2009, p. 28). The four standards consist of a principle and a number of expected outcomes, with Standard One also having an ‘intention’ of acting as the umbrella for the other three standards. They consist of: 1. Management systems, staffing and organisational development; 2. Health and personal care; 3. Resident lifestyle; and 4. Physical environment and safe systems. Aged care facility life is characterised initially by four clinical domains, those being health management, behaviour management, care planning and coordination and prevention of illness and injury as well as socio-cultural issues that affect quality of care and QoL. The 44 standards attempt to cover these issues. However, the scope for dynamism and catering for qualitative aspects of peoples’ lives is limited by the rigidity of assessment criteria. The standards are detailed in Appendix A, along with comments on their expected outcomes.

RACFs are subject to this quality assurance process and must comply with all 44 expected outcomes to demonstrate continuous quality improvement, and show that care has been provided accordingly (ACSAA, 2012). The certification process has the overall aim of encouraging advancement, particularly of the physical standard of residential aged care buildings, rather than measuring the quality of care provided or the QoL of those who live in RACFs (Productivity Commission, 2008, p. 25). The process of accreditation is outlined in the *Accreditation Grant Principles 2011*, whereby each RACF undertakes a self-assessment against the standards and applies for accreditation (Part 2 of the *Principles*) followed up by an assessment by a team of registered aged care quality assessors at a site audit (Part 3 of the *Principles*) (Aged

Care Act, 1997). The Aged Care Standards and Accreditation Agency (ACSAA) evaluates compliance with the standards through periodical full audits, as well as unannounced visits to RACFs. During these visits, assessors review documented procedures, resident records, staff rosters, incident reports, care plans and complaints registers; observe the practices; and talk with residents to get their feedback about their satisfaction with the care and services being provided (ACSAA, 2012). Standards 2 and 3 specifically relate to the experiences of health care and lifestyle. However, despite the lengthy and complex compliance items that RACFs must satisfy, these standards cannot assure a quality experience for those living in RACFs. De Bellis (2010, pp. 119, 161), researching the construct of nursing practice in Australian RACFs, asserts that nurses continue to be dominated by a rationalistic rhetoric of quality of care ensured by accreditation, documentation, funding and the complaints scheme. Whilst it would be helpful to unpack all of these standards as they relate to the aims of this study, it is outside the scope of this thesis. It is important to note however that accreditation and the associated policies affect the lives of older persons in RACFs and their subsequent QoL. The system of governance resulted in time controls that have a negative impact on nursing care high workloads for staff consistently resulted in delays in care for older people, possibly putting them at risk. It was concluded that accreditation implied only a minimal level of safe practice, and did not ensure optimal services that contribute to a high QoL for those who live in RACFs (De Bellis, 2010, pp. 161–162).

The successful attainment of accreditation is linked with government funding (Finch, 2004, 77). Braithwaite, Makkai and Braithwaite (2007, p. 36) suggest that this results in a system that is compliance driven with less of a continuous improvement model. DHA (2008b), in its review of the accreditation process, found the biggest criticism of the standards was the lack of specificity, contributing to 'loose' interpretations with a potential 'blurring' of roles between the regulator and the agency with respect to compliance. One important consideration is discussed by O'Reilly, Courtney and Edwards (2007, p. 181), in their review of monitoring in Australian nursing homes. These authors found that while the Standards may be aimed at improving quality of care they only represent minimum (rather than optimal) standards of quality.

Submissions received by the Productivity Commission to their inquiry *Caring for Older Australians* by user groups such as COTA and Uniting Care Australia have also criticised the system of accreditation as focusing on processes and inputs rather than actual outcomes. Wesley Mission Victoria similarly found that there was a focus on monitoring compliance rather than quality improvement (Wesley Mission Victoria, 2009, p. 12). Further, the Australian Nurses Federation (Thomas & Chaperon 2010, pp. 4, 27) sees problems with the training of assessors and the lack of appropriate benchmarks for assessment. It recommended to the Productivity Commission that a national education programme be developed by the ACSAA to ensure consistent application of national benchmarks of their accreditation standards and quality care principles.

Research by De Bellis (2010, p. 110) and Courtney, O'Reilly, Edwards and Hassall (2007, pp. 582–583) found that facility accreditation did not always ensure residents' QoL nor did it ensure that high-quality nursing care was provided. Kendig and Duckett (2001, p. 33), in their assessment of policy reform in aged care, found that while reports from the accreditation processes provided a basis for improvement, there was opportunity for operators to contest recommendations in the interest of profit maximisation. Issues with inequalities in funding, especially with respect to the behavioural domain, and the reliance on documentation, have also arisen with the implementation of the ACFI (Productivity Commission, 2011, pp. 119, 128).

### **2.3.5. Challenges revisited and legislative changes**

The review of the literature, policies and legislation around the Australian aged care system has provided a snapshot of the system and circumstances within which older persons live in RACFs. There are many positives within the regulatory framework, such as the aim to protect the interests and rights of the older person, as well as to monitor standards of care and services. However, this review has uncovered those elements of the aged care system that continue to provide challenges for the government in policymaking, and for government and service providers. It is important to acknowledge the alternative policy approaches and how they meet health

care needs. While an exhaustive discussion of all the challenges is outside the scope of this study, a summary, provided by the Productivity Commission (2011, pp. xxv–xxvi), is discussed where they are of particular relevance to this study.

Some of the major identified concerns with the current system are delays in care assessments and limits on the number of bed licences and care packages; fragmented care across the packages of community-based services; complex pricing structures; difficulties in obtaining finance by providers; financial inequities; insufficient and inadequate funding for restorative/re-ablement and palliative/end-of-life care; variable care quality across the system, which older Australians and their carers find difficult to navigate; uncertainty about care availability; workforce shortages due to low wages and high administrative costs; complex, overlapping and costly regulations; insufficient independence of the complaints-handling process and incomplete and overlapping interfaces within and between jurisdictions. The OECD (2006, p. 10) has indicated that health system performance is under considerable scrutiny globally and this is mainly due to demands of an increasing ageing population, rising costs and reduced quality and variations in practice.

The next section discusses the different and emerging concepts surrounding understanding ageing, as well as the corresponding dynamics surrounding relationships of care of older people.

## **2.4. Perspectives of ageing**

### **2.4.1. Context of ageing and ageism**

The preceding discussion identified the policy and reform agenda that governs the provision of aged care services in Australia. Those policies clearly affect the lives of people who live in RACFs and some of the reports and literature reviewed suggests that older people may be living in less than acceptable conditions. To what extent the outcome of these policies has achieved their stated objectives is also debatable (Andrews-Hall, Howe & Robinson, 2007, p. 619; Angus & Nay, 2003, p. 131; Han et

al., 2005, p. 10; Hamilton & Menezes, 2011, pp. 399–340). It is clear from the literature that concerns over the quality of aged care services are not unique to Australia, as from an international perspective, many older people experience health and care services that are not responsive to their main needs (Themessl-Huber, Hubbard & Munro, 2007, p. 222). The quality of care concept is largely based on a medical model of care, which emphasises aged care facility management and professional perspectives based on health care interventions, rather than reflecting consumers' preferences (Wan et al., 2010, p. 6; Diekelmann, 2002, p. 14). Conceptualising ageing is complex and interdisciplinary: a brief discussion here of the biological, psychological, sociological and phenomenological approaches to ageing gives a broad context to this study by discussing how older people are perceived in society. This study can be enriched by gaining an understanding of how older people's lives may be affected by societal perceptions of ageing.

Historically, perspectives of ageing have stemmed from biomedical approaches to ageing, where the focus was on, for example, biological changes involving illness, decline and death; and free radical theory that proposes that reactive agents in the body cause serious malfunctions and disease over time (Adams & White, 2004, pp. 331–332; Harman, 2003, p. 557). The perception that physical frailty, decline, deficit and infirmity is just one way of considering older peoples' place in society, so this perspective is relevant when considering the experiences of older people who live in RACF. Historically, there has been a similar perspective by policy makers when it comes to the social context of ageing (represented in the policy framework), with a corresponding acceptance of a deficit model of aged care services, which assumes that older people are a burden and that the increase in the ageing population is problematic (Lloyd, 2000, 173).

This perspective has also stemmed from psychological theories that have advocated such concepts, for example the functionalist disengagement theory (Cummins & Henry, 1961), which sees social disengagement as a natural part of physical and mental decline—an adaptive response to ageing in which older persons abandon their traditional roles. This theory has been largely discredited (Harwood, 2007, p. 13) and,

conversely, activity theory (Havinghurst, 1961, p. 8–12) has posited that maintenance of older people's relationships, activities and adaptations to a changing society were key to successful ageing (Neugarten, 1964, p. 194).

Sociological theoretical approaches to ageing are associated with social group interaction, and are explicated in implications for providing aged care services, financial planning, health care decision-making and personal relationships (Harwood, 2007, p. 14). For example, conflict perspectives such as modernisation theory examine the way in which older people lose power and influence (status) as a result of the decline in familial support for older people (Aboderin, 2004). As societies modernise, with urbanisation, technological advancement and social mobility, families tend to disperse resulting in less family involvement with older people with a resultant devaluing of wisdom of older people (Moody, 2006, p. 7). However, Tornstam (2005, p. 140) suggests that despite this view, older people are relatively well integrated in society with only a minority being socially isolated. Other approaches, such as age stratification theory advocates that age structures form a system of interdependent parts that we refer to as an 'age stratification system' (Perek-Bialis & Shippers, 2013, p. 80). Members of society are segregated by age with varying access to political and economic power, such as in aged care facilities whereby the residents are confined to a 'single age stratum' (Riley, Johnson & Foner, 1972, pp. 5–6, 205). Consistent with this is exchange theory, which is underpinned by the assumption that dependence increases with age with older persons less able to engage in exchanges (Dowd, 1975, p. 585).

However, some critics express too much reliance in their focus on physical exchanges rather than those non-material relationships such as friendship and care. As with a symbolic interactionist approach, interactions influence the way older people perceive themselves and 'makes separate individuals out as symbolic' (Mead, 2009, p. 217). This approach posits that changes associated with old age, have no inherent meaning, but rather symbolic meanings attached to older people are rooted in society (Andersen & Taylor, 2008, p. 387). Similarly, Tornstam (2005) advanced a symbolic interactionist theory of gerotranscendence, which advocated that that as people age,

they transcend the limited views of life they held in earlier times and accept ambiguities and apparent contradictions, and develop more lenient views of right and wrong. This line of thinking represents a shift from a traditional positivist view to one where disengagement is phenomenologically understood (Tornstam, 1989, pp. 55–56), with the process of ageing resulting in new individual perspectives. Again, according to Tornstam (1994), there is a natural shift in meta-perspective where reality is defined differently than in mid-life, enabling the older adult to experience increased life satisfaction and a new concept of value in old age. Similarly, Wang (2011, p. 2,635) found a geotranscendence model facilitated successful ageing and life satisfaction. Wadensten & Carlsson (2003, p. 469) in their study of developing guidelines for practical use in the care of older people, found that the theory of geotranscendence can assist in facilitating and furthering personal growth in older people, specifically due to understanding those issues of importance to the older person in the process of their ageing. Hence, this study draws on phenomenological principles to explore the lived experience of people who live in RACFs.

Phenomenology, the theoretical framework and methodology adopted in this study, offers epistemological underpinnings to assist in understanding theories of ageing (Bengtson, Gans, Putney & Silverstein, 2009, p. 17). Alternative theories, such as feminist theories of ageing, are grounded in understanding gender as an organising social principle that shapes interaction and results in an inequitable experience of ageing and ageism against women (Calasanti & Slevin, 2001, pp. 21, 32, 36). Conversely, recent perspectives are founded in post-modernist approaches that focus on the experience of ageing as affected by a changing world, such that new frameworks are required to interpret society and ageing (Bass, 2009, p. 359). Gillearn and Higgs (2000) and Bass (2007, p. 408-409) see the change from an industrial society to a consumer-driven one, with a focus on flexibility of opportunities, customised services and choice for older people who have increased leisure time and greater security in later life. Critical perspectives of ageing see ageing as a socially constructed process where the interaction between the state and economy results in inequalities in the experience of ageing such as in living standards, life expectancy and expectations of older people of daily life (Phillipson, 2009, p. 616). However, for

the purposes of this study, a phenomenological approach was considered the most appropriate to underpin the aim of exploring what it is like for older people to live in a RACF.

Minichiello, Browne and Kendig (2000, p. 262) found that older people who live in RACFs are most vulnerable to the negative consequences of ageist thinking, and that the pressure of demanding workloads on staff may increase ageism. In a study of five aged care facilities in Australia that examined ageist attitudes, through stereotype reduction models, of caregivers towards older people by using a survey to assess education, contact and training, Reyna, Goodwin and Ferrari (2007, pp. 50, 54), found contact by care staff with older clients alone did not reduce stereotypes, and may actually reinforce these stereotypes if the contact focuses on the older person's dependency. This study concluded that education in general and education about ageing of older adults in particular were associated with less stereotyping and more positive attitudes towards older persons (Reyna et al., 2007, p. 54). This suggests that staffing shortages and a lack of education for staff influences their perceptions of older people, all of which contribute to QoL of those who live in RACFs.

The issues of QoL and ageing well, in a social context, should not be confined to issues of chronological ageing (Bowling, 2005, p. 201), nor concentrate on the preoccupation of how resources should be allocated to respond to the increasing demands for aged care (Lloyd, 2012, p. 8); but should focus more specifically on high levels of physical and psychological functioning with an associated active engagement with life (Brownie & Horstmanshof, 2012, p. 777). A counter discourse to a negative view of ageing has seen positive, or healthy, ageing as an important part of academic research and thinking. Rowe and Kahn (1997, p. 145) advocated a notion of positive ageing where extrinsic factors play a neutral or positive role in ageing. This has shown older people to be productive, functional, positive and embarking on a search for self-fulfilment and empowerment despite growing older (Gibson & Singleton, 2012, p. 32). However, it has been suggested by some that this shift in thinking may have led to a reduction in services (Lloyd, 2012, p. 137) by concentrating on advocating care by and in the community. While some core concepts

of positive ageing assist in offsetting negative stereotypes of older people, the dominance of political and economic agendas largely ignore the rights and voices of the older person and fail to address obvious inequalities of health service provision (Lloyd, 2012, p. 136). Therefore, this study adds to what is known about what it is like to live in a RACF in Australia.

#### **2.4.2. Negative versus positive paradigms of ageing and relationships of care**

As discussed in the preceding section, ageism has emerged as a negative response to the role of older people in our society, and a general acceptance that dependency by ‘older people’ is the antithesis of a meaningful role in society. Advancement of ageing and activity participation of older people in society to maximise physical and mental potential has emerged to oppose the traditional models of care, which emphasised a dependency model based on deficit concepts of disengaged social roles and a preoccupation of diminished capabilities and preparing for death (Wells, Foreman & Ryburn, 2009, p. 84). Internationally, most developed countries experience similar challenges, resulting from increased longevity, with a correspondingly larger older population and a relatively smaller working population. This places pressure on publicly funded health and social services including health care and residential aged care (Taylor, 2011, p. 3). Stabile and Greenblatt (2010, p. 21) have suggested that a radical overhaul of health care systems is inevitable, based on a need to provide universal health care for an ageing population, that cannot solely be met by tax contributions, but in part, needs to be funded by the older population. According to Bloom and Canning (2008, p. 17), publicly funded services will be reduced to a basic minimum, conflicting with many social welfare models. However, according to Christensen et al. (2009, pp. 1,204–1,205), longevity can enable older people to continue as workers, volunteers, consumers and carers for much longer, assimilating a life course approach to care provision. Stauner (2008, p. 206) suggests that this requires policy reform in pension systems, health insurance and flexible working structures to allow older workers and those with caring responsibilities to continue working. Along with this is the understanding that, other than policy and financial models of care, other frameworks of caring relationships exist. There are

numerous model of care, all with their own assumptions. Although a comprehensive discussion of models of care is outside the scope of this study, a few relevant models are presented and discussed to inform insights into how older people who live in RACFs experience their everyday lives. The following discussion focuses on changes in conceptualising ageing and some relationships of care, all of which provide background to the experiences of older people in RACFs.

Conceptualisation of older age is changing, with many people in the ‘fourth age’ being independent and capitalising on autonomy (Bowling et al., 2003, p. 270). While a rejection of a negative paradigm of ageing has emerged, merely focusing on a positive account of ageing may promote an idealistic version of an older person who is self-reliant and does not need support or care (Lloyd, 2012, p. 137). Society overwhelmingly regards those persons who do not have autonomy as dependent, a reflection of a negative paradigm of ageing. Positive ageing policies challenge ageism by advocating autonomy as part of an older person’s agenda for QoL. A criticism of ageing policies in the UK has shown that autonomy for an older person does not recognise social inequalities in aged care, by expecting older people to facilitate their own social agenda and finance their own health and lifestyle (Boulton-Lewis & Tam, 2012, p. 4).

It has been suggested that transition to a RACF results in a loss of independence and autonomy, and an increase in dependence on staff manifesting as an institutionalised ‘learned helplessness and instrumental passivity’ promoting dependency and discouraging independence (Harper Ice, 2002, p. 346). Obstacles to fostering reciprocal relationships and wellbeing perpetuate the continuance on dependent relationships in RACFs. This ultimately presents as the reality of how older people experience the everyday world. It appears that the issues of QoL in RACFs, principles implicit within the resident’s Charter of Rights, as viewed by older people, are manifest in their perception of lived experience. Ethical approaches within aged care policy frameworks encouraging personal responsibility, self-management and participation in a collaborative caring framework, such as those advocated in the

Netherlands, which have embraced principles of positive ageing, and reinforced integrity and wellbeing in the older person (Huber et al., 2011).

A focus on interdependency and relational autonomy has been suggested as a better model, directing focus away from care reliance to reciprocal support (Tanner & Harris, 2008, p. 10). Earlier authors such as Formosa (1997) found that older people had an interdependent lifestyle based on reciprocal interdependence among family, friends and carers. In an assessment of new regulatory framework assessment strategies in the UK, Furness (2007, pp. 24–25) suggests that the inclusion of older persons' views regarding their care will result in older people having greater control over their own lives and promote their interdependence with rather than dependence on carers and family, with the aim of improving QoL.

Current models of institutionalisation create dependence in older persons and affect their ability to engage actively in life. While the goal of many RACFs is to promote the attainment of meaningful lives and reflect an experience of being at 'home', the reality is that older people often experience a loss of autonomy and increased dependence because of entering, and living in, such a facility (Fay & Owen, 2012, p. 35). This is mainly due to decisions, and personal preferences, being taken out of the hands of the older person and exercised by owners and care providers. Anderberg and Berglund (2010, p. 66–67) similarly found that older people struggled to maintain control and connectedness, resulting in an inhospitable existence in a RACF. Conversely, the Eden alternative is a humanistic model that rejects traditional institutional models of aged care, and is based on a philosophy that aims to promote autonomy, independence and choice for older people in RACFs, through older person directed care in a 'home life social environment' (Thomas, 1996, p. 2). An Australian assessment of the *Principles for Older Persons* (UN, 1991) and a relationship with the Eden alternative has been undertaken by Brownie and Horstmanshof (2012, p. 784), who found that institutional life, the living environment and limited staffing support constrained personal control and self-fulfilment, affecting autonomy and reciprocity in social support.

Studies into care-as-service, where care staff fulfilled their obligations towards older people in terms of attending to their care needs, and care-as-comfort, where care is provided outside the daily functional requirements of care service and older people experienced personal reassurance, friendship and empathy from staff, have been undertaken by Bowers, Fibich and Jacobson (2001, p. 539). These researchers have shown that older peoples' best and worst experiences in the care home were contingent upon the satisfaction level of their relationships with staff, and the experience of positive care can be expressed in terms of the close relationships and intimacy they shared with staff. Healey-Ogden and Austin (2011, p. 92) suggest that the nursing staff relationships with older people can foster their wellbeing and reflect experiences of their previous home life. Cook and Brown-Wilson (2010, p. 24) see issues such as being ignored or receiving uncaring assistance as examples of negative experiences for older people, and this is often associated with the pressures that nursing staff are under, caused by dominant policy problems and resourcing, which ultimately has an adverse effect of the older persons' quality of care and life.

The former dominant paradigm of conceptualising ageing and models of care has assumed that the observer, or health professional, is outside the phenomena being observed and is able to control medical science and illness. Merleau-Ponty acknowledges that:

Science manipulates things and gives up living in them (1964, p. 159).

More recently, there has been an attempt to acknowledge the importance of being involved with the observed phenomena. Bringing together the subjective worlds of professionals and patients, where health professionals can be self-reflective in their own interpretations of health, illness and old age, enables a greater awareness and responsiveness by professionals to the experience of those in their care (Tresolini & Pew-Fetzer Task Force, 1994, p. 22). This enables an understanding of lived experiences as essentially governed by relationships of meaning and is consistent with the frameworks of phenomenology as they allow us to embrace all experience, not just cognitive and practical spheres (Crowell, 2013, p. 10).

## **2.5. Quality of Life in residential aged care facilities**

### **2.5.1. Concept of Quality of Life**

The term QoL is a concept relating to perceptions and measures of relative experience of wellbeing and satisfaction. Some of the problems associated with this concept are those of definition, quantification and analysis. QoL is difficult to define, but has been described by Mason and Faulkenbury (1978, p. 123) as being concerned with comparing or measuring individuals' experiences and perceptions against some set standards. WHO (1997, p. 1) has defined QoL as 'Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'. Further, the concept is seen as one that is affected by the individual's relationships with areas of importance in their own environment, physical and mental health, level of independence, personal beliefs and social relationships. It is assumed that early users of the term related QoL to wellbeing and individuals' life experience. This is consistent with a phenomenological view of exploring daily life as experienced from the first-person point of view. As such, QoL forms part of an important context for this study, as one of the aims is to understand what core elements of life are important to the older person and essentially contribute to their lived experience.

Historically, interest in assessing QoL began with Gruin, Veroff and Feld (1960), Cantril (1965), Bradburn and Caplovitz (1965), Andrews and Withey (1976), and Campbell, Converse and Rodgers (1976). These researchers conducted large surveys of happiness to examine the influence of social-structural or demographic factors on individual feelings of wellbeing. One of the first major studies concerning QoL was a study investigating Americans' mental health and economic conditions by Gruin et al. (1960, p. i), who created a basic measure of wellbeing related to a sliding scale of happiness. Bradburn and Caplovitz (1965) built on this study to include comparisons of negative and positive effects of happiness, and found that the absence of negative effects does not indicate the existence of a positive effect. Cantril (1965) advocated scales of satisfaction and dissatisfaction and Campbell, Converse and Rodgers (1976, pp. 8–9, 15), in their study of American QoL, adopted both happiness and satisfaction

measures in relation to a variety of life domains, where happiness was concerned with feelings of euphoria, while satisfaction was a cognitive, subjective experience based on an individual's comparison of goals to actual accomplishments.

Ormel, Lindenberg, Steverink and Vonkorff (1997, p. 1,051) suggest that contributions from sociology, economics and psychology helped QoL grow as a paradigm and aided assessment and measurement of health-related QoL. Sociologically-based beliefs about quality of care that include more extensive psychosocial and cultural components, based on the older people's viewpoints (Chapelhow et al., 2005, p. 43) have generally not been incorporated into Australian aged care policy. In health care, QoL is generally considered as an outcome measure in the assessment of care rather than an important element to inform policy formation (Courtney, Boldy & Moyle, 2009, p. 539).

In relation to this study, it is considered that elements of quality of care should be a core component of QoL in residential aged care, as it adds to the totality of the experience of those who live in a RACF. The relationship between quality of care and QoL has been the subject of much research; however, in policymaking, it appears that the more humanistic elements of older people's lives are not clearly taken into account. While the quality of care provided to those who live in a RACF is an important part of the older people's overall wellbeing, QoL relates to the experience of overall wellbeing and their rights to comfort, happiness, dignity, privacy and autonomy, as well as self-fulfilment. This is wholly supported by Kane et al. (2003, p. 241) who suggest that health-related QoL is only a subset of QoL, and such a narrow view cannot fully explain the life of older people in aged care facilities. In Australia, and internationally, there is a growing interest in QoL in older age, mainly due to increased expectations of the ageing population, a social focus on wellbeing and policy reforms designed to reduce reliance on government-funded care. There has been a recent corresponding focus on exploring RACF life from resident's perspectives to ascertain what wellbeing actually means to older people: there is no agreed measurement 'tool' for ascertaining QoL, as it means different things to different people (Ward, Barnes & Gahagan, 2012, p. 28). It is considered that the

older person's perspective of those elements of importance that have meaning for them in their everyday lives should be at the forefront of any discussion of quality or wellbeing in a RACF, and subsequently reflected in policies. For the purposes of this study, the elements that constitute QoL, including quality of care, for the older people who participate, will be consistent with a phenomenological stance of their subjective experience.

### **2.5.2. Changes in approach of assessing Quality of Life**

Over time there have been many studies assessing QoL in care facilities, with varying results relating to those elements constituting QoL. While a little dated, van Campen & Kerkstra (1998) state that QoL for aged care settings is defined as:

the resident's judgement on his/her sensory, physical and psychosocial functioning and his/her perceived autonomy and perceived safety (van Campen & Kerkstra, 1998, p. 11).

More recently this view has been augmented by the work of Kane (2001, pp. 295, 299), who found an emphasis on the care aspect of nursing homes and associated QoL for older people includes factors such as security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual wellbeing and functional competence. While there are fundamental differences between expectations among older people, Kane (2001, pp. 296–297) suggests each variable is expressed as an outcome experienced by a resident rather than by the processes or structural features of the RACF.

In a mixed methods design study by Hall, Opio, Dodd and Higginson (2011, p. 507) in the UK, the researchers asked respondents to assess the importance and satisfaction of domains they nominated as most important for QoL. The most important QoL domains identified were leisure activities, family, relationships, social life, independence and peace and contentment; while participants found the survey challenging due to physical limitations and difficulty in understanding instructions. Willemese et al. (2011), in their mixed methods study into QoL of older people with dementia in nursing home care in the Netherlands, found that the organisation of care

(such as care concept or philosophy of care) and staff ratios are important for QoL outcomes related to this group of older people. However, investigation into the lived experiences of participants with dementia is outside the scope of this current study.

Tseng & Wang (2001, pp. 307–308), in their research in 10 nursing homes in Southern Taiwan, used a satisfaction survey consisting of a two-part scale that rates the satisfaction and importance of individual items. This study found that activities of daily living, social support from nursing staff, socio-economic status, physical function and frequency of interaction with family contributed to QoL. Research by Holtkamp, Kerkstra, Ribbe, van Campen and Ooms (2000, p. 1,346) in the Netherlands, used the QoL *Somatic Nursing Home Older People Questionnaire*, and identified five dimensions of nursing home life that reflect the participants QoL. These were sensory functioning, physical functioning, psychosocial functioning, perceived autonomy and perceived safety. The study found that the higher the quality of care, the fewer the gaps between the older people's needs and the care they received. Such care was found to meet older people's physical and psychosocial needs and correspondingly improved their perception of QoL.

A quantitative and qualitative study involving 140 selected older people living in three public nursing homes in Amman, Jordan was conducted by Fakhri (2011, p. 169). This study used questionnaires during one-on-one, face to face interviews with older people in residential aged care facilities in order to examine QoL as perceived by older persons. This study found that the QoL of older people was affected by age, gender, marital status, level of education and length of stay in the nursing home, and the value of QoL was determined by physical and psychological status, social relationships and environment. However, those values differed for each resident. What seemed to be missing in a number of these studies was the perspectives of older people themselves.

However, Bowling (2009, p. 23) contends that, while there is no clear consensus about the definition of QoL, measurement has seen a shift away from physicians' and carers' perceptions of QoL to the individual's subjective feelings of their own health

and QoL. Similarly, Banerjee et al. (2009, p. 20) indicate that subjective measures of health-related QoL involves variables such as self-perceived physical, psychological and social functioning, and individuals' overall health and satisfaction with life as a whole.

It appears that the most important domains of health-related QoL are those cited by older persons and this supports research underpinned by a phenomenological approach. There has been a corresponding trend to acknowledge older people's perspectives and experiences of RACFs so that policies may encourage more personally orientated care. For example, suggesting resources that may enable providers and care staff to help optimise QoL for older persons in care has been an objective of Help the Aged in their research report titled, *My Home Life: QoL in care homes* (National Care Homes Research and Development Forum, 2007, p. 5). This report indicated emerging new approaches to quality of care-based on the priorities of individual services users themselves (Davies & Heath, 2007, pp. 30–31).

### **2.5.3. The constituents of Quality of Life that matter to older people**

In response to shifts emphasising the importance of older people's perspectives of QoL, many quantitative and qualitative studies have emerged, addressing those elements of importance to older people. A brief of some international and Australian studies assists in providing a context to conceptualising the first-hand experiences of older people as they are lived.

A sentinel research project based on a national survey of the QoL of persons aged 65 and over in the UK, exploring older people's definitions of QoL, found that good social relationships and health are the main predictors of QoL (Bowling et al., 2003, p. 269). The themes that emerged constituted a multidimensional model of good QoL, with the main elements of QoL being good social relationships; engaging in social roles and activities; having a positive psychological outlook; living in a home and neighbourhood that gave pleasure; having good health and mobility; having enough money to meet basic needs, and retaining individual independence and control over

life (Bowling et al., 2003, pp. 277–282; Gabriel & Bowling, 2004, p. 675). Resident satisfaction surveys and resultant subjective opinions of over 4,000 older people living in Australian RACFs, ‘the population of interest’, identified four key themes of importance to the participants’ QoL, these are: physical environment; social environment; governance; and support for active living (Harris, Grootjans & Wenham, 2008); these formed an appropriate basis for policy formation.

Some recent studies that draw on a participatory research methodology with older people living in RACFs in the UK have been undertaken for the purpose of policy development, with the aims of understanding what wellbeing means to older people and what affects older people’s lived experiences (Bowers et al., 2009; Ward, Barnes & Gahagan, 2012). To explore the issues of voice, choice and control of older people in long-term care in the UK, Bowers et al. (2009, p. 12) found older people’s voices were ‘practically silent’, as compared to those who spoke on their behalf, such as family members and health professions. This study was extensive and invaluable to understanding the older persons’ perspective and it is acknowledged that further discussion would assist in understanding this importance of this approach, however it is outside the scope of this study to expand on this. The sentiments of this study are therefore contained for the purposes of highlighting this issue of importance. This represented a significant power imbalance between those receiving care and those providing it (Bowers et al., 2009, p. 53). In their vision for a ‘good life’, the participants focused on personal identity and self-esteem; meaningful relationships; personal control and autonomy; home and personal surroundings; meaningful daily and community life; and personalised support and care (Bowers et al., 2009, p. 47). Ward, Barnes and Gahagan (2012, pp. 15–16) noted that older people found it hard to maintain a sense of wellbeing, either because of the loss of friends and family, health issues or loss of identity and experienced a corresponding difficulty in adjusting to personal changes and to changes in the world around them.

In an Australian study of 1,100 older people in community residential care, Horner (2005) used semi-structured interviews and observation to reveal that successful ageing-in-place is represented by an older person’s ability to access services that met

increasing dependency needs over time. This was a critical element of QoL. Older persons wanted to age-in-place, as this gave them a sense of empowerment. The interviews with older persons in high care facilities revealed that the most important elements contributing to their QoL were personal care and personal comfort; communication and interaction with staff and family; physical environment (as their room was essentially their home); and good skilled staff (Horner, 2005, pp. 148, 151). Older people in low care and independent living facilities rated access to social activities and participation; independence; health; safety and stability; ability to retain personal belongings; and knowing there was access to assistance as those elements of QoL that were most important (Horner, 2005, pp. 152–154). In a follow-up research study, assessing these findings and QoL for successful ageing-in-place, Horner and Boldy (2008, p. 364), found the lines of demarcation between independence and dependency were not clear across accommodation levels provided and, as such, policy acknowledging dependency levels rather than accommodation type provided more appropriate benchmarks for care.

Along with Bowling et al. (2003), these studies of QoL provide a benchmark for assessing the elements of RACF life that matter to the older person. While this research was undertaken with older people in their own homes, it is understood that elements of importance of QoL for older people should not be any different than for those people in RACFs (Gerritsen, Steverink, Ooms & Ribbe, 2004, p. 12). The purpose of this study is to emphasise the importance of personal perspectives and interpretations of older people in high care and, as such, the themes for QoL as identified are important for understanding subjective experience; a true reflection of the phenomenon.

#### ***2.5.3.1. Personal care and personal comfort***

The study by Horner (2005, p. 148) revealed that older people did not want to be rushed through activities of daily living, such as showering or dressing, and wanted staff to spend time with them. Their ‘home’ was their bedroom and facility surrounds,

and the staff and people they shared this with (Horner, 2005, p. 151). In an extensive review of literature relating to truth-telling by care providers, culture and work practices in high-level RACFs in Australia, Tuckett (2005, p. 222) found that practices concentrated on providing instrumental care, promoting a culture of ‘doing for’ rather than ‘being with’ and creating the antithesis of a ‘home-like environment’, in which the older person becomes silenced and isolated due to staff being starved of time. Changes to aged care policy create the conditions where skilled nursing care required by older people in Australian RACFs is provided by assistants rather than by enrolled nursing staff resulting in a reduced time allocation for daily life activities (ADLs) (Jackson, Mannix & Daly, 2003, p. 43). Problems with staff turnover and shortages can also contribute to a lack of continuity in care and the older people’s needs being unmet (Ball, Ford & Smith, 2005, p. 44), which may lead to issues of harm, injury or abuse.

Personal care and comfort, and resultant QoL, in RACF life is therefore constrained by the conditions under which the older person must live and the issues regarding staffing and their environment (Horner, 2005, p. 151). Due to the intensification in dependency levels and need for support with personal care in long-term RACFs in Australia (Andrews-Hall, Howe & Robinson, 2007, p. 620; Chalmers, Carter, Fuss, Spencer & Hodge, 2002, p. 30), this element of QoL appears to be constrained in its success.

#### ***2.5.3.2. Communication and interaction with staff and family***

Fulfilling relationships with others are another key determinant of QoL for all people and this is particularly so for those who move into residential aged care (Kane et al., 2003, p. 240). Older people feel better about settling in if they have continued contact and support from their families, a sense of being accepted by the other older people, company and having someone they know in the home (Thein et al., 2011, p. 4). However, Jilek (2006, p. 11), in research into the lived experience of men entering Australian RACFs, found a largely negative association with aged care facility life, due to feelings of disempowerment, institutionalisation and social isolation.

Social contact with family, friends and carers, both inside and outside the nursing home, contributes to wellbeing (Robison et al., 2011, p. 280), a reduction in loneliness (Prieto-Flores, Forjaz, Fernandez-Mayoralas, Rojo-Perez & Martinez-Martin, 2011, p. 189), enhances the older people's identity and purpose (Keefe & Fancey, 2000, p. 240). It also results in less depression, a more positive outlook and a greater sense of happiness (Carpenter, 2002, p. 286). Edwards, Courtney & O'Reilly (2003a, p. 40), in their Australian study, found that older people's QoL improved with valuable interactions with staff, as older people preferred to be cared for by people whom they knew and trusted, knowing that they would receive care when required. Research in both Australia and internationally indicates that while support and friendship from staff was valuable, due to the professional, task-orientated processes that consume their time, the relationships were generally more functional and care-focused (Carpenter, 2002, pp. 286–287; Cook & Brown-Wilson, 2010, pp. 24–26). However, loss of relationships resulted in loneliness (Brownie & Horstmanshof, 2012, p. 780) and seclusion (Adams, Sanders & Auth, 2004, p. 82).

Parmenter and Cruickshank (2010, pp. 62–63), in their research into social lives of older people in rural Australian aged care facilities, similarly found that while the significance of social ties to the health and wellbeing of older people represents an important part of aged care facility life, the risk of social isolation due to changes in relationships can have serious consequences for older people's QoL. In a recent study by Friis and Harder (2010, p. 48) into nursing home residents' experience of nursing home life in Denmark, the authors also found that despite disruptions in their social relationships, such as a lack of social contact and a perceived lack of self-governance, residents felt secure in their daily lives, as they knew that staff were available for assistance at all times.

### ***2.5.3.3. Physical environment***

Fleming, Crookes and Sum (2008, p. 298) suggest that while progress has been made in identifying the principles that inform good environmental design for older people

living in Australian aged care facilities, there are concerns regarding the implementation of these principles in practice, due to budgetary constraints and pressures of providing quality outcomes. Acknowledging a growing awareness of the effect of the physical environment of aged care facilities on older residents' independence, mobility and QoL, Australian research by Moore et al. (2011, p. 416) into the quality and safety of the physical environment in nine RACFs, found that providing a safe and older person-friendly physical environment was problematic due to physical hazards that increased risk of falling, discouraged use and affected safety and independence (Kayser-Jones et al., 2003, pp. 78–79). Tsai and Tsai (2008, pp. 1,918–1,919) similarly found participants in their study experienced reduced autonomy and social interactions with others, due to the preventative environmental design.

Bowers et al. (2009, p. 38) identified privacy, warmth, safety and familiarity as features of importance to create a home-like environment, as well as having choice and control over personal and private areas. However, this was generally not achievable. Further, Edwards et al. (2003a, pp. 40–41) found that older people valued the ability to personalise their rooms, as this gave them a connectedness to their previous home life. Similarly, Teresi, Holmes and Ory (2000, p. 418) found that in residential care where people live together with varying cognitive and physical capacities it becomes difficult to individualise the environment to meet everyone's needs, and this can impact on QoL and the ability to exercise independence and dignity (Clare, Rowlands, Bruce, Surr & Downs, 2008; De Bellis et al., 2011; Vickland et al., 2012).

#### ***2.5.3.4. Good skilled staff***

Australia's aged care infrastructure and funding is suggested by Foley (2010, p. 19) as contributing to substandard care, where care is provided by a workforce that has inadequate numbers of educated and regulated nurses and other care workers, as a result of inappropriate government funding, policies and practices. In line with changes to the aged care system in 1997, 24-hour care is not compulsory in some

facilities. De Bellis (2010, pp. 100, 101), found a situation dominated by inadequate numbers of skilled staff and by sub-optimal residential aged care policies that resulted in a substandard level of nursing care provision. In a public policy discussion document into aged care in Australia, prepared for National Seniors Australia by Access Economics (2010), the issue of workforce investments has been described as critical for quality care. This document reports that older people experience greater satisfaction and better health outcomes when there are higher proportions of registered nursing staff.

The quality of nursing home care, according to Castle and Engberg (2007, p. 1,823) is affected by a range of staffing characteristics such as staff numbers, education, qualifications, turnover and stability, and the number of agency staff employed. These authors conclude that greater attention should be given to reducing the use of agency staff and increasing staff stability to facilitate better relationships between staff and residents. Donohue (2011, p. 3) also suggested that there is a perceived negative association between turnover of staff, lack of coordination and quality of care, as well as a cost impost of training new staff who do not stay in the industry and higher costs to employ temporary staff.

Edwards et al. (2003a, p. 40) found that reduced staff numbers meant staff were unable to respond in a timely manner to older people's requests and were not able to do 'special extras', which had a negative impact on the older people's QoL. It is clear that older people's living conditions and safety are enhanced with adequate numbers of suitably qualified staff and, according to Castle and Anderson (2011, p. 545), Harrington and Swan (2003, p. 366), Han et al. (2005, pp. 10–11) and Seblega et al. (2010, p. 340), improvements in remuneration, staffing levels, decreased turnover, reduced agency use and provision of adequate professional staff skill mix will improve quality of care and life for older people.

### ***2.5.3.5. Independence, autonomy and dignity***

Loss of independence, autonomy and dignity are familiar worries for older people in RACFs (Brownie & Horstmanshof, 2012, p. 780), where a loss of personal control can contribute to a less than enjoyable lived experience. Older people, according to Bowers et al. (2009, pp. 6, 21) still want to contribute to decisions that affect their daily lives. While care providers report that older people are involved in the decision-making process, these authors stress that the decision-making process is out of the control of older people, and their access to resources is restricted by professionals. An earlier Australian study into the older person's experience of nursing home life identified issues such as abandonment and loss of home, and loss of autonomy and privacy, as concerns facing older people who need residential care (Fiveash, 1998, p. 168). Entry into a nursing home, according to Perron (2008, p. 15), can result in fewer personal freedoms, not being able to take their own medications and having little choice and control. Older people may have neither participated nor been engaged in the decision to move, effectively removing control over the transition (Johnson, Popejoy & Radina, 2010, p. 361; Shield, Wetle, Teno, Miller and Welch (2010, p. 573). This results in a challenging position for the older person (Johnson, Popejoy & Radina, 2010, p. 362), limiting the success of admission and adjustment to care home life (Andersson, Pettersson & Sidenvall, 2007, p. 1,713). However, research by Popejoy (2008, p. 326), identified benefits of aged care facility admission, such as acknowledging the safety issues of remaining at home, when the older person has participated in the decision and has recognised the increased risk of living at home and realised the change to an aged care facility would provide a safer environment. Australian research by Nay (1995, p. 139), Pearson, Nay and Taylor (2004, p. 86) and Haesler, Bauer and Nay (2006, p. 228) into relatives' experience of aged care facility relocation and admissions found that families experienced difficulties in finding a suitable facility, were disheartened by the admission processes, and suffered a broad range of emotional responses including guilt, distress and relief.

Recreational therapy can have a major positive impact on the lives of older adults in aged care facilities, and is representative of older people's independence. Australian

research by Edwards et al. (2003a, p. 40) found that activities, both individual and as a part of a set programme, were important in older people's QoL. However, these activities needed to be understood by the older people to contribute to their enjoyment and needed to suit to older people's preferences to be valued.

Choice and control over daily activities and maintenance of dignity affects the everyday lives of aged care facility older people. Researchers such as Edwards et al. (2003b, p. 34) and Kane et al. (2005, p. 2,076) have stressed the significance of preserving resident choice, autonomy, control and efficacy; as well treating older people politely and with respect, gentle provision of care, respecting modesty and staff taking time to listen as important elements of dignity and QoL. Robison et al. (2011, p. 279) add that some older people shared rooms and bathrooms with others, which had a significant impact on their dignity and contributed to a sense of reduced autonomy because older people could not go to bed when desired or get up out of bed when ready as shared spaces required compromise. This author also found other aspects of aged care facility life that affected older people's perceptions of autonomy, such as decisions over what clothes to wear and being successful in making changes in aspects of aged care facility life that they do not like (Robison et al., 2011, p. 283).

It is also important to consider that aged care facilities deal with the dying and death every day and, as such, according to Osterlind, Hansebo, Andersson, Ternstedt and Hellström (2011, pp. 540–541), in their review of Swedish nursing homes, the predominant theme in communication between staff and older people is about the factors surrounding death, although these authors found a general reluctance by staff to speak about death and dying with older people. Older people see others dying with their privacy and dignity affected (MacKinley, 2012, p. 26). Jeong, Higgins and McMillan (2011b, p. 166) found that the issue of having the right to express wishes regarding end-of-life decisions was widely supported. However, there were barriers to older people's autonomy over this situation, such as in the case of cognitive impairment. This is supported by Tuckett (2007, pp. 130–133) and Gjerberg, Førde and Bjørndal (2011, p. 42), who found that older people considered facilities as a dormitory in which they waited to die and in which preferences for end-of-life care

were largely ignored. This suggests that dying older people may defer, voluntarily or involuntarily, to the demands of their families and health care providers, which may affect their sense of dignity and sacrifice their own personal autonomy.

There is limited contemporary Australian research into the lived experiences of older people in high care aged care facilities. Fiveash (1998, pp. 166–167) studied the articulate resident's experience of nursing home life, using an ethnographic method, and presented the findings as four themes: against my will, living in a public domain, cultural implications of living with others, and the impact of nursing home residency. Fiveash (1998) concluded that while some older people found the experience of living at a home acceptable, for others the experience was constraining and dehumanising. However, as this study was conducted more than a decade ago the results may not be relevant to the lives of current aged care facility older people. This research attempts to explore the dimensions of aged care facility life from the older persons' perspective. It aims to 'fill a gap' in research by exploring older people's experiences of life in high care aged care facilities in Australia. Using a phenomenological research strategy, the lived experiences of the participants will be investigated in depth. This allows that experience to be described by the older people as they live it and for me, as the researcher, to interpret the meaning of those experiences as they relate to those elements of RACF life that matter to older people.

This study will draw on phenomenology as a theoretical framework for exploring the participants' experiences and the construct of QoL. The next section presents and justifies the use of the theory of phenomenology as the theoretical framework used in this study.

## **2.6. Phenomenology as a philosophical framework**

### **2.6.1. Introduction**

The purpose of this section is to provide a summary of how the research paradigm phenomenology is used as a theoretical framework for this study to understand lived

experience. As such, this section will give the context regarding how this study is underpinned by phenomenological theory. Interpretative phenomenology, informed by Heideggerian theory, and the methods espoused by van Manen, is used as the methodology for this study and described in detail in Chapter Three: Methodology. Understanding a research methodology must be differentiated from understanding the philosophy from which the method arose. The importance of distinguishing between phenomenology as a philosophical movement and as a research technique reinforces clarity in the study's aims and methods. Phenomenology, as advocated by Husserl, Heidegger and others, facilitates a research method, but it is not the same as adopting phenomenology as philosophical framework for the research.

The value and importance of understanding the theoretical and philosophical foundations of research is paramount in conducting any study (Snape & Spencer, 2003, p. 2), so that the researcher is able to select an appropriate methodology (Crotty, 1998, p. 34). Methodology is, in essence, the theoretical assumptions underlying the methods used to understand the nature of knowledge (Cheal, 2010, p. 4; Meleis, 2012, p. 65), where researcher biases are understood and exposed (Flowers 2009, p. 1). The methodological and interpretative assumptions that influence research have been referred to as the 'analytic lens', and are embedded in the underlying assumptions about the nature of knowledge (epistemology) and the nature of reality (ontology) (Caelli, Ray & Mill, 2003, pp. 1–3). Denzin and Lincoln (2011) have described the researchers' epistemological, ontological and methodological praxis as a 'paradigm' (Denzin & Lincoln, 2011a, p. 13) or set of guidelines that connect theoretical frameworks to strategies of enquiry and methods. It is these ontological and epistemological assumptions that underpin views and understandings about what human knowledge and reality is for the individual. Ontology and epistemology are always interchangeable and mutually reciprocal (McNiff, 2013, p. 25) as they identify how understanding of knowledge is constructed and interpreted. A more thorough discussion of ontology and epistemology is provided in the next chapter.

The main purpose of this study is to explore what it is like for older persons living in RACFs. As this study is based on meanings given to experiences by human beings, a constructionist approach is appropriate. The phenomenon of lived experiences in RACFs is deeply embedded in the human world and needs a theoretical framework to address it in context, to assist the researcher to uncover rich descriptions and elucidations, and meanings ascribed from the participants' point of view. The study is underpinned by a phenomenological stance where the older persons' experiences are taken as a true reflection of their lives in a RACF.

### **2.6.2. Conceptualising lived experience as a philosophy**

This study is a qualitative analysis that attempts to understand the insider perspective on 'lived experience' (Rosu & Millar, 2004, p. 1) in a RACF. This is based on the assumption that individuals are shaped by personal experience. Consistent with Gadamer's self-forgetfulness, 'being outside oneself and the possibility of being wholly with something else' (1960, p. 126), an intention of this study is to understand the older persons' narratives and to explore the meanings of experiences, as opposed to explaining behaviours.

There is an inherent difficulty in defining the term 'lived experience', as pointed out by Burch (1990). Translation and linguistics differ, as language is the primary means of communication. The initial consideration of the term has been the focus of writers through history, as it was early assigned meaning by Kant (1929) and further defined as:

full meaning of experience emerges from explicit retrospection where meaning is recovered and re-enacted, for example, in remembrance, narration, mediation, or more systematically, through phenomenological interpretation and 'inscription' (Burch, 1990, p. 133).

Schultz (1967) continues this consideration to include the experience as directly and uniquely one's own (Schultz, 1967, p. 70); thus, meaningfulness is the core of experience. Literature on this concept has been further developed (Husserl, 1970, p.

877; Heidegger, 1977, p. x) to include the historical, anthropological and natural dimensions of lived experience. As van Manen wrote:

phenomenology describes how one orientates to lived experience (van Manen, 1990, p. 4).

Lindseth and Norberg (2004, p. 145) suggest that this comprehensive understanding discloses new possibilities for being-in-the-world. It is this process that contributes to our understanding of lived experience in RACFs.

An etymological approach to understanding the meaning of phenomenology can be traced back to the Greek terms *phainómenon*, which, according to the *Oxford English Dictionary* means ‘that which appears’ and *lógos* ‘study’.

In its purest form, phenomenology is a philosophy dedicated to describing experiences as they present themselves to consciousness, without recourse to theory direction or assumptions (Dreyfus, 1996, p. 104). The root of phenomenology therefore means ‘to show itself’ (Dreyfus, 1996, p. 31).

Phenomenology has been conceptualised by many writers. In 1907, Husserl defined phenomenology as the critical part of philosophy that has to provide metaphysics with its proper foundations, and later postulated the aim of the philosophy as being to prepare humanity for a genuinely purely philosophical form of life where each human being obtains rule through reason (Kockelmans, 1994, p. 11). In Heidegger’s search for the meaning or sense of being in *Being and Time* he defines phenomenology as:

to let what shows itself to be seen from itself, just as it shows itself from itself (Heidegger, 1996, p. 30).

According to Heidegger, it is the philosophical framework that allows phenomena to be explored as the phenomena they are (Blattner, 1999, p. 8). Van Manen describes phenomenology as something that asks for the very nature of a phenomenon, for that what makes a ‘thing’ what it is (van Manen, 1990, p. 10).

Phenomenology ‘honours human experiences’ (Drew, 1993). As such, it is an ideal philosophical perspective for many kinds of health research. The goal of phenomenology is to study the meaning of phenomena in particular situations and to capture and describe the meanings from the perspective of those who have the experience. Merleau-Ponty (1962) refers to it as the study of essences, and ‘the spontaneous surge of the life-world’ through vocative dimensions and reduction.

As the main objective of this research is to explore the experiences of older persons living in RACFs, and the study does not aim to generate any new theory (as in grounded theory) or interpret a cultural group (as in ethnography), a phenomenological approach was considered appropriate, from both a philosophical and methodological standpoint. To further justify phenomenology as the chosen philosophical perspective, it is helpful to understand how the movement developed historically. The chapter continues this exploration of phenomenology by summarising the philosophical assumptions that underpin understandings of the phenomenological movement, a summary of the preparatory stage, German phase, French phase and the Dutch school of thought along with the main writers and change in assumptions to the various approaches.

### **2.6.3. Historical development of phenomenology as a philosophy**

#### ***2.6.3.1. Preparatory stage***

The preparatory stage started as early as the seventeenth century, when philosophy began to separate from theology and place itself in science, with Rene Descartes (1596–1650) trying to determine what could be known with certainty, viewing mind and matter as having separate properties that could be perceived apart from one another (Armitage, 1950, p. 1). Cartesian thought viewed the mind as being wholly separate from the corporeal body, with the only reliable truths to be found in the existence of a metaphysical mind (Taylor, 2003, p. 28). Since the time of Descartes and the Enlightenment, traditional scientific views of the world were accepted where knowledge could be determined by scientific observation and method.

Phenomenology began to appear in the philosophical writings of Immanuel Kant (1724–1804). His work *Critique of Pure Reason* explains his view of the world and how we come to know things about it. He distinguishes between noumenal reality (the world of things outside us, the world of things as they really are) and phenomenal reality (the world that we perceive and interpret). Science describes a systematic view of the phenomenal realm, but cannot deal with the noumenal world (Soccio, 2010, p. 323). Thus, the need to further phenomenology as a philosophy was created. Phenomenology became more prominent around 1807 when George Hegel (1770–1831) published *Phenomenology of the Spirit* as part of his philosophical stance (Mohammadi, 2008, p. 60). He viewed the study of phenomena as phenomenology, and focused on the many degrees of reality within various mental phenomena.

### ***2.6.3.2. German phase***

The continuance of the historical evolution of phenomenology is attributed to Edmund Husserl (1859–1938) who developed pure or transcendental phenomenology. Husserl established phenomenology with the intention of debating positivistic approaches that relied on a reductionist attitude to human inquiry, as he was more concerned with the notion of ‘getting back to things themselves’ to investigate how reality is available as a reflection of the human consciousness, that being the evidence of our lived experience (Jay, 2009, p. 94). This was later expanded into other divisions including the philosophies of his student Martin Heidegger (1889–1976), Hans Georg Gadamer (1900–1902), Paul Ricoeur (1913–2005) (hermeneutic phenomenology) and Max van Manen (1942–); Jean-Paul Satre (1905–1980) and Maurice Merleau-Ponty (1908–1961) (existential phenomenology); and experiential phenomenology or phenomenology of practice (Max van Manen 1942–). Embree (2001) summarises the growth and revision of the ‘agenda of issues and approaches’ (Embree, 2001, p. 4) in the history of phenomenology, while other writers (Giorgi, 1997; Koch, 1995; Streubert & Rinaldi Carpenter, 2007) have looked at the results of phenomenological work. To appreciate the relevance of van Manen’s phenomenological method used in this research (an interpretative stance), the differences between the Husserlian (transcendental) tradition that describes the lived

world from the viewpoint of the observer irrespective of the researcher's preconceptions, and the Heideggerian (existential) tradition involving the researchers' intrinsic involvement in the process, need to be explored.

The German phase of development included both Edmund Husserl (1859–1938) and Martin Heidegger (1889–1976). Husserl is known as the father of phenomenology by virtue of his book *The Idea of Phenomenology*, published in 1906. Husserl presented phenomenology as a philosophy and a psychology that did not separate mind from matter; rather it pointed to experience as one of transcendental subjectivity where the 'absoluteness of conscious existence' (McCall, 1975, p. 56) was possible. For Husserl, phenomenology was a rigorous human science as it investigated the way that knowledge came into being and clarified the assumptions upon which all human understandings are grounded (van Manen, 1990, p.184).

Husserl was concerned with the notions of intentionality, essence, life-world, and bracketing. Central to his philosophy is the notion of intentionality, which refers to the intentional structure of all consciousness as the only way in which one can access the world; that is intentionality correlates 'self' with 'world', where there is a unity of subject and object (Lavery, 2003, p. 23; Yegdich, 2000, p. 37). Husserl developed the notion of intentionality from his teacher Brentano Franz Brentano (1838–1917), who discussed the concept in his 1874 book *Psychology from an Empirical Standpoint*. Husserl viewed intentionality as based on the assumption that our own conscious awareness was intentional awareness, one thing of which we could be certain that would produce knowledge of reality (Koch, 1995, p. 828; Lavery, 2003, p. 23).

Husserl's philosophy sought to define the essence, a thorough and full understanding of the meaning of the objects of perceptions of a phenomenon, a descriptive analysis of the essence of pure consciousness (Lindlof & Taylor, 2011, p. 37; Zahavi, 2003, p. 51), as they are encountered in lived experience (van Manen, 1997, p. 10). Lived experience was the world perceived pre-reflectively rather than something that was categorised or conceptualised (van Manen, 1997, p. 9). Husserl saw the disclosure of a realm of being by penetrating deeper into reality, arising from experience, as a true

reflection of meaning where particular realities could be described (Laverty, 2003, p. 23).

Husserl saw the life-world as the unique world of being, which was typically experienced as timeless, objective and inevitable, and thus was the 'natural attitude' (Lindlof & Taylor, 2011, p. 37). Understanding of the world was constructed by human perceptions about surroundings, where we construct our own realities (Walliman, 2006, p. 24); the natural attitude was to describe the relationship of ordinary consciousness to ordinary experience. However, in trying to determine how the life-world acquired its natural quality, Husserl developed transcendental reduction (Moran, 2005, p. vii), which describes pure or transcendental phenomenology as an 'eidetic' (mental image) reduction, by means of which the phenomena are described (Giorgi, 1997, p. 237).

The tendency to consider philosophy and phenomena in the formal, cultural and naturalistic sciences was a theme central to Husserl's transcendental phenomenological approach. This method allowed 'bracketing' or suspending the natural attitude, which negated the need to include the personal interpretations or standing of the researcher (Lowes & Prowse, 2001, p. 473), so that the phenomenon could be interpreted in its own right: to achieve contact with the essences (Laverty, 2003, p. 23). Bracketing allows conceptualisation of things themselves preceding any notions of a peripheral reality, and consequently allows our experience as a whole to reveal the life-world (Yegdich, 2000, p. 37).

The basis is therefore epistemological and explores the nature of knowledge and how we know what we know, acknowledging an empirical reality. It embraces a positivist epistemology, one that is value-free and recognises that the world is objective and knowable. This method requires bracketing to identify the essences or structures that constitute consciousness and lived experiences (Earle, 2010, p. 288). This approach is not appropriate to this research as this study does not attempt to bracket or reject the researcher's influences.

Heidegger's early work, *Being and Time* (1927) was ideologically at odds with Husserl's idea of transcendental phenomenology, especially with the concept of phenomenological reduction. Husserl had spoken of a '*Lebenswelt*' (life-world) to emphasise the human encapsulation within reality, a focus on understanding beings or phenomena (Lavery, 2003, p. 24). Heidegger experienced a change in focus from an epistemological based approach, to one of trying to appreciate being a person positioned in the world, incorporating an ontological premise. However, Heidegger stressed the importance of making sense of the issue of being, the human being, referred to as '*Dasein*', which literally means 'being there' (Nancy, 2008, p. 14), 'the mode of being human' or 'the situated meaning of a human in the world' (Lavery, 2003, p. 24). Heidegger (1927/1996) saw that clarity could be found through *daesein* 'being there' and this was through:

Regarding, understanding and grasping, choosing and gaining access to, are constitutive attitudes of inquiry... Thus to work out a question of being means to make a being... This being which we ourselves in each case are and which includes inquiry among the possibilities of its being we formulate terminology as Da-Sein (Heidegger 1927/1996, p. 6).

Heidegger's method of phenomenological enquiry was underpinned by the assumption that an analysis of the self could not disassociate itself from the self; where a human being cannot be taken into account except as being an existent in the middle of a world among other things (Warnock, 1970). Heidegger postulated that the world 'is', and that this fact is naturally the primordial phenomenon and the basis of all ontological inquiry; such that the world is here, now and everywhere around us. The ontological structure of the 'world' and its 'in-the-world-ness', is reflected in the everyday lived experience that reflects the wholeness of being (Hornsby, 2008), contrary to Husserl's epistemological stance, focusing on understanding beings or phenomena. Central to the philosophy is a rejection of intentionality in support of an existential phenomenological understanding of *Dasein* (Earle, 2010, p. 288).

Fundamental to appreciating Heideggerian phenomenology and hermeneutics are the notions of background, pre-understanding co-constitution and interpretation (Koch, 1995, p. 831). Background is what culture gives a person from birth and presents a

way of understanding the world; what is real to a person (Koch, 1995, p. 831). This is presented in consciousness, and is a construction of historically lived experience, one's background or situatedness. Polkinghorne (1983, p. 225) suggests that consciousness is located within our historicity, and determines our ways of seeing, attitudes and concepts, already embedded within our culture and language. Therefore, knowledge cannot exist outside the conditions of our nature as historical beings. However, according to Heidegger, that background cannot be made entirely explicit, as the background can only exist when one is not paying attention to it (Dreyfus, 2012, p. 4).

Pre-understanding, for Heidegger (1927/1996, p.141), relates to the notion that every interpretation of something *as something* is essentially grounded in fore-conception, where everything encountered must have a reference to a person's background understanding (Lavery, 2003, p. 24). This translates as a structure for being-in-the-world, as the pre-understandings of cultural meanings, within which we are constructed. According to Koch (1995, p. 831), this is not something that can be bracketed, as it is already with us in the world. This is consistent with the assumption underpinning existential phenomenology of co-constitution, which holds that people and objects all are mutually constituted by the other, and people shape their realities and these realities simultaneously shape the people (Rodgers, 2005, p. 78).

Therefore, it follows that interpretation is influenced by a person's background, pre-understanding and co-constitution. Through acts of interpretation, the world operates at a cultural level, and due to our historicity, we are able to understand. According to Polkinghorne (1983, p. 50), knowledge gained through understanding (*verstehen*) cannot be objective and is subject to the investigator's own bias or interpretative influences. The hermeneutic circle reintroduced by Heidegger allows for the reciprocal activity between pre-understanding and understanding (Earle, 2010, p. 288). Kvale (1996, pp. 46, 34) saw the purpose of hermeneutical interpretation as a way to uncover a valid and common understanding of text. He saw the research interview as a means of conversing about lived experience with the participant, and again with the text, to interpret intended or expressed meanings. The interpreter

understands parts of the text in relation to the whole, and the whole of the text in relation to its parts, allowing understanding to be enlarged and deepened (Geanellos, 2000, p. 112).

The notion of temporality traditionally refers to the linear progression of past, present and future. For Heidegger, understanding the horizon of all possibilities of experience, incorporating past, present and future, is the basic existential meaning of existence:

The unity of the horizontal schemata of the future, having-been, and present is grounded in the ecstatic unit of temporality (Heidegger, 1927/1996, p. 334).

This is particularly relevant for this study as temporality illustrates being in time as something that reflects our own personal and historical context, and how this assists in understanding human existence in everyday life.

Hans George Gadamer (1900–2001) aligned his philosophy with Heidegger in his book *Truth and Method* (1960/2004), where he asserts that the goal of objectivity is unattainable, and rejects the notions of reduction and bracketing. Instead, meaning is achieved through our own prejudice whereby pre-judgement or pre-understanding, relates to one's own preconceptions, is part of our linguistic experience and is the means by which the truth of a phenomenon is established (Earle, 2010, p. 288; Maggs-Rapport, 2001, p. 377). Gadamer (1960/2004, p. 38) himself sees, in the untiring power of experience that humans continuously form, new pre-understandings. Ray (1994, pp. 124–125) suggests that the connection of common human consciousness between persons, through everyday language use and persons who understand, illustrates universality, a key concept in Gadamer's philosophy of being, similar to Heidegger. Language is a universal medium in which understanding occurs, and it is through interpretation that understanding is achieved. The notion of the fusion of horizons (Gadamer, 1960/2004, p. 360) for Gadamer, refers to interpretation resulting in a present understanding or horizon being moved to a new

understanding or horizon by an encounter, thus combining into something of living value (Clark, 2008, p. 59).

Gadamer believed that understanding and interpretation are bound together and interpretation is always an evolving process. Thus, a definitive interpretation is unlikely (Annells, 1996). The fusion of horizons is continuously dynamic, as we need to test, expand or reject prejudices. This interpretation is known as the hermeneutic circle; moving from the whole of the subject to the parts in particular and back again in relation to the whole, as Annells (1996, p. 708) suggests, uncovering lived experience of an inner relationship to life. According to Gadamer, the philosophical method of hermeneutics:

is not to develop a procedure for understanding, but to clarify the conditions in which understanding takes place. But these conditions do not amount to a 'procedure' which the interpreter must of himself bring to bear on the text; rather they must be given (1960/2004, p. 295).

Therefore, prejudices cannot be rejected and must occupy the process of understanding, as these are based on our history of understanding. The philosophical ideas underpinning hermeneutics form part of this research, as the investigation into the phenomena of lived experience of the participants in RACFs has moved between understanding the experience of life in a RACF to the experience of the individual older person, and developing the interpretation of the experience as a whole by examining the common experiences of individual older persons. It is through the methods of van Manen (1990, 1997), underpinned by existential phenomenology, that these experiences can be understood.

### ***2.6.3.3. French phase***

The third phase of the phenomenological movement began in France with Gabriel Marcel (1889–1973), Jean-Paul Sartre (1905–1980) and Maurice Merleau-Ponty (1908–1961) (Dowling, 2007, pp. 132–133). For Merleau-Ponty and Marcel, phenomenology was a way through which to understand human reality in a

metaphysical sense; and for Sartre through art and literature (Jones, 2001, p. 368). Embodiment and being-in-the-world were key concepts of this phase. According to Csordas (1994), embodiment is situated at the level of lived experience and not dialogue, as it is about understanding in a pre-reflexive world forming part of our being-in-the-world.

Merleau-Ponty's *Phenomenology of Perception* (1945/1962) was developed through the influences of Husserl and Heidegger (Dreyfus, 1996). He believed that human beings are situated in the world, to the extent to which human subjectivity is essentially an embodied phenomenon (Spurling, 1977, p. 10). This embodies existential phenomenology, as his ideas were based on the concept that people are situated in a world existing before any reflection, where there is a dialectical relationship between people with the world (Earle, 2010, p. 289). Merleau-Ponty saw the life-world as critical to perception. He considered that different individuals inhabit different life-worlds at different times (Sadala & Adorno, 2002, p. 287). He saw the necessity of describing phenomena as precisely and completely as possible, where objectivity (lived experience) is reached, reflecting a direct and primitive contact with the world (Kvale, 1996, p. 53; Merleau-Ponty, 1945/1962, p. vii). The emphasis on description, rather than interpretation, is different to that espoused by Husserl, as Merleau-Ponty rejected positivism and acknowledged the impracticality of a complete reduction (Merleau-Ponty, 1945/1962, p. xiv; Earle, 2010, p. 289).

Merleau-Ponty contended that by using a phenomenological approach to examine perception, researchers could gain a greater understanding of the essences of the lived embodied experience, not only the sense experience (Priest, 2002, p. 101). He believed that 'consciousness is in dialogue with the world' (Spurling, 1977, p. 10).

#### ***2.6.3.4. Dutch School: Van Manen's philosophical interpretation***

Another school of phenomenological thought is referred to as the Dutch or Utrecht school, and its approach combines the characteristics of descriptive and interpretive phenomenology. Its application to social science has been promoted by van Manen

(1984) and focuses more on the general insight that phenomenology research offers, as opposed to the more structured methods of Husserlian phenomenology, as practised by Colaizzi (1978) (Holloway & Wheeler, 2010, p. 224).

Van Manen (1997, p. 25) identifies the distinction between the two main schools of phenomenology by identifying phenomenology as pure description of lived experience, while hermeneutics is an interpretation of experience through some text of symbolic form. Earle (2010, p. 289) points out that van Manen uses the term 'description' to refer to both descriptive and interpretive components. Van Manen offers more specific methodological guidelines and his particular approach is more action sensitive, while appreciating the foundations of the philosophical methodology of phenomenology. These are more fully discussed in Chapter Three as they apply to this study.

#### **2.6.4. Summary of application of theoretical framework**

The phenomenologies of Husserl, Merleau-Ponty and Heidegger were written as philosophy and were not originally intended for applied research. Phenomenology as a philosophical framework is concerned with how we can get to know the world and gain knowledge from its operation, and more specifically, what information will answer questions to understand a particular phenomenon (Robson, 2002, p. 195). Phenomenology strives to understand and illuminate a human experience (or phenomenon) as it is encountered and explain the meaning embedded within lived experiences. The emphasis in phenomenology is at all times the human life-world, and describing and interpreting how a phenomenon is experienced pre-reflectively rather than theoretically. As with phenomenological research, the aim is to explore the subjective meanings associated with the experience and this is particularly relevant for nursing and social science research (Lopez & Willis, 2004, p. 726). The aim of phenomenological studies is interpretive enquiry; it focuses on participant accounts of subjective lived experience (Reeves, Albert, Kuper & Hodges, 2008, p. 631).

This study has used phenomenology as both a philosophical framework and methodology to understand the lived experiences of the participants. This has implications for the approach to ontology and epistemology, discussed in the next chapter. This study draws on phenomenological approaches espoused by van Manen (1990) to investigate the lived experience of older people, to seek a deeper understanding of how the participants experience their lives in aged care facilities. This type of study attempts to illustrate phenomena engaging directly with the consciousness, without reference to its psychological origin or its causal explanation, therefore examining a phenomenon of the consciousness in its own element of awareness (Crowell, 2002). It is through retrieving lived experience that investigators may achieve understanding of meanings and perceptions of another person's world. As such, this approach constitutes the foundation of an interpretative or Heideggerian hermeneutic phenomenological methodology.

According to Steeves (2006, pp. viii, ix), Husserl (1970) emphasised 'returning to the things themselves', referring to the meaningful ways in which things are experienced, made sense of and enacted in everyday life. A thing in the phenomenological sense does not exist primarily in itself, but rather in the meaning that individuals attach to it, such as those experiences of older persons as they see them (Neergaard & Ulhøi, 2007, p. 76). Its aim is to consider and illuminate a phenomenon and describe the life-world or '*lebenswelt*' (Holloway & Wheeler, 2010, p. 3). However, this approach concentrates on the notion that people are only people because of their actions experienced in the world, and ignores the reciprocal relationship that phenomenology insists upon: that human's actions define the context within which they find themselves. In turn, the world context defines human actions (Stewart & Mickunas, 1990, p. 36).

This research adopts the perspective that constructivist/interpretive approaches are underpinned by the assumption that knowledge is constructed out of human engagement with objects already in the world, where true lived experiences are presented. This philosophical stance, unlike that espoused by Husserl, focuses on the external structures of perception rather than individual consciousness, thus

reaffirming the reality of the world external to consciousness; it is existential and orientated to lived experience. It is important to re-iterate that existential phenomenology was stimulated by Heidegger's work *Being and Time* (1927), claiming the importance of 'being', or *Sein*, based on the premise that people are not separate from the world but are experienced as 'being-in-the-world' (Spinelli, 1989). This study incorporates the understanding of being an older person in a RACF, and refers to the issue of temporality. How older people interpret their past, present and future in relation to their daily lives in RACFs is of interest and can be understood within this philosophical framework.

The implications of adopting phenomenology as a philosophical framework include the need to expose the biographical, social and historical positions of the researcher. These must be taken into account in interpretative phenomenology, as there can be no understanding without prior knowledge (Fleming, Gaidys & Robb, 2003, p. 116). In this study, my biases and assumptions are not set aside, but are embedded within the interpretative process. Accordingly, I discussed my motivations and the assumptions that drove this research in Chapter One. Specifically, my own biases and opinions are not bracketed or set aside, but are embedded in the interpretative process of reflection between the research and the researcher.

It is not an objective of this research to prove whether a certain experience actually happened in the way it was described, but to investigate whether a lived experience was meaningful in the respect that it was true to the older person as it was lived. It is the older people's perceptions, illuminated in narratives, which elucidate meaning, and provide a true reflection of lived experience. Consistent with the above discussion, assumptions, underwritten by phenomenological perspectives, give a consistent foundation for this study (Cohen, Manion & Morrison, 2000, pp. 17, 22):

The aim is to construct an animating, evocative description (text) to human actions, behaviours, intentions, and experiences as we meet them in the life-world. (van Manen, 2002, p. 19).

The interpretive paradigm used in this study employs methods grounded in those espoused by van Manen, underpinned by existential phenomenological foundations.

## **2.7. Conclusion**

This chapter has provided a comprehensive review of the available literature regarding aged care policy and funding, along with the perspectives of ageing, models of care and QoL issues as perceived by older people themselves. Both international and Australian literature has been discussed as there is a lack of available Australian literature. The elements of aged care facility life have been systematically discussed in relation to the system within which they are regulated and controlled.

The chapter also presented phenomenology as the theoretical framework underpinning this qualitative study. This research attempts an interpretive assessment of the perceptions of older peoples' lived experience, and as such, a philosophical framework that allowed the essence of experience to be revealed was required. The history of the phenomenological movement, along with a summary of its applicability to this study has been presented.

The next chapter discusses the methodology used in the study, which is van Manen's approach to uncover experience, as underpinned by phenomenology, and why it was chosen as the method to explore the lived experiences of older people.

## **Chapter 3: Methodology**

### **3.1. Introduction**

This chapter describes and justifies the research design chosen for this study as it is consistent with the phenomenological philosophical position underpinning this study. The methodology supports the main aim of the study, which is to explore the lived experiences of older people residing in high care facilities. This chapter also describes ontology and epistemology as the building blocks of understanding the nature of reality and knowledge for this study, the methods used, consistent with a phenomenological foundation and the approach developed by van Manen (1984, 1990). Details are provided regarding the location and setting for the study, data collection and data analysis procedures. Ethical considerations are then discussed as are issues of rigour and trustworthiness. Finally, the methodological limitations are discussed.

### **3.2. Research paradigm and method**

The importance of understanding the theoretical and philosophical foundations of research is paramount in conducting any study (Snape & Spencer, 2003, p. 2), so that the researcher is able to select an appropriate methodology (Crotty, 1998, p. 34). In essence, methodology is the theoretical assumptions underlying knowledge generation (Meleis, 2012, p. 65). In turn, theory organises concepts and understanding in a systematic way. Thus, theory evolves, improves, modifies and yields to provide a better explanatory framework to a research study:

A research design describes a flexible set of guidelines that connect theoretical paradigms first to strategies of enquiry and second to methods for collecting empirical material (Denzin & Lincoln, 2003, p. 36).

Ontology is the study of existence itself, a way of understanding ‘what is’ (Crotty, 1998, p. 10), and its basic assumptions concern the form and nature of reality (Guba & Lincoln, 1989), and whether reality exists independently of human perception or

requires a social construction perspective (Crotty, 1998, p. 24). Ontological views shape epistemology. Epistemology concerns the study of knowledge, the conceptualisation of the approach to the issue or problem, how it is judged to be true, and the most appropriate ways of enquiring into the nature of the world (Bryman, 2012, pp. 11–12; Easterby-Smith, Thorpe & Jackson, 2008, p. 58). Our epistemological beliefs are concerned with the relationship between the knower and what can be known (Lincoln & Guba, 1985), and this informs how we view the world and our understanding and the purpose of understanding.

Epistemological theory of knowledge can be interpreted within, but not limited to, two main paradigms, positivist/objectivist or constructivist/interpretive. The epistemological choice that underpins this study needs to be presented to justify the methodological choices made to conduct this study. An ontological position of a positivist paradigm was considered inappropriate for this study; it argues that the world is objective and knowable through observation and measurement and it assumes a realist reality, where reality exists as external to the researcher, undistorted by the observer's expectations (Giacomini, 2010, p. 131). Reality is considered as static and observable, existing externally to the individual (Guba, 1990, pp. 23–24). Epistemological assumptions ascribing to the positivist paradigm assume non-interactive observation, with the values or biases of the researcher being independent of outcomes (Stahl, 2007, p. 143), with quantitative, hypothesis based research and theory testing (Gerber & Moyle, 2004, pp. 34, 36). Scientific methods are not adopted in this research, as this approach was considered inappropriate to achieve the study aims, of understanding lived experience as it is seen from the participants' views. This type of method is less useful for human research as it assumes that reality exists independent of human conceptualisation (Bryman, 2012, pp. 16, 507). It is important to note that this qualitative study draws on phenomenological principles within an interpretative paradigm.

The appropriate epistemological approach for this study is understood from an interpretive paradigm, where reality and knowledge are considered subjective and are created through constructionism as people relate to each other and form reconstructed

understandings of the social world through symbolic interaction (Guba, 1990, p. 26; Gerber & Moyle, 2004, pp. 34, 36; Lincoln, Lynham & Guba, 2011, p. 92). A constructivist methodology is inter-subjective: dialectic conversations are produced and analysed, and distinctions are found (Pernecky & Jamal, 2010, p. 1,065). As such, a relativist approach is chosen where relativist realities exist in the form of multiple realities (Annells, 1996, p. 380; Denzin & Lincoln, 2011a, p. 13). This paradigm is clearly appropriate for this study as it is concerned with understanding social conditions through the meanings individuals ascribe to their personal experiences (Krysik & Finn, 2013, p. 15). As such, this research assumes there may be several versions of the truth. The version adopted by the researcher will depend on the researcher's own reflections, and this reality should be exposed in research. This reflexive stance is shaped by the researcher's background and experiences, and consequently mediates interpretation of reality (Russell & Kelly, 2002). As researcher, I recognise that my background has shaped the personal lens inherent in this research. As such, I may hold value-laden ideas and occupy a subjective orientation to the phenomenon being researched that may influence the research process. Therefore, I have reflected on my motivations, context and biases in Chapter One, to inform the reader and to make my role in this research more transparent. The epistemological approach adopted in this study therefore accepts a relative ontology, acknowledging the subjectivist position of the researcher in a qualitative enquiry.

### **3.3. Justification for the use of phenomenology as a methodology**

While phenomenological inquiry cannot be formalised into a series of rigid technical procedures, a variety of activities can be identified that contribute to it (van Manen, 2002). The framework used in this research process is based on van Manen's framework (1984, 1990 & 1997) for a research process. It reflects the philosophical assumptions of phenomenology, aiming to uncover meaning from the life-world and the essence of human experience to understand its meaning and nature, rather than merely seeking empirical explanations:

It requires that we be attentive to other voices, to subtle significations in the way that things and others speak to us. In part, this is achieved through contact with the words of others (van Manen, 2006, p. 713).

Van Manen (1984) proposes five characteristics of phenomenological research that are directly relevant to this study as they relate to the aim of investigating lived experience. He identifies it first as the study of lived experience, or the life-world (van Manen, 1990, p. 9), where perceptions of lived experience are captured in language (van Manen, 1990, p. 181). In this way, it is possible to uncover human existence as human beings experience it, describing a phenomenon as it is experienced, not as it is theorised or conceptually processed.

Phenomenological research is the study of essences (van Manen, 1984, p. 38; 1990, p. 10), where the researcher seeks to identify the very nature of a phenomenon, or what makes a 'thing'. It also identifies a 'thing' as something without which it could not be what it is. This true essence is uncovered in writing. The essence of the phenomenon is presented when awareness results from reading the phenomenological writing.

The third characteristic is 'the attentive practice of thoughtfulness' (van Manen, 1984, p. 38; 1990, p. 12). All aspects of the phenomena are considered with inquisitiveness, sensitivity and persistence, regardless of their perceived significance: it is in the everydayness of the phenomenon that the essence will be discovered.

The fourth characteristic of phenomenological research is 'a search for what it means to be human' (van Manen, 1984, p. 38; 1990, p. 12). Deeper understanding of the richness of human nature is gained through phenomenological research. A greater awareness of the intricate nature of a human person allows us to become more fully aware of whom we are.

Finally, van Manen (1990, p. 13) likens phenomenological research to poetising, where researchers attempt to speak in a more primal sense, rather than using abstract words to describe experience. In this way, the essence of an experience can be uncovered through language that 'speaks the world'.

### 3.4. Use of van Manen's approach to data collection and analysis

#### 3.4.1. Introducing van Manen's six methodological themes

Van Manen (1997, pp. 29, 27) stated that a method is a set of investigative procedures, while methodology is understood to be the philosophical framework with assumptions and a human science perspective. However, van Manen was clear that the practice of phenomenology should not be governed by a set of predetermined fixed procedures. Instead, he advocated themes that would guide researchers into the phenomenological worldview. These themes are underpinned by the philosophical tradition of phenomenology. They are not intended to be followed in any linear form, but rather used as activities that could be undertaken contemporaneously. This research process is based on van Manen's framework for a research process, reflecting the core philosophical assumptions of phenomenology, such as it aims to uncover meaning from the life-world. It does not require bracketing of the researcher's pre-understanding and assumptions.

Four procedural activities, with 11 specific actions (shown in italics), originally proposed by van Manen in 1984, were refined into six methodological themes as outlined below (van Manen, 1990, pp. 30–31). These latter themes are discussed in the first part of this chapter:

1. Turning to a phenomenon that seriously interests us and commits us to the world (*turning to the nature of lived experience*).

*Associated activities: (i) orientating to the phenomenon; (ii) formulating the phenomenological question; and (iii) explicating assumptions and pre-understandings.*

2. Investigating experience as we live it rather than as we conceptualise it (*existential investigation*).

*Associated activities: (iv) exploring the phenomenon: generating data; and (v) consulting phenomenological literature.*

3. Reflecting on the essential themes that characterise the phenomenon (*phenomenological reflection*).

*Associated activities: (vi) conducting thematical analysis; and (vii) determining essential themes.*

4. Describing the phenomenon through the art of writing and rewriting (*phenomenological writing*).

*Associated activities: (viii) attending to the speaking of language; (ix) verifying the examples; (x) writing; and (xi) rewriting.*

5. Maintaining a strong and orientated pedagogical relation of the phenomenon.

6. Balancing the research context by considering the parts and whole (adapted from van Manen, 1984; 1990).

In summary, using this process of turning to the nature of the lived experience of older people residing in RACFs, the existential investigation and phenomenological reflection are explained. Further, the value of focusing on phenomenological writing is presented in this study. The importance of the relationships with the phenomenon and balancing the research context are discussed. This will ultimately achieve the aim of phenomenological research, which is to transform peoples' lived experience into animated, evocative description, through text, of human actions, behaviours, intentions and experiences as they happen in the lived world (Ajjawi & Higgs, 2007, p. 662). This is consistent with van Manen's approach to thematic analysis. The following section will describe how this research addressed each theme, with a discussion of how these relate to the methods used in this study (these are discussed later).

#### ***3.4.1.1. Turning to the phenomenon that seriously interests us***

The first activity is turning to a phenomenon that seriously interests us and commits us to the world ('turning to the nature of lived experience'). The phenomenon of interest was the lives of older people who resided in RACFs. This was a human experience, which raised many questions and ambiguities, and presented a phenomenon holding great interest. I sought to investigate the lived experience of these older people in depth, to find the essence of the phenomenon from their

perspectives. The study did not emerge in an ethereal way: rather, it evolved because of my being aware and involved in the care of older people:

It is always a project of someone: a real person, who, in the context of a particular individual, social and historical life circumstances, sets out to make sense of a certain aspect of human existence (van Manen, 1990, p. 31).

While bracketing the researcher's assumptions, motivations and beliefs was advocated by an earlier phenomenologist, Husserl (Husserl, 1962; Koch, 1995, p. 823; Schultz, 1970), in this study I thought that consideration of my pre-existing knowledge and assumptions was required to more fully understand the phenomenon. These have been discussed in Chapter One.

The research question orientated itself towards investigating the lived experiences of older people in high care facilities. It was in this way that I hoped to explore deeper issues of life for older people living in RACFs. The question clearly had a phenomenological basis as it sought to understand human phenomena. As such, the question was continuously revisited to ensure that the method of investigation remained relevant.

#### ***3.4.1.2. Investigating experience as we live it***

The second activity is investigating experience as we live it, rather than as we conceptualise it ('existential investigation'). The issue of lived experience requires the researcher to be immersed in the concept as well as gaining meaning from it, while acknowledging a new way of looking at the world. An initial starting point is to describe the experience as lived without offering—as van Manen suggests (1990, pp. 54, 66–67)—causal explanations, interpretative generalisations or 'flowery terminology'. van Manen (1990, pp.17, 65) saw the danger in less talented persons may use flowery or self-indulgent discourse at the expense of reflecting on the living essence of an experience. In reflecting on one's own experiences, the understanding of the data can be enriched through more informed conceptualisation of the phenomenon.

This included etymological research into words such as ‘live’, ‘life’, ‘old’, ‘elderly’ and ‘being’. This process provided an appreciation of words as the building blocks of language, and their historical meanings prior to assimilation into everyday use. Idiomatic phrases too, according to van Manen (1990, pp. 60, 62), result largely as from lived experience and are a finite source for phenomenological investigation. It was worthwhile to remind myself that some commonly heard terms may hold relevance to conceptualising older people and their life: ‘older than the hills’, ‘old hat’, ‘life is too short’, ‘live out one’s life’, ‘have one’s foot in the grave’ and ‘God’s waiting room’. Some of these rather negative phrases may reflect a belief that older people are no longer valuable or useful to society.

In this research, exploring the lives of older people in RACFs through interviews provided a way to gain insights into how the people ‘lived’ (Earle, 2010, p. 290). In this study, participants were asked how they viewed their lives and their experiences relating to everyday life. Open-ended interview questions started from a general perspective, and as the interviews developed into conversation, fuller, richer issues came to light, reflections of meaning and of those matters that were important to the individual participant. This enabled me to become more fully informed, through ‘re-living’ facility life as described by the participants. Observing and talking to the participants about their lives within the RACF enabled a clearer understanding of their situatedness:

We gather other people’s experiences because it allows us to become more experienced ourselves (van Manen, 1990, p. 62).

#### ***3.4.1.3. Reflecting on the essential themes***

The third activity is reflecting on the essential themes that characterise the phenomenon (‘Phenomenological Reflection’). To interpret the essence of the resident’s experience, it is necessary to reflect on what life is like for them. A true reflection is:

A thoughtful reflective grasping of what it is that renders this or that particular experience its special significance (van Manen, 1990, p. 32)

Reflection is critical to expressing the real essence of the phenomena and is demonstrated through thorough and meticulous consideration of the data. The emergent themes determine the core components of which the experience is composed. The process of phenomenological research involves, according to van Manen (1990, p. 32), reflectively bringing to attention what is likely to be obscure and provides a structure from which to begin to re-examine and interpret the text.

Van Manen (1990, p. 30) points out that the difference between incidental and essential themes when interpreting text is that incidental themes are influenced by historical events or culture, and essential themes belong to the phenomenon in such a way that without these essential themes the phenomenon would not be what it is. A challenging aspect of human research is to decide whether a theme is essential and, if removed, whether the meaning of the phenomenon would be lost or changed (Earle, 2010, p. 290).

In this study the words, statement and phrases have been selected according to these activities and this necessitated reading and re-reading, and repeatedly listening to the taped interviews. Once the themes were identified specific phrases were chosen to illustrate the themes, and these are presented in Chapter Four.

#### ***3.4.1.4. Describing the phenomenon***

The third activity is describing the phenomenon through the art of writing and rewriting ('Phenomenological writing'). The activities identified by van Manen (1984) for phenomenological writing include attending to the speaking of the language, verifying the example, writing and rewriting. In phenomenological research he talks of 'bringing to speech' an awareness of the meanings of lived experience (van Manen, 1984, p. 36); this is done through thoughtful description. In writing and rewriting, the specific undertones of the language, and therefore meaning, can be exposed. It is through the writing that sense is made of the essential structure of the phenomenon. Van Manen (1997, p. 64) suggests that writing forces an individual into

a reflective attitude. Responsive reflective writing, according to van Manen (1997, p. 132), is the very act of doing phenomenology.

In this research I not only conducted all interviews, I transcribed the interviews verbatim and, as such, had already, by this very act, begun to reflect on the meaning of the participants' words. The transcription of the interviews allowed me to immerse myself in the lives of the participants, as their feelings and emotions were transcribed. I found that this writing and rewriting tended to focus reflective awareness while simultaneously drawing attention away from my own contextual background and biases.

#### ***3.4.1.5. Maintaining a strong relation to the phenomenon***

The fourth activity is maintaining a strong and orientated pedagogical relation to the phenomenon. In any research process, it is plausible for researchers to become disenchanted with the research process. Van Manen (1990, pp. 151–152) emphasised the focus of writing and research must be continuous, to produce a strong text; one that is 'concrete' and aims for the strongest pedagogic interpretation ('pedagogic' meaning that which is inherent in the human experience of teaching). A strong interpretation is made possible by the researcher's awareness of the lived experience, and this culminates in a text which is deep and exposes meaning.

In this research, I have been careful to remain cognisant of maintaining a strong commitment to the question of the lived experiences of the participants, and, as such, have not deviated from this objective. It was helpful in acknowledging this theme, to record journal notes of any preconceived notions I held about the perceptions of the participants. This is consistent with the process of the decision trail (Koch, 1994) establishing rigour in any research process. In accordance with that objective, my aim was to produce rich data that reflected the lived experience of my participants as told to me, with my own knowledge assisting in informing the interpretation process.

#### ***3.4.1.6. Balancing the research context***

The fifth activity is balancing the research context by considering the parts and whole. The reflection on essential themes tests our direction of the research process. A clear research plan is important; however, van Manen suggests that the research study process formulates the details as it proceeds. This was demonstrated in this study by the back and forth movement between the researcher and the text, akin to the philosophical stance of the fusion of horizons (Clark, 2008, p. 59; van Manen, 1990), or consultation of horizons where some horizons change or become more informed. The participant's narratives evoke concepts and themes, and these are analysed and reviewed in relation to the whole phenomena.

In this research, the individual participant's experiences of facility life are dynamic and interrelated phenomenon. Annells (1996) suggests that the researcher constantly scrutinises the phenomenon by moving between the parts of it and the whole picture. For example, in this research, I used a circular process that required interpretation between seemingly meaningful words and phrases, and delving more deeply to understand the meaning underlying these concepts more fully. The words and concepts emerge from the text, and they are then reviewed as part of the whole phenomenon. The study had to be grounded in a deep examination of the question, with individual interpretations of perspectives in light of the experience as a whole. Van Manen emphasises that this process is necessary to retain sight of the research question:

one needs to consistently measure the overall design of the study/text against the significance that the parts must play in the total textual structure (van Manen 1990, p. 32).

The next sections describe the specific methods undertaken in the study.

### **3.5. The research question, study location and criteria for participants**

#### **3.5.1. The phenomenon of interest**

When turning to the nature of lived experience, a researcher should consider what phenomenon holds a serious domain of interest (van Manen, 1990, p. 29). My interest in older people and their lives in RACFs resulted from family caring roles and working in a RACF, as described in Chapter One, which led to my desire to know more about the phenomenon of how older people ‘live’ in RACFs. Given the political and community interest in aged care, relating to current issues of the plight of older people, as discussed in Chapter Two, I believed that this was an experience worthy of further research. I also need to reflect on my own pre-understandings to recognise how they sat within the concept of aged care, ensuring credibility. This was undertaken when studying the role of personal carers in aged care, researching for candidature into this doctoral-level study and discussing the research focus with my supervisors. The explication of these processes allowed me to question my own horizons and step back from my own experiences. However, I was continuously mindful that I should maintain a solid and orientated relationship with the phenomenon throughout the research process, focusing on the nature of this human experience.

To obtain dependable and trustworthy information about the phenomena of lived experiences of older persons, the key question for the participants was developed to ask ‘What is the lived experience of older people in high care RACFs using phenomenological investigation?’. It is clear that discussions can only relate to their experiences in their RACF. Those persons who lived in RACFs were those who had that experience. To access that valuable information, the research process required a variety of processes such as gaining ethics approval, deciding which RACFs to approach, participant inclusion and exclusion criteria, compilation of explanatory statements, consent forms and a review of interview questions. Analysis was required to glean the rich information from the resultant interviews. The following section details the process of existential investigation, exploring the phenomenon and

generating data. The process of using personal experience as a starting point and tracing etymological sources and idiomatic phrases sources has previously been discussed.

### **3.5.2. Locations of the study**

To undertake this study I needed to recruit facilities and older people residing in them to participate. Firstly, the study was conducted in two states of Australia, Victoria and Queensland. These locations were selected based on my ability to access potential sites within the time limits and unfunded scope of this project.

All participating facilities were located in regional suburban areas of the capital cities of each state. The locations of the facilities were characterised by being in a residential area, close to public transport, recreational facilities, shopping centres, professional services and with access to a host of social opportunities, such as cinemas and clubs. No facilities were located remotely. Each facility had their own philosophy of care determined by their charter, which were all underpinned by a quality of life ethic of care. The study collected data in three high care residential facilities in Victoria (three providers with a total of 149 high care residents), and two in Queensland (two providers with a total of 181 high care residents). All facilities had both high care and low care accommodation components, with a greater number of beds for high care residents. All facilities were privately owned and funded under the auspices of the Commonwealth Government of Australia, and were managed by Directors of Nursing. The facilities were staffed by full-time and part-time staff, each relying, to varying degrees, on agency staff to fill temporary vacancies. Similarly, all facilities offered both in-house and off-site activities for the residents, as well as visiting medical and allied health specialists to attend to residents' needs.

To gain ethical approval to conduct this study from the University of New England Human Research Ethics Committee (HREC), I compiled a list of potential sites across the two states and contacted the Directors of Nursing (DONs) (or managers) of these

aged care facilities and invited them to participate. This is discussed later in more detail.

### **3.5.3. Inclusion and exclusion criteria for older people**

Participants for this study were selected through purposive sampling (Streubert & Rinaldi Carpenter, 2011). This necessitated determining inclusion and exclusion criteria. Initially, it was not possible to determine the exact number of residents to be interviewed; this was later determined by obtaining rich descriptions of experience (Llewellyn, Sullivan & Minichiello, 2004, p. 231). The sampling strategy targeted those who met a selected criterion within the wider group (older people in the aged care facility). In this case, inclusion criteria included people who were aged 65 plus years, had lived at a facility for three months or more and who were able to answer questions over a period of time, in stages if necessary (adapted from Cheek & Ballantyne, 2001). It was anticipated that older people who had lived in the facility for three or more months would be able to engage in dialogue on aged care facility life, rather than someone who was very new to the experience.

The decision was made to exclude those older people with dementia from the study. This choice was centred on the fact that the study was time limited and unfunded, making it difficult to devote sufficient time and resources to engaging with older people with cognitive dysfunction, although it is acknowledged that an exploration of the experiences of this group could have provided further insights into life in an aged care facility.

Further exclusion criteria included those older people who were deemed to be too frail or ill, or emotionally vulnerable (as determined by the DON or manager of the facilities), as well as those older people who were unable to converse in English. It was also necessary to consider those older people whose vision or hearing, or other impairments, including difficulty understanding, made it difficult for them to participate, and that issue was left to staff to decide. It was also noted that potential

participants whose relatives or advocates had any concerns or objections to their involvement in the study were also excluded.

### **3.6 Recruitment**

Van Manen (1997, pp. 62–63) suggests that the aim of participant selection is not based on statistical criteria; rather selection is based on whether the participants have lived the experience under investigation, and whether they are eager to converse about their understanding of the phenomena, which may vary between them, to give rich and distinctive narratives.

Strategies to recruit RACFs for involvement with the project included first-hand contact by telephone, email, mail-out information and personal visits. My first point of contact with each potential facility was through a telephone conversation with the DON or manager of each facility. During the initial telephone conversation I introduced myself and explained the reason for the call, citing the approval from the HREC. I explained the study concisely and asked if their facility would be happy to participate. The DONs and managers were all very interested and understood the study to be worthwhile.

Upon receiving a favourable indication from the DONs and managers that they would be interested in participating in the research, I arranged a time for a meeting to elaborate on the study and discuss the protocols and procedures that I would undertake. I also emailed, and sent by post, all of the relevant information. That information included:

- an introduction letter explaining who I was and what the research was about
- an organisational consent letter
- a project synopsis
- an information sheet for participants (Appendix B)
- a consent form for participants (Appendix C).

The DONs were also given copies of the ethics approval to undertake this study from the University of New England HREC (Appendix D).

Of the four nursing homes approached in Queensland, two agreed to participate, and out of five approached in Victoria, three agreed to participate. One of those who declined did so due to an outbreak of a contagious illness in the aged care facility, not because they were not interested in participating. The other three declined due to work commitments such as pending accreditation and lack of resources to assist with the study.

I was able to meet with the DONs or managers, giving them sufficient time to receive and review the information. The time was mutually agreed, with some DONs and managers handing over the more procedural duties of the facility's involvement to delegated staff, such as activities officers. However, the authority to undertake the study at the facility was agreed to by the DONs or managers. I had provided the facilities with additional information statements so the potential participants could be given a written description about the study when approached.

Potential participants were identified by facility staff, who initially invited them to participate. The staff also contacted the older person's family member or advocate to determine whether there were any objections to them participating. No concerns were raised by any family member or advocate. The selected older people were given information statements and the option to participate and the choice was left with them. Potential participants at all facilities were informed by the staff that they had the right to make their own decisions, and therefore their decision to participate was completely voluntary. I reinforced this prior to each interview. A verbal consent was given to the facility staff by the potential participants, and a written consent was obtained by me before each interview commenced.

The list of any potential participants was forwarded to me by facility staff to follow up. I arranged a meeting with the staff member to discuss the next steps, such as approaching the potential participants and any limitations that may arise. For

example, in one facility, after receiving the list of potential participants and discussing the next step of speaking with them, it was clear that some of the willing participants were not able to meet the criteria as they were too frail or ill. One lady was confined to bed and spent the majority of time sleeping. Her moments of wakefulness and awareness were limited and unfortunately I was not able to devote enough time to conducting the interview over several days.

I sought facility staff advice about the most appropriate time to meet with each older person, their perceived capabilities for the initial meeting and interviews and their rest time preferences. I also asked the staff members if there were any activity periods or regular visitor times that the residents enjoyed so I could arrange a time that did not clash with these activities.

The participant recruitment process required me to have an initial meeting and then one follow-up interview (or more) with those older people willing to participate. A total of 18 participants were eventually interviewed across all facilities. In most cases, mid-morning was the most convenient time for the participants to undertake the first brief meeting, as it was after breakfast and outside any organised activities. This initial meeting was more of an informal chat so the participant could decide if they wanted to take part and to allow them to meet me. I generally met with residents in their own rooms; however, some participants preferred to meet in common rooms or alcoves.

During these preliminary meetings I provided a copy of the information sheet and answered any queries they had. Residents who then agreed to participate were invited to sign the consent form prior to the commencement of the interview. All of the older people in the study were able to give informed consent: they were able to understand the information given to them and were aware of their options in relation to changing their mind about being interviewed or stopping the interview at any time. Informed consent was gained by a signature of the participant on the authorised consent form. At all times I ensured that the information gained would remain confidential and pseudonyms would be used. Importantly, no recruitment incentives were offered. The

issues of confidentiality, privacy and rigour and trustworthiness were all important concepts to appreciate at this initial stage of the research process, and their applicability to this study are more fully discussed in the sections below.

Interviews were arranged at the initial meeting for specific days and times, contingent upon the availability of the participants. Most chose mid-morning for the interview proper, with only a few deciding on an early afternoon time. Thus a total of 18 interviews were conducted and, in consultation with my supervisors, it was agreed that the data collected would satisfy the research question's objective.

### **3.6. Data collection**

#### **3.6.1. Introduction**

Data collection involved reviewing etymological and idiomatic sources (as previously described), undertaking a pilot study, conducting interviews, keeping a journal and recording and transcribing interviews. As researcher, I was fully aware that I was the instrument that sought to 'mobilize participants to reflect on their experiences' (van Manen, 1990, p. 99). As such, I approached the data collection procedure with my own preconceptions of RACF life as a starting point so I could relate to the participants; however, I was conscious that my own personal experience was not relevant to the analysis.

#### **3.6.2. Pilot studies**

After reviewing existing literature relating to aged care facility life and phenomenological studies, I gained a sense of what issues may be relevant to ask the participants relating to their life; to get to the essence of lived experiences of these older people. The general questions emerged and these were first trialled in a pilot study. This is consistent with van Manen's method (1990, p. 74), where this beneficial process enabled familiarity with the research topic and approaches to investigate the phenomenological experience.

Teddlie and Tashakkori (2009, p. 203) describe pilot studies as ‘test driving’ the researcher’s implementation of their research design, where usefulness is contained within the parameters of refining procedures, identifying problems of data collection protocols and setting the stage for the actual study. This description was appropriate to this study, as I was able to refine my interview skills and develop an appropriate design for the questions, based on the interview data collected during the pilot study and feedback from my supervisors. While the study questions were semi-structured, the interview process required a flexible approach to allow a conversation to flow between myself and each participant. The pilot study aided me to develop key opening questions that would allow the conversation to flow naturally and follow-up questions that aided the flow of data towards the research question, to stay orientated towards the phenomenon of interest. The emergent themes therefore flowed from the conversations rather than from the question design itself.

The pilot interviews were assessed by my supervisors with respect to the flow of conversation. The pilots were also useful in making me aware of issues such as environmental factors, for example the noise level within the facility. The pilot interviews were extremely valuable to help me refine my interview skills and to develop strategies to improve one-on-one discussions with each participant. I found that the techniques needed to elicit rich data emerged over time and as a part of the process of improving my interview strategies.

From the pilot interviews I realised that the more structured the questions were, the more rigid the answers were and did not lend themselves to free flowing conversation. In changing my approach to ask very open-ended questions, I found that more meaningful dialogue emerged, which gave greater insight into the lives of the participants. I was also appreciative of moments of silence, which indicated that the participant was highly reflective within themselves; as van Manen (1990, p. 131) suggests, researchers should be ‘sensitively attentive to silence around the words’.

I had also assumed that comprehensive note taking would occur throughout the interview. However, during the pilots note taking proved to be a distraction, as eye contact was lost and I felt that the attention was on writing rather than listening. So following the first pilot interview, I reserved note writing for after the interviews in the form of a reflective journal. I also noted in that journal, from an observational point of view, the participant's body language, affect and general mood.

From an environmental situation perspective, to improve the conditions and suitability of the interview surroundings, I was conscious to eliminate as far as possible any internal noise sources within the participant's room, such as television and radio, so I sought the participant's permission to turn off (or down) these sources of noise. I was also conscious of the need to make the interview friendly and informal, and to allow regular eye contact and to develop a 'closeness' so that the participant felt they had my undivided attention and could converse without difficulty. I was also conscious of any bright lights or glare from windows that may have been distracting and/or uncomfortable. Similarly, interview times were made outside meal times and activity periods, when the participant had free time. At all times I was aware of the valuable time given by the participant and I wanted the participant to understand that I appreciated the time they gave and that I respected their experiences.

After reviewing the pilot interviews, I made sure that the aims and objectives of the study were consistent with the data received, thus maintaining a strong orientation to the phenomenon. I also simultaneously asked my supervisors to review the pilot transcripts and provide feedback. This was an invaluable part of the process as it enhanced my interview skills.

### **3.6.3. Data collection procedures**

A basic demographic information sheet (Appendix E) was used to outline the participant's background. This was an important part of the research as it helped to understand the participant's circumstances and time-of-life in the facility. This data

was kept in a secure location and referred to in the writing up of the data analysis chapter.

The phenomenological data was collected using the individual face to face interviews with the participants, consistent with qualitative research methods (Richie & Lewis, 2003, p. 36). This involved a dialectical relationship, as the semi-structured questions allowed for free-flowing conversation (Fontana & Frey, 2000, p. 645). Each lasted for approximately one hour, and some were longer. Two separate sessions were held for two participants, as those interviews were interrupted by visitors. All interviews were audiotaped and were immediately transcribed verbatim, as the conversations were fresh and I was able to relive the interview experience. This required playing and replaying the tapes, and, consequently, the search for themes began. I found this to be important as the tapes were sometimes unclear due to background noise. However, I could recall the words accurately. Any identifying information was deleted as the participant's pseudonyms were used immediately in the transcripts. This experience in itself made me aware of the residents' stories again and in using journal notes the interviews could be relived in terms of rapport and body language. For my own benefit and to appreciate meaning within the text, notes were made against specific phrases or statements during the transcriptions. This proved to be helpful in considering the text and journal reflections of the interviews in the thematic analysis.

A journal was used to record my observation of the participant's environment, including reflections on informal interactions, the general mood and affect of the participant, and the success of each interview process. This was important to reflect on the rigour of the process and contribute to the decision trail. The use of study diaries focus not only on the story being told (semantic expression), but also on the emotive qualities of data collection (mantic expression) which together offers a more holistic view of experience (Rapport, 2005, p. 134). These notes were useful as key points were recorded in the journal notes (e.g., effect on the participant of the interview, level of confusion (if any) and challenges. They also assisted in 're-living' the discussions.

Open-ended, semi-structured questions explored the participants' lived experiences. The participants 'steered' the conversations with their responses. Some participants got tired or confused, and during some interviews there were breaks or silences, which were totally appropriate. At all times I was conscious of the value of the information that the residents were imparting and the interview process accommodated the participant as far as possible. In this way it is the absence of speaking, as it is in silence, that one may find the taken for granted or self-evident (van Manen, 1990, p. 112).

Conversations began with open-ended semi-structured questions, followed by semi-structured or unstructured questions that assisted the participant to remain orientated towards the phenomenon. Questions are detailed in Appendix I.

Not all questions were used for every interview, as the intention of the interview was to create a dialectical relationship that would inform the study's aim. To develop trust between the participants and myself, I practised empathetic listening with few interruptions. These active listening techniques aided the flow of conversation. As such, the interviews allowed for the collection of a breadth of data and freedom of answers, through an opportunity to engage in meaningful dialogue with the participants.

If the participant wanted a break, or I sensed that they had become tired, I would ask if they wanted a break. If this occurred, I would leave the room and wait for them to be ready to continue. Assent to continue was given by the participant verbally inviting me to re-enter their room. During the break, the tape recorder was turned off and restarted once the interview recommenced.

At all times, I was aware that the participants may be in a vulnerable position and might be anxious about telling someone about their personal circumstances and perceptions of aged care facility life. I was also aware that they might have considered their own position, such as possible ramifications from management, in the aged care facility prior to deciding to participate. I made it clear to all that their confidentiality

would be protected and that their trust would be respected, as there would be no disclosure of identity. Participants were also asked if they wanted to review the interview transcripts; they all declined this invitation.

### **3.7. Data analysis**

#### **3.7.1. Introduction**

A methodological structure of data analysis suggested by van Manen (1997) was employed in this study. This approach is considered appropriate for this study as it concentrates on everyday language, using first-hand accounts, and requires the co-relationships between language and meaning to emerge. It allows meanings to be uncovered as well as reflection on hidden meanings, which will flow from the establishment of a dialectical relationship (Rapport, 2005, pp. 133–134). A more detailed discussion of the activities is presented next.

The purpose of phenomenological reflection is to grasp the meaning of something, where reflective determination and explication is a process of clarifying and making the lived experience explicit (Lindseth & Norberg, 2004, p. 145). Van Manen describes our understanding of actions through verbal expression as ‘challenging us to return to the pre-reflective state’ (Rapport, 2005, p. 134). The procedural activities of data analysis employed in this study are described as reflective methods and the process of reflection is exercised in the activities of thematic analysis and determining the essential themes.

#### **3.7.2. Thematic analysis**

Van Manen (1990, p. 93) suggests three ways to discover the essence of a phenomenon. Firstly, a holistic approach seeks to find the overall meaning of the text; secondly, phrases stand out and can be interpreted; and lastly, a detailed line-by-line interpretation is made (Hjaltadóttir & Gústafsdóttir, 2007, p. 50; Polit & Taranto

Beck, 2014, p. 586). Although all three of these strategies were used, the main approach in this study was the selective highlighting approach.

First, a 'naïve' reading (Streubert & Rinaldi Carpenter, 2011, p. 95), consistent with a holistic approach, was undertaken, where the text was read as a whole and initial impressions gained. Further, each transcription was meticulously read and re-read, and the tapes were again listened to, ensuring accuracy against the transcribed interviews. In this stage, I read all interviews to gain a sense of the whole experience. From this, themes started to emerge. Smythe and Spence (2012, p. 14) indicate that this stage enables the researcher to become familiar with the text as meanings begin to reveal themselves.

The next step of the analysis included identifying patterns of meaningful connection, where statements or meaning units were identified as being particularly revealing of the experience. This involved a thematic analysis approach, which uncovered common themes, as well as sub-themes that presented as common for some participants. Phrases and statements were highlighted or underlined manually and resulted in 'selected sentences and part-sentences' which were thematic and enlightening (van Manen, 1990, p. 94) of lived experience in aged care facilities. The highlighted sections were re-examined to uncover themes, and this allowed a comprehensive reflection on the phenomenon of lived experience in RACFs. Considering the emergent themes against the whole text allowed a greater awareness of the phenomena.

The highlighting approach allowed structural analysis in the form of identification of meaningful connections (Streubert & Rinaldi Carpenter, 2011, p. 95). This assisted in the discovery and understandings of the realities of the phenomena studied. I was able to extract phrases, key words and sentences from the text, which were illustrative of the same theme, through a cut and paste activity. This process required careful consideration about links and similarities between meaningful data, and these categories were reviewed against re-reading of the transcriptions. The newly labelled themes were then pasted into a separate document to allow for concentration on the

words and phrases. The inductive analysis of the transcripts provided a degree of validity (Cheek, Ballantyne, Byers & Quan, 2007, p. 11; Lindseth & Norberg, 2004, p. 145).

Concepts emerged because of this process that represented the lived experience under investigation. Implicit themes in the phenomenological research were identified, remaining true to the essence of the phenomenon (van Manen, 1997, p. 97). They emerged after several readings of the text and, while this can never be fully achieved or completed, it allowed me to appreciate a new understanding, or horizon, of the experience, consistent with the process of fusing of the horizons (Lawn, 2006, p. 66). The ongoing dialogue with the transcript allowed me to remain orientated to the phenomenon and appreciate the emergent themes.

Although not relied on, a line-by-line approach was also implemented to ensure that any words or part-sentences were not missed or overlooked in the process (van Manen, 1997, p. 93).

### **3.7.3. Determination of essential themes**

Van Manen (1997, p. 106) points out the difference between incidental and essential themes when interpreting text. Incidental or fundamental life-world themes, known as 'existentials', are common and are influenced by historical events or culture (van Manen, 1997, p. 101). The essential themes belong to the phenomenon in such a way that without these essential themes the phenomenon would not be what it is (Holloway, 2005, p. 133; van Manen, 1997, p. 107). This approach was important to this study as it allowed me to explore the lived experience as a true reflection of the older persons' lives as they are invariably linked to the older persons own context. Initially, I had to determine what was common to the experience of being an older person and living in a facility, and then I looked at what elements focused on both experiences, as not all themes that emerged were unique to the experience of older people living in RACFs.

This process illustrates how I moved from a basic understanding of residents' experiences to a more unambiguous appreciation of the perceptions of lived experience, which have been elicited using thematic analysis and data interpretation as discussed in the next chapter.

### **3.8. Ethical considerations**

#### **3.8.1. Introduction**

An ethics application was approved by the UNE HREC (which complied with the *National Statement on Ethical Conduct in Human Research, 2007*). It reflected how this research study would address any ethical issues and possible risks to the research participants in accordance with research protocol. As stated in the form, risk is the potential for harm, whether physical, psychological, social, economic or legal, or the potential to cause people to think they have been treated disrespectfully.

I applied principles that protected the research participants from risk or harm under the auspices of the codes of conduct as determined by the university. The principles include, in a general sense, respect for autonomy, non-maleficence, beneficence and justice, and these are essential human rights for all social research (Holloway & Wheeler, 2010, p. 54). They are linked to veracity, privacy, confidentiality and fidelity (Burns, Bradley & Weiner, 2012, p. 417).

#### **3.8.2. Participant information, risks and fairness, and privacy**

Informed consent (outlining participant confidentiality) was obtained from the participants and the aged care facilities with a consent form (Appendix C). Participants were given information sheets (Appendix B) detailing the research objectives and processes, details relating to the approximate length of time it would take, the place of interview (being the participant's room or other quiet area) and the voluntary nature of the interview. All participants were given opportunities to ask questions, decline to be involved and were made aware that they could participate on their own terms. Risk factors were also detailed with contact details nominated in the

information sheet, in case of distress during the interview. Full details of confidentiality were given, including data usage and storage. I also provided this information verbally to the resident. All verbal explanations of the consent form and process were audio taped. Due to the sensitivity of the research, repetition of the confidentiality of data was reinforced with each willing resident, to respect their autonomy. There were no prior relationships between myself as the researcher and the participants (also stated on the consent form). All participants (as identified in the sampling process) were able to give informed consent and sign the consent form.

In terms of the residents' informed consent, the question 'Does the information provided indicate that the power relationship between the researcher and the participant is suitably balanced to favour the needs of the participant?' arose as a relevant consideration. One of the intentions of the interview situation was to make the older person feel comfortable and not overwhelmed. The participants were also made fully aware that they could withdraw from the interview at any time.

One ethical consideration considered was that the interview might cause distress. I had to consider the possibility of anguish or sorrow expressed by residents. The information statement expressly outlined that, if this situation arose, the interview would be terminated, and may or may not be resumed at a later stage, depending on the participant's wishes. Residents were provided with contact details for a counsellor if required. I, as the interviewer, would also provide comforting and mediated closure of the interview. No such circumstance arose during the interviews.

As stated, the majority of interviews were conducted in the participant's room, with the door closed (with the participant's permission). Confidentiality was an important point raised at the beginning of the interviews, with the participant being reassured that their name would not be used. They were advised that none of the identifiable information provided would be shared with anyone, and pseudonyms would be used in the thesis text. Additionally, I informed the participant that they could call for the nurse at any time should they require one.

Journal notes have been kept to record the research process and results (Minichiello, Aroni, Timewell & Alexander, 1995), and three types of note have been collected: the transcript file (raw data from interviews); the personal file (demographic and facility setting information); and the analytical file (reflective notes on the research interview).

Transcripts of the interviews are kept in password protected computer files as well as being recorded as a hard copy. The hard copy, tapes of the interviews, personal file and the analytical file, are all kept in a password protected safe. Only my supervisors and I have access to these files. The data will be stored at the School of Health, University of New England, as required by the HREC and will be destroyed after five years.

### **3.8.3. Rigour and trustworthiness**

Rigour, the adherence of an accurate, ordered and visible approach in research (Davies & Dodd, 2002, p. 280) and trustworthiness, the honesty of the data collected from and about participants (Macnee & McCabe, 2008, p. 173) are important concepts in research. Morse (2005, p. 827) advocates that rigour is practised by the use of adequate methods of data collection to address the questions proposed and analysis that requires solidity and transparency in documenting methods. Denzin and Lincoln (2000, p. 7; 2011, p. 2), and Mertens and Ginsberg (2009, p. 153) further suggest continuous acknowledgement of relevant philosophical assumptions and frameworks inherent in research paradigms should be undertaken. Rigour assists in guaranteeing that the research methods are justifiable, and literature regarding research methods suggests that rigour is demonstrated by achieving validity and reliability (Davies & Dodd, 2002, p. 280; Tappen, 2011, p. 153).

Johnson and Christensen (2010, p. 264) state that the tests for validity and reliability applied to quantitative research are not generally as suitable for qualitative research. These ideas are not applicable to this research, nor to qualitative methodologies in general and this is explained by Davies and Dodd (2002, p. 281), who argue that the

application of rigour in qualitative research should differ from that in quantitative research as there is a quantitative bias in the concept of rigour, where the subjectivity, reflexivity and social interaction of interviewing is not considered.

Reliability and validity remain appropriate concepts for attaining rigour in qualitative research, and can be implemented by verification strategies adopted by the researcher during the conduct of research. There are various terms used in interpretive phenomenology such as credibility (evaluating believability) and authenticity, which point to trustworthiness (Fleming et al., 2003, p. 119; Sheppard, 2008, p. 85; Speziale, 2002, p. 169; Taylor & Francis, 2013, pp. 197–198). Terminology is dependent on the framework used to guide the methodology. Trustworthiness relates to the validity and reliability of qualitative research; the research is trustworthy when it accurately represents the experiences of the study participants (Streubert & Rinaldi Carpenter, 2011, p. 96). Graneheim and Lundman (2004) suggest that trustworthiness can be verified if the process is reliable, achieving credibility. Guba and Lincoln (1989) suggest if the study is transferable to another context and the reader is able to follow the decision trail of the researcher, dependability occurs. If the researcher shows how interpretations have been determined, then conformability is achieved. The functions offered by Lincoln and Guba (1985, p. 189), to reflect the intent of the qualitative approach are credibility, transferability (or applicability), dependability (or consistency) and confirmability (or neutrality) respectively. Lincoln and Guba (1985, p. 189) argue that sustaining the trustworthiness of a research study depends on these issues, and the idea of discovering truth through measures of reliability and validity is replaced by the idea of trustworthiness, which is ‘defendable’ as establishing confidence in the findings. The four approaches are discussed here to establish trustworthiness and the decision trail in this study.

Dependability and auditability relate to the steps of the research process that must be identifiable, including a clear record of documentation throughout the research process and analysis (Fleming et al., 2003, p. 119). Koch (1994) similarly suggested that to establish rigour in qualitative research, there should be a decision trail auditing the events, actions and decisions of the researcher. Auditability in this study was

achieved by careful reflection and dissemination of my aims and objectives, a comprehensive discussion of method and methodology presented, and written descriptions were provided to support and illustrate processes and decisions. Numerous drafts of research proposals, interview approaches and questions, and notes taken during and after interviews all combine to establish the audit trail. A methodological praxis was clearly underpinned by a phenomenological theoretical framework and methods analysis, which identified strengths and limitations that informed the reader of the process.

My interpretations of the transcriptions identifying experiences were checked by my supervisors to identify accuracy and provide feedback on my interview skills and interview techniques. Journal notes and draft analysis reflected how I moved from the phrases and sentences expressed by the participants to links with the text as a whole. Highlighted parts of text were linked with coded areas of the transcripts, all because of re-reading the transcripts and the themes. The supervisors reviewed the transcriptions of the interviews, further reinforcing my own skills and thoroughness. This all being fully documented, I thus completed an audit or decision trail, as proposed by Halpern (1983) and Koch (1995) and discussed by Cutcliffe and McKenna (2004, p. 127) and Lincoln and Guba (1985, pp. 318, 321). Further, interviews were analysed and produced as written descriptions as a true result of a fully audited interpretive process.

Tappen (2011, p. 161) suggests that confirmability is satisfied when qualitative researchers report the process, analysis and conclusions in context. This was achieved in the study by careful consideration of how all aspects linked to address the aims appropriately. Faithfully representing texts, according to Fleming et al. (2003, p. 119), is an ideal only in interpretive research, and cannot be achieved entirely as all readers will have different interpretations of texts, although truthfulness may be achieved in analysis by reflecting on the meaning from the participants' perspective. Confirmability relates to ensuring mutual understandings and fusion of horizons through returning to participants during the research process (Fleming et al., 2003, p. 119).

Returning to the participant for clarification on specific issues during the interviews also aided truthfulness and credibility. In this study, confirmability was achieved by interviewing participants comprehensively, with some residents interviewed in stages. During the interviews the participants were encouraged to relate their stories and experiences by semi-structured and open-ended questions. Silence was acknowledged concurrently. I revisited key phrases, concerns or areas of importance of the participants and returned to these during the interviews. These were further discussed and expanded upon during the interviews.

Strategies to achieve rigour in this study included a time frame of approximately 12 months for the research, which allowed an unhurried approach to interview preparation. A pre-meeting with potential participants, as well as the time taken in the interviews, allowed for a trusting relationship with the participants and the accumulation of information-rich data. All participants spoke freely and were happy to engage in conversation. As mentioned earlier, none of the residents accepted the invitation to review their transcripts, so in this study confirmability depended on my thoroughness to transcribe each interview accurately.

Credibility, according to Fleming et al. (2003, p. 119) relates to ensuring that the perspectives of participants are represented as clearly as possible. The preceding discussions in this chapter identify the method used in this research, where I explained the rigour inherent in van Manen's (1984, 1990, 1997) approach. This was often repeated as I needed to make sense of the phenomenon of lived experience in RACFs in relation to the content of the texts, the co-dependent status of the residents and myself during conversations, and the depth of data between the research, participants and texts. Credibility was established by continued reflection during interviews, transcription and interpretation throughout the analysis. In discovering themes of experience, I rechecked the participant's narratives in the transcriptions to confirm that the ideas and themes were definitely grounded in the data, and re-consulted the journal notes to ratify those conclusions. Each theme was reworked

against the text until it clearly and unequivocally represented a faithful description of their experiences as they were told to me.

Credibility was achieved by including numerous quotations from the participants' experiences, allowing their voices to be heard. Communication with my supervisors allowed confirmation that the themes emerged as credible reflections of the residents' lives. When the participants' concerns and experiences were discussed throughout the interview, the participants readily endorsed the issues as reflective of their experience, further supporting the data's credibility.

According to Gasson (2004, p. 79), different criteria of rigour that acknowledge the researcher's assumptions need to be developed to reflect research in an interpretive paradigm, such that rigour in qualitative research requires being attentive to preconceptions, values and beliefs. I have discussed my motivation for undertaking this study and the assumptions on which the study is based. Whitehead (2004, p. 516) also recognises the influence of the researcher on the conduct and presentation of a study and the ability to describe and interpret their experience as an integral part of the research process, and it is vital that some information about the researcher is presented. I have presented my background and associated influences: as such, this strategy has addressed the criteria of credibility.

### **3.9. Limitations of phenomenological research**

Phenomenology is a human science within which there is debate regarding appropriate research methods, rendering it difficult for novices to apply (Findlay, 2003, p. 6), as it constitutes a complex topic with inherent contradictions in the philosophical approaches (Cohen & Omery, 1994, p. 126). Ray (1994, p. 123) suggests that, especially in nursing research, there is a lack of understanding of phenomenology from its philosophical underpinnings and the process of reflection, which affects credibility. Further, Finlay (2009, pp. 7–8) suggests that there is continuing debate surrounding the boundaries of what constitutes phenomenology as there are many types of qualitative research that focus on subjective and interpretative

analysis. Any research needs to explicate specifically the methodology used with a clear understanding of the philosophical traditions as espoused by the key philosophers (Ray, 1994, p. 123). In this study, I have been especially cognisant of elucidating the study's purpose of investigating the lived experience of older people in RACFs, along with its underpinning relationship of phenomenological traditions. In this study, I needed to clarify that the issue of examining a human phenomenon was one which needed an oriented methodology that attempted to capture the essential meaning of lived experience. The consistency between the theoretical and philosophical framework, methods and analysis as portrayed in this study are representative of rigour in a true phenomenological study.

Concerns have also been raised with the process of 'reading between the lines' and the extent to which this approach involves going beyond what has been said and interpretation (Finlay, 2009, p. 10). Such resultant approaches need to be identified in research. Since findings are grounded in the participant's life-world experiences, criticism has been directed at the heavy reliance on interpretation, as the participants first interpret their own experiences, and the research interprets the interpretation (Berglund, 2007, p. 89). Similarly, phenomenological language has 'never been clear' and researchers may use the language of other traditions, thus highlighting a lack of understanding of philosophical traditions (Cohen & Omery, 1994, p. 152). Interpretation in this study has been represented in reflection, as advocated by van Manen, while maintaining a focused orientation on the study question. I have also been aware that the language used should represent the phenomenological tradition; this has been reflected in the philosophical framework and method discussions.

Other issues in phenomenological research include the extent to which researcher subjectivity or reduction should be controlled in an approach that advocates an open attitude (Giorgi, 1997, p. 205); as well as those surrounding the need to respect scientific rigour, openness and flexibility. However, Koch and Harrington (1988, p. 887) suggest there has been a re-conceptualisation of rigour in phenomenology such that plausibility may be possible with reflexive exploration, and an audit of the events, of the research process. Reliability and validity cannot be central to quantitative

research (Ray, 1994, p. 94) as the terms are traditionally grounded in scientific positivism. However, Guba and Lincoln (1985, pp. 290, 296) offer the criteria of applicability, neutrality, truth-value and consistency to give trustworthiness to naturalistic enquires, where multiple constructed realities inherent in the inquiry reflect credibility. This limitation has been discussed in the preceding section and, as the decision trail and trustworthiness have been established, the study represents credibility.

### **3.10. Conclusion**

This chapter has presented and justified the research methodology, as well as the praxis of the research. The methods used to conduct this study have been presented and discussed and ethical considerations identified and discussed. The issues of rigour and trustworthiness are explained along with the justification of a substantiated decision trail. The limitations that relate to phenomenological research have been addressed against this study and conclude this chapter. The next chapter presents the analysis of data, which is organised into themes that reflect participants' experiences.

## Chapter 4: Data Analysis

### 4.1. Introduction

This chapter presents the analysis of data gathered from the participants through interviews. It commences with a summary of the participant's profiles to give context to the analysis. It provides an analysis of the process of identifying how each theme was derived from the narratives, consistent with representing a true, recognisable experience consistent with Koch's (1994, p. 976) ethos of research. The preceding chapter explained the steps that underpin the process used, as suggested by van Manen (1990, 1997). This chapter explains the analysis as it relates to van Manen's six steps, including uncovering the essential themes. The process of identifying the themes—using tables to organise the iterative process—is also included. The analysis is further informed by Streubert and Rinaldi Carpenter (2011) in relation to highlighting key words. In this way, a clear decision trail is presented.

Turning to the phenomenon of interest has been previously described, along with a discussion relating to the investigation of the experience as we live it, that being by interview. The analysis has been undertaken by returning to the importance of the study question, including the purpose and aims of the study, and revisiting the interviews themselves. This chapter discusses the processes inherent in identifying essential themes to present the phenomenon and then describing the phenomenon through writing and rewriting. This process of analysis has been informed by using van Manen's (1990) approach, as discussed in Chapter Three. This process included identifying statements and phrases that stood out as thematic of older persons' experiences in a RACF; key words and concepts were identified; and the data was revisited many times until incidental and essential themes emerged. Additionally the tapes were reviewed to totally immerse myself in the data, a concept identified as central by Streubert & Rinaldi Carpenter (2011, p. 95). This provided accuracy against the text and interpretation, and contributed to the method's rigour. This

process has also ensured maintenance of a strong and orientated relation to the research question. I have attempted to balance the research context by re-examining the whole interview data and then isolating parts of that data, by identifying key words, concepts, sub-themes and themes, and re-checking those parts with the whole data.

Three themes emerged from the analysis, and they contained a total of ten sub-themes. These are:

Theme One: 'You can't do exactly what you want to do': issues of self and control.

Sub-themes: 1. relocation  
2. loss of identity and independence  
3. the paradox of care.

Theme Two: 'If you haven't got that sort of contact, it would be difficult': important relationships.

Sub-themes: 1. continuity of carers  
2. relationships with family and friends  
3. living in a public realm  
4. more than care.

Theme three: 'You make the best of it': resigned acceptance.

Sub-themes: 1. mortality  
2. dual realities  
3. ageing.

The overall research aim and purpose of this study were to investigate the experience of older people living in RACFs. This purpose was explored through four specific aims. The first aim was to investigate the impact that living in a RACF has on the older person's care and experience. This has been addressed in theme one. Theme one has three sub-themes that reflect the older person's experience of entering and living in the aged care system, which they felt affected their ability to make choices relating to leaving their own home, maintaining identity, and feeling dependent.

The second aim was to assess those elements of RACF life that made a difference to the older person. This is partly addressed in theme one, where older people are thankful for the care they receive, but mourn their loss of independence, and also in theme two, which describes how older persons' experiences are greatly affected by their continuity of care, contact with family, living with others in a public arena and engaging in close associations with staff above the care relationship.

The third aim was to understand the older person's QoL issues, such as, but not limited to, independence, dignity, autonomy, communication, relationships with staff and explore their perceptions of their QoL. This is reflected in both themes one and two, and partly in theme three, which explains how older people's QoL is challenged by a number of factors as well as enhanced by staying positive, even though they often 'trade-off' independence to have their care needs met.

The final aim was to explore the overall perception of RACF life and how care might be improved, from the participants' perspectives. This is reflected in all the themes and most particularly in theme three. This theme indicated that while the participants all discussed the need to think positively, they developed coping mechanisms to address their distress, in relation to living with ageing and understanding their own mortality. The findings are somewhat sad as the participants found little hope of improvement in their QoL. They indicated a resigned acceptance of their experience: 'I haven't got that much longer to live... it's as good as I'll get' (Fred).

## **4.2. Demographic data**

The demographic data collected from the participants is presented in Table 1, describing the diverse characteristics of the participants. A total of 18 participants were interviewed in aged care facilities in Victoria and Queensland. The participants were all 65 years of age or older and had lived at their respective aged care facilities for at least three months. They all spoke English and were able to respond to the interview questions. As mentioned, a basic demographic information sheet was used

to gather information about the status of each participant and their background (Appendix E). This information provided a rich description of the profile of the participants and helped to understand the participant's time-of-life in the home.

At all times I, as the researcher, was clearly aware that the older people may be in a vulnerable position, and may be anxious about telling someone about their perceptions of aged care facility life. As described in Chapter Three, I clarified to all participants that their rights would be protected and that their trust would be respected: pseudonyms are used to protect the participants' identities.

The table below includes the participants' pseudonym, gender, age, the length of time they had lived in the aged care facility and their marital status. It was important to collect this information to establish that the participant had lived in the home for three months or longer. This contributed to ensuring the participants would be able to give an informed discussion of their perception of lived experience as they would be more familiar with aged care facility life. Additionally, the participants' marital status was identified, and this information was important as the roles of relationships with significant others is discussed in the literature and emerged as a key theme in this analysis.

**Table 1: Demographic profile of the participants**

<i><b>Participant pseudonym</b></i>	<i><b>Gender</b></i>	<i><b>Age</b></i>	<i><b>Time in nursing home</b></i>	<i><b>Marital status</b></i>
<i>Alice</i>	<i>f</i>	87	<i>12 months</i>	<i>widow</i>
<i>Beryl</i>	<i>f</i>	84	<i>18 months</i>	<i>married</i>
<i>Charles</i>	<i>m</i>	77	<i>2.5 years</i>	<i>widower</i>
<i>Derek</i>	<i>m</i>	84	<i>4 years</i>	<i>single</i>
<i>Ethel</i>	<i>f</i>	82	<i>2 years</i>	<i>widow</i>
<i>Fred</i>	<i>m</i>	89	<i>3-4 months</i>	<i>widower</i>
<i>Gerry</i>	<i>m</i>	88	<i>3 years</i>	<i>widower</i>
<i>Hyacinth</i>	<i>f</i>	79	<i>20 months</i>	<i>widow</i>
<i>Isabella</i>	<i>f</i>	96	<i>3 years</i>	<i>widow</i>
<i>John</i>	<i>m</i>	85	<i>2.5 years</i>	<i>married</i>
<i>Kitty</i>	<i>f</i>	95	<i>15 months</i>	<i>widow</i>
<i>Leo</i>	<i>m</i>	87	<i>3.5 years</i>	<i>married</i>
<i>Maude</i>	<i>f</i>	83	<i>18 months</i>	<i>married</i>
<i>Nellie</i>	<i>f</i>	88	<i>4.5 years</i>	<i>widow</i>
<i>Odie</i>	<i>m</i>	86	<i>9 months</i>	<i>partner</i>
<i>Pricilla</i>	<i>f</i>	89	<i>20 months</i>	<i>married</i>
<i>Quentin</i>	<i>m</i>	79	<i>2.5 years</i>	<i>married</i>
<i>Ruby</i>	<i>f</i>	85	<i>3 years</i>	<i>widow</i>

The ages of older people were also identified, acknowledging that aged care facilities have a proportion of ‘younger’ older people and this study aimed to look at lived experiences of a range of residents in high care RACFs. Ethnicity was not included as this study did not focus on identifying specific constraints or issues related to cultural backgrounds. There were no discernible differences in ethnicity between the participants. Although this is an important aspect of RACF life, it is outside the scope of this study, but may be an area for consideration in future studies.

### **4.3. Thematic analysis**

#### **4.3.1. Early analysis**

The early analysis involved going from the parts of the text to the whole and back again. The first stage of this analysis involved a detailed reading approach to become more familiar with every transcribed sentence or group of sentences, to understand what it exactly revealed about the phenomenon. Some key words were identified against these clusters of sentences. These key words represented general categories of ideas and allowed grouping of the key words and links with concepts (Coffey & Aitkinson, 1996). Specific sentences were identified that contained a common thread of meaning. The second stage of analysis involved selective highlighting, representing something that was singularly explicit about the phenomenon under study. The approaches allowed the identification of groups of ideas, specific words, key meaning words (an intuitive call) and concepts. It was instrumental to link the key words back to the whole data. After re-reading the data, the concepts common to participants were reconciled against key words and highlighted phrases and words. The links eventually revealed a thematic result. An example of a particularly revealing concept is as follows:

Oh well, **it’s different** anyway, it’s just different. Well, **I’d like to (have) freedom** to get around, and get around the back yard and little things like that but **can’t bear it** when you’re locked, **you’re locked in**, you’re just in all day, in the room. So it all goes back to living at home, like I, I don’t, don’t go, my daughter, my son visits and, but (to) **take me**

**home** for a day, or two, half a day or something, it would make **a hell of a difference**. (Odie)

These sentences were highlighted and assigned key words such as ‘freedom’, ‘choice’ and ‘independence’. The highlighted phrases/words lead to the interpretation of the key words’ meanings. This example was linked to the emerging concept of ‘missing home life and things of importance’. Based on the final analysis, the quote was linked to the sub-theme ‘loss of identity’ and the essential theme issues of ‘self and control’. Other phrases with groups of similar ideas were also linked with key words, and were then revisited to consider linking with evolving concepts. This is consistent with the approach of Streubert and Rinaldi Carpenter (1999) who advocate patterns of meaningful connection by extracting words and phrases that are linked with ideas and concepts.

An example of the process of moving from words and phrases to linking them with key concepts are presented in the table below. This part of the analysis informs the decision trail and allows the reader to become aware of how some concepts emerged from the data. Detailed examples of the development of these concepts as they emerged from each participant’s transcript are included in Appendices F–H. This part of the analysis assisted in organising the data to allow me to reflect and interpret the essence, as described by van Manen (1990).

This example of early analysis shows how two of the participants, Leo and Nellie, describe living in a RACF compared to their previous home life, including their sense of loss. Leo lamented the loss of personal possessions and space when entering the home, and acknowledged the difficulty in adjusting to his new life, but found that friendships with staff helped maintain a family feeling. Nellie too missed her previous life with her family, and acknowledged that good staff relationships also made a difference. While the experiences differed, the narratives evoked key words of ‘anguish’, ‘loss’, ‘closeness’ and ‘friendships’. These key words were linked with the concepts of ‘missing home life’, ‘things of importance’ and ‘friendships make a difference’. Leo understands that the home will be the last place he will live in. Similarly, Nellie thinks it is probably her final place. Although these experiences

vary, both ideas evoke the concept of ‘acceptance’, and this key word was linked to the concept of ‘finality of place’.

**Table 2: Early analysis—linking key words and concepts**

Participant’s stories/phrases	Connecting Key words	Emerging concepts
<p><i>Well, you have to get away <b>without a lot of your personal belongings</b>, sort of thing. ...some of the things that I made over the years, ah, but there was a lot of things that <b>we had to leave behind</b> there ‘cos we couldn’t take in here, we are <b>confined</b> to a certain area down here. ...It is sort of, quite a <b>change in life</b> rather and it <b>takes a bit of adjusting</b>. (Leo - one of a couple)</i></p> <p><i><b>It’s not the same as home</b>. Oh, (missing) everything, the kids, I think. The family, oh, they’re, they’re not home now, they’re at work, but they used to call in and see me a lot. It’s just that, I just don’t like being away from home, that’s all. But it all comes to somebody sometimes. Oh, <b>it’s a terrible thing</b> really. (Nellie)</i></p>	<p>Crisis of identity, anguish, loss</p>	<p>Missing home life and things of importance</p>
<p><i>Absolutely yeah, if you haven’t got that sort of contact (relationship with the staff) there, it would be difficult. Oh yes, there are some that come in and talk for about 10 minutes and talk about their personal troubles or experiences, or after they have been on holiday, and when they go on holiday, they’ll say “See you in a fortnight”. We get all their stories about their teenage daughters and we say we’ve been there, done that. That <b>contact</b> the girls have, I reckon, <b>makes all the difference</b>, you know, you’ve got sort of <b>a family feeling</b> with them. (Leo - one of a couple)</i></p>	<p>Grateful for extra attention, closeness, friendships important</p>	<p>Friendships make a difference</p>
<p><i>You’ll get one who will just come and dump everything, your meal and everything in front of you and say nothing or some, <b>they’ll come in and talk</b> and carry on, they’re, <b>they’re a lot different</b>, but, well, you’ve just got to put up with that. (Nellie)</i></p> <p><i>It’s a part of it now, isn’t it, we’re used to it now, sort of thing. We know <b>we can’t go back</b> on our own, on our patch anymore. But, no, you know beforehand when you get here, that <b>it’s the last stop</b>, inmit? (Leo - one of a couple)</i></p>	<p>Acceptance, acquiescent</p>	<p>Finality of place</p>
<p><i>Oh yes, but it’s, ah, <b>the place to be</b> if you’re not well and your husband can’t look after you. Yes, I don’t think I’ll ever get out of here. <b>I don’t think I’ll ever get out of here</b> now. (Nellie)</i></p>		

Analysis of the lived experience of the participants moved on from these early ideas to identifying patterns of meaningful connection by re-reading the transcripts as a whole and searching for the implicit and explicit themes. In going from the parts back to the whole, words and phrases that exhibited meaning and significance were highlighted, grouped together and married with the emerging concepts. Sub-themes

emerged out of this continuous re-thinking of similar groups of thoughts, and these too were combined to underpin and form the themes. An example of the formation of a theme is presented in Table 3 below.

**Table 3: Formation of the themes**

Participant's stories/phrases	Emerging concepts	Sub-theme	Theme
<i>No. It's (living with dementia/palliative older people) a <b>very difficult position</b> to be in. Sometimes I take it, sometimes I don't. You understand me? I mean if I think they're being pushy, <b>I just tell them.</b> I say that's enough. (Pricilla - one of a couple)</i>	Upsetting emotions	Accepting ageing	Resigned acceptance
<i>Yeah, it <b>does get me down</b>, lying here, thinking things through. I don't know what, there's only me and another two who are normal. All the others are old, have got something the matter with them. Yeah. A lot of them, a lot of them just sleep, sleep all the time. No, no, no. (Kitty)</i>			
<i>I didn't think I'd end up in a nursing home, but ... I did, so. Oh, it's quite good. Been pretty good. Oh, occasionally, I <b>get a bit depressed</b>. I don't know how to get over it, <b>I just have to</b>. Yes, <b>you're here to stay</b>. (Ruby)</i>			

Many of the participants had upsetting emotions ('gets me down', 'depressed'). acknowledged that these older people found it challenging to cope with living within the home. The concept evolved from intuitive key words such as 'depressing', 'upsetting', 'resigned', 'invidious'. This shows how sub-themes evolved from the participants' common concepts and ideas, and how this has been married with other sub-themes of 'mortality' and 'dual reality' to form the theme of 'resigned acceptance'. Many understand that they are never going 'home' and they have understood this is something they have to accept.

#### **4.3.2. Holistic reading approach**

The holistic approach allowed a revisitation to the whole text to identify specific implicit meanings of the phenomena, or the hidden meanings surrounded by all the words. In uncovering significant meanings, it was necessary to be aware of the experiences uncovered in the concepts. For example, for the third theme, I found

‘resigned acceptance’ a particularly memorable phrase emerging from the participants’ stories. This was due to the participants resigning themselves to their ‘lot’ in life and accepting their conditions. While they were confronted by their own, and others mortality, and their loss of independence, they tried to remain positive and accepted that they would spend the end of their days in the RACF. An example of this is:

So I **haven’t got that much longer to live** so ... so I’ll be alright. Yes, that’s what I mean, so **I don’t worry** about that. **It’s as good as I’ll get**, and what could I ask for? (Fred)

This specific quote was linked to key words such as ‘accepting’ and resigned’ and linked to the concept of ‘finality of place’. The theme was linked back to the sub-theme of ‘mortality’. This sub-theme was particularly relevant as it grew out of the realisation that entering a RACF is inextricably linked with the end of one’s own life. This realisation for many resulted in an acceptance of an invidious situation.

The participants’ words have been used as titles for the themes. This approach is consistent with letting the themes emanate from the data, reflecting the participants’ own thoughts and reality. The next section of the chapter discusses the analysis of these themes.

#### **4.4. Theme one: ‘You can’t do exactly what you want to do’: Issues of self and control.**

##### **4.4.1. Introduction**

This theme illustrates the participants’ perceptions of aged care facility life from the perspective of facing a new life in a RACF. This is associated with being removed from their home life and perceptions of losing control over making life choices. This is linked to their experiences of losing identity to a certain extent, as the connections with their previous life are reduced and they lacked the power to change their situation. The lack of control over decision making is reflected in their experiences of accepting dependence and the dominance of regulated control and care practices in the RACF.

All older people were asked a general question relating to how they felt about living in the aged care facility, and, if required, additional questions relating to aspects of entering the home, home life and what they liked or disliked about it. The decision trail for this first theme is presented in Appendix F.

#### **4.4.2. Sub-theme 1: Relocation**

The first theme is about ‘relocation’: the words of one participant exemplifies the overall concept of this sub-theme:

They (family) said I had to go straight to the nursing home, and they arranged it. I wasn't too keen to come here, to be honest. I had no choice.  
(John)

Relocation to a RACF was often the decision of others, generally those with authority such as a medical professional, or members of family who took over the participants' control regarding making the decision to go into the home.

Well, no, it wasn't, no, wasn't my choice. And then my time was up (in rehabilitation) and I moved up to here, which I'm glad of, but it's too far from home. (Odie)

I had in mind that I would (go to a nursing home), that he (husband) would put me in here, because I realised that he couldn't look after me. And he couldn't go to work or he couldn't leave home, and he'd have to be with me all the time. So I realised I'd have to go somewhere. So I came here all of a sudden. I fell over and I couldn't walk, I, I didn't think I was going to get better. (Nellie)

My daughter looked after me for over 10 years or more on her own. Anyway, it was getting her down, you know. And she wanted a break, so her husband said, ‘Would you mind coming in here (referring to the nursing home)?’ No, I knew, I knew it would be (for) a while. (pause/silence) I think it is gonna be forever. (Kitty)

This sub-theme highlights that, for the majority of the participants, going into an aged care facility is an experience outside their control. Illness or concern for the pressure from family members contributed to their need to relocate. Journal notes taken after the interview with Kitty reflected her change in behaviour during the conversation,

from one of being quite animated to looking rather despondent when talking of moving into the care home, as she described her realisation of the permanency of this move.

In some instances, the move happened quite suddenly:

And we had to get one fairly quickly, so ... we have a son (who lives near here) so we came up here. Well, it wasn't too bad, so to say, because we got in the next day. So it was a short period of time that we got in. And, ah, the good ones were booked out so far ahead. (Beryl—one of a couple)

I really didn't want to come in here. I don't like these sorts of places. But we had to make a very quick decision because this unit, as you can see, that we've got here, is ours. We bought, we sold our house, or our son did, and we had to make up our minds very quickly because we didn't have anywhere else to go. (Pricilla—one of a couple)

A number of the participants described their children had explored the aged care facilities for them. In only one case was the older person involved in looking as well. The sense of urgency experienced by several of the participants resulted in them being in a situation where they had to accept what was available. The reality was that their relocation was not something they could take their time to consider, reducing the opportunity for them to have meaningful input into choosing their future home.

#### **4.4.3. Sub-theme 2: Loss of identity and independence**

The relocation experience underpins the participants' experiences of their new life outside their familiar home; it also presents a clear introduction to the lack of control over decisions underpinning their reality. Their experiences are largely associated with previously being in command of their own home and, in losing that, they experienced a loss of identity.

Odie mentioned being '...too far from home', and this, along with missing his home life, was an experience common with many participants.

All the participants mentioned missing home life; Leo explained that he had ‘...to get away without a lot of your personal belongings’ (Leo—one of a couple). Other participants agreed that due to space restrictions they had to live with a less than acceptable amount of their private belongings. Relinquishing personal possessions invariably lead to letting go of their connection with their previous life. The reality is that the care facilities do not have the capacity to accommodate all the older people’s cherished belongings. To experience a connection with home, it was important for all the participants to have a few limited personal effects to create a sense of home:

so a lot of the stuff had to go. Suits of mine and other personal belongings that we couldn’t take. As far as furniture was concerned so, some of the things that I made over the years, ah, but there was a lot of things that we had to leave behind there ‘cos we couldn’t take in here, we are confined to a certain area down here. And other things we had there sort of thing, pictures and clocks and other things, more or less, something to make it homely. It is sort of, quite a change in life rather and it takes a bit of adjusting. (Leo—one of a couple)

Many participants explained their loss of identity as not having the ‘...freedom to get around’ (Odie), and this evoked feelings of sadness. Participants experienced this as a loss of freedom to participate in the activities that defined their previous life. This understandably caused distressing emotions and a realisation of identity loss, as they were not able to connect with those aspects of their life that were important:

Oh well, it’s different anyway, it’s just different. Well, I’d like to (have) freedom to get around, and get around the back yard and little things like that but can’t bear it when you’re locked, you’re locked in, you’re just in all day in the room. So it all goes back to living at home, like I, I don’t, don’t go, my daughter, my son visits and, but (to) take me home for a day, or two, half a day or something, it would make a hell of a difference. (Odie)

Oh, I miss a lot of that. I was a great one going out shopping. But, um, I do miss that. Yes. Not walking is a bugbear. (Ruby)

And sometimes I used to go out and sit out in the sun with the dogs. Do I ever (miss it). That little (name of dog) sees me and she goes for the life and I go and sit in the lounge ... and she flies and sits on top of me and licks me. (Kitty)

In Odie's quote, he mentioned that he would like freedom to get out and that he was locked in. In saying this he readily acknowledged that he was not really locked in his room, and that he could go out, within the confines of the aged care facility, but this was not the same as having the independence and ability to go out whenever he felt like it. Journal notes taken at the end of the interview record that Odie was very despondent. As well, he showed signs of irritation, demonstrated by clenching his fist and hitting the arm of his wheelchair. For Odie, he missed the physical side of his independence. However, it was reflected in his lived experience that he felt locked in; for him this was frustrating.

Missing previous enjoyable or familiar experiences has become a major part of the perceptions of the participants in relation to living in a RACF. People missed the everyday things, such as shopping, having a pet companion or just pottering around their own homes or gardens. Missing possessions and activities, and home life in general, was linked by all the participants to their lack of autonomy and choice. It was clear that the participants found the transition to RACF difficult:

But I like it here, it's quite nice, it took me a while to settle in. I had everything at my fingertips (at home), friends ... and it was hard. Oh yes, it was hard, really hard. (Alice)

It's not the same as home. Oh, (missing) everything, the kids, I think. The family, oh, they're, they're not home now, they're at work, but they used to call in and see me a lot. It's just that, I just don't like being away from home, that's all. But it all comes to somebody sometimes. Oh, it's a terrible thing really. (Nellie)

Oh, well, chatting to everyone I know and home life and everything, years ago we used to do fishing trips ... and that's something I miss, doing that, really. But, (sighs) life goes on. That was really the best of it. (gets upset) But don't worry about me, I get broken up (pause/silence) when I talk about things. (Quentin)

The reality for the participants was that they felt that the link with their identity and their home had been severed. Journal notes taken with the interview with Quentin indicated that he needed to pause during the conversation many times as he became very 'down', quiet and despondent, as well as 'tearing up' at times. However, he

indicated that he did not want to cease the interview and went on to discuss the positive sides of his life.

The lives of the participants were invariably linked to their loss of independence. For some of the participating older people, their inability to maintain control over decisions relating to things of importance to them was a real challenge: ‘Well, my independence is being able to do cooking or sewing or whatever I wanted to do’, (Pricilla—one of a couple). While the activities that contributed to independence appeared to differ between older people, the loss of control over their lives was the unifying concept:

I see (the cleaner) doing some dusting, and you think ‘I have already done that’ or ‘I can do that myself’, ‘I can fix it’. And that’s what I say to them ‘I’ll do that, I am going to do that in five minutes’. And in five minutes (the cleaner) got it all done. My daughter will come in and she’ll do something for me and she’ll take washing home and do it, and I’ll say ‘Look, don’t do that, I’ll just do a few things for myself for today’, and she’ll say ‘No’, she says. (Alice)

He’s the one (refers to husband in bed) who hasn’t settled down. He wanted his home, home-cooked meals and everything that went with it. Well, I mean, you don’t get that here. The main thing I miss is my cooking. Well, you see, I’ve always been a cook, I’ve always loved cooking. Pottering around, yes. Now you can’t, they won’t let us have a little microwave here. Well, the worst part I think is that you can’t do exactly what you want to do. (Pricilla—one of a couple)

The inability to do what they wanted is reflected in their experience of being made dependent. Pricilla is stymied in her attempt to gain some independence due to the regulations of the care facility; and Alice similarly, as well as being made dependent by a family member. These experiences illustrate how the participants felt they were expected to be submissive and compliant.

It is interesting to note that none of the participants indicated they ever insisted on doing things for themselves, or took up these issues with management:

Yes, oh, it (independence) has changed, well, it does. Because it’s got to really, hasn’t it? Oh, I don’t know, being independent. I think I can’t, can’t just say, “Right, I’ll go and do something today”, I can’t do that now. I’ve just got to stay here. Oh, well, I used to go and come as I

pleased, I could go, I couldn't go up the street now, now I couldn't walk. I used to walk up the street nearly every day for an outing. Oh, you lose your independence. Oh, I never notice it now, I think I've got used to it. (Nellie)

Oh yes, it did (feel like independence was lost), this place is not like home. But, anyway, I've got over that and here I am. (Odie)

It's a different life altogether, I get very frustrated. We all do. Even though we have a lack of independence, I don't think you could, ah, get much better. (Beryl—one of a couple)

Yes, it was a bit of a change, oh, as far as that was concerned, and the shock in so far as losing your independence and, it takes a heck of a time to, ah, get adjusted to it. Yes, absolutely (you lose) all of your independence really. (Leo—one of a couple)

All of the participants felt they had reduced independence. Now that everything was done for them, for some of them independence seemed to be reduced as time went on. Most participants couldn't pinpoint all the areas of independence they missed, while others suggested that they willingly 'traded off' independence for being cared for. Meanings inherent in the narratives suggest an unspoken understanding that they have to accept being cared for as it was '...a matter of having to and that was it.' (Leo—one of a couple). The reality of surrendering independence resulted in many of the participants experiencing frustration. This experience reflects not only their changing health needs that contributed to their dependence, but also their perception that their loss of independence and physical limitations were neither clearly understood nor acknowledged by their families or the RACF staff:

Yes, I have lost a bit (independence)...I don't ring the buzzer, very, very seldom I ring it, and I hate ringing it. And, I am so used to doing everything, sort of thing, for myself. And I have had that taken away from me. (Alice)

I loathe, and I mean loathe, having to ring that bell. (Maude)

I've taken bad, and it's before I could get to the toilet it's all come away and I'd better not ring them and tell them, I'll clean it up, and I've cleaned it up myself. Because I, I was too embarrassed to ring it (the nurse's call bell). Yeah, I know, I know, and they (the nurses) tell me (not to worry), they tell me that but I still, still do that. (Maude)

Alice and Maude similarly described their dislike of ringing the bell for assistance. This was a common theme from most participants and is closely linked to the issues of depending on staff for personal needs and maintaining their sense of self and autonomy. The meaning of this experience is reflected in the very strong words of 'loathe' and 'hate'. Journal notes reflect that Maude especially would shake her head from side to side and shut her eyes when describing her feelings of embarrassment in having to seek help with personal functions.

The reality is that frailty and illness have rendered some of these older people with limited opportunities to have control of their own lives, leaving them with no other option but to seek assistance. The experience can be described as one where the participants mourned the loss of their independence, but accepted this necessity to receive the help and care they required.

#### **4.4.4. Sub-theme 3: The paradox of care**

Maintaining a sense of dignity and privacy was a common element of the participants' experiences of living in an aged care facility. Clearly, the care practices of the homes meant that the older people were sometimes confronted with inadequate care and behaviours of others that were beyond their control. However it is acknowledged that moving into a RACF almost inevitable results in a loss of autonomy and dignity whilst paradoxically older people should be treated with respect as autonomous human beings whereby their independency and dignity should be maintained. Living with limited privacy often evoked unsettling emotions:

Oh, most of them go out when you tell 'em. Yes. I had a man come in here once, he came in here in the 'nuddy' one night. He got into bed with me, and I, I rung the bell and I tried to get him out. (Hyacinth)

No, they (other older people) just come in. They took all the chains off (from across the door), I don't know why they (management) took all the chains off (the door). Oh, he was always coming around here. No harm in him, but I didn't like the men coming in my room. Yeah, I'd say 'You stay there', or 'Get back into your room'. They (the chains) haven't been put back on, I don't know why they took 'em off. (Kitty)

Yes, sometimes, there was a couple of them (other older people) walking and they were coming in and taking things, you know? Taking everything, and they were annoying me and getting to the stage where I, I thought, oh God, I couldn't stand it and I shut the door but they keep.(they) learn to open the door. And then they come in, and one, one lady took, took me, took the walker and she, she pinched the, we had the walking stick in there (points to walker). They don't mean to take anything, but they do (Nellie).

Dignity was also discussed in terms of living with others, consistent with the concept of living in a public realm as opposed to living in a private environment where one has greater control. The essence of the experiences indicated that the participants felt their dignity was lost due to circumstances beyond their control and their inability to change the situation. For example, some female participants had to share a bathroom with a male resident, while others were concerned about having to use a commode in their room (sometimes in view of people passing by) as well as being exposed to others residents during toileting:

That's the only trouble I have with me is my toilet. Yes, that's why I've got that there (refers to the commode). I have to go on there because there's someone in there (refers to the man using shared bathroom adjacent for a shower). (Kitty)

No, they just had the one, this is the only room that (they) had, that had the toilet and bathroom all out there, out that door and, ah, I have to share it with a man, there's a man, in there, in that next ward. None of the others have to share anything, but I have to apparently and because he can't get out of bed. But I have to share a toilet and that with him. Sometimes I open the door and he's in there, I shut it again. (Nellie)

Such practices made the participants feel ignored and disrespected and this was reflected in their experiences. While these are only examples of issues with privacy and dignity, similar themes were reflected in many of the participants' narratives. Ruby in particular was upset that the new manager did not take the time to meet the residents of the home; while this was important to her, she was afraid of retribution if she spoke her mind. This indicates she felt she could not make complaints. This may also reflect power relations within the home, which was exemplified in another participant's experience, when staff assume they have a right to access residents' belongings without asking:

No, they've just changed managers (of the home). And I haven't even seen her, she didn't even come and introduce herself to us. No, no, 'you'd think she would (introduce herself), wouldn't she', I said to the nurse. But it wouldn't have hurt her to come in and say hello. Oh well, I suppose I'll be disowned. (Ruby)

Yeah, ah, no, they (the staff) don't even ask, they come to your drawer, my drawers and all that and they don't even ask what they're looking for. And they just come and have a look. And one of the girls just helps herself to me lollies, she doesn't even ask. She just helps herself. (Kitty)

I said 'I don't snore', and she (daughter) said 'You bloody snore all right'. And when the girls (nurses) come in, they come in to bring something into me or something and that, and they said to me and they say 'You snore like a pig'. (Kitty)

Kitty also describes living with less than respectful behaviours. However, she did not indicate whether she complained about the incidents. Some prompting questions such as 'How did you react to this situation?' directed to all participants indicated that they would not do anything about these situations. The reality for the participants was that they believed they had no control over the situations they lived within, and therefore there was little use in complaining:

Of course I will take that one (Parkinson's medication). Anything else I don't want. No, I don't like going to the manager, I loathe having to complain, I loathe it when anything is wrong. There's no use complaining. (Maude)

You might have to wait some of the time (for the nurses), but that doesn't matter. I don't know about that (reporting problems to management). I'm not one to complain really. You can get annoyed but you keep it to yourself. I don't know (why I don't report it). Just me. (Ruby)

Journal notes taken at the time of interviewing Ruby indicate that she became quite watchful and quiet when discussing concerns she may have had with the care home or the care received. This suggests worry, as it reflects living in a system where the participants felt they were unable to make their voices heard to improve their situation. This finding supports previous research indicating that older people rarely have a voice in determining their own life choices (Bowers et al., 2009, p. 53).

The older people in this study felt they could not complain as they had relinquished autonomy for care and attention. While care is meant to be personalised and meaningful, in accordance with the objectives of the aged care system, unmet client expectations are often the reality (Healy, 2011, p. 7), and this is reflected in the lived experience of these participants. A common reality among the participants was that they needed to wait for assistance, even when they were in severe pain:

I have to wait ... in particular ... when I had the spasms ... and me leg was doing sort of that. I had to wait an hour and three quarters. They've got to wait until someone comes down there ... I rung the bell again, but it was one and three quarter hours. (Hyacinth)

Oh, I've only got to press a button and someone will come. Oh, sometimes you've got to wait a while. Doesn't matter. The other night I had a bad night with me leg. The right leg, the pain was something shocking. They, they come around and give me a couple of Panadols and then I said to the girls "If I had one of me, me knives ... still got, had one of me knives, I'd take my leg off at the knee. They said 'Gerry, don't start talking like that'. I said 'Well, I mean it'. (Gerry)

Due to the time it sometimes took to get assistance participants felt that their care needs, and subsequently their rights, were not always met. This reality also exemplifies how the focus of the aged care system is more on governance and compliance with policy and practices (de Bellis, 2010, p. 19), which reduces the time staff have to provide care. However, the participants were aware of the pressures on staffing in the aged care sector:

I think I'm quite lucky, but there are times, and things don't go right, such as last night. I take, (Ruby shows me a Webster pack). No one ever comes to see whether you've taken them or not. Oh, everyone here says they (the visiting doctors) only come in every now and again too. I said I don't want to end up around in the coroner's court. (Ruby)

Oh, I'm starting to walk around a bit now, I don't use me whasaname (walker). I just walk around. Yeah, and they go crook, because I'm not supposed to. (Kitty)

I'm not supposed to, but I do, I get up and have a shower. There's supposed to be somebody around but they've got other people to attend so I shower myself, but I get, have to get them to make the bed and that. Staff everywhere is very hard to get. (Maude)

It was 11 o'clock when they came to shower me, and I'd had it, I was wild, I mean they could have put another girl on and be a bit better

organised. I said to the girl 'I wasn't happy with that, I didn't have anybody.' And the bed wasn't made until nearly 12. You know, I was fed up. And I thought I wasn't very popular, I'd said too much. I thought 'Oh well, blow it.' I said 'I've been easy, I've been easy.' She said 'Yes, you're one of the easiest patients we've got.' 'Well,' I said 'I'm not now.' I said, 'I'm cross.' Because I was left to that hour, nobody came near me, no one came in that door. No, that's about all. I'm getting over it. But I think they are a bit inclined to do that, that, they'll cut down on all the staff, and the patients suffer. And that's not right. They shouldn't do it. (Nellie)

The participants felt they had to accept sub-optimal care practices as part of their daily lives such as poor monitoring of their medications, walking unassisted when they should be supported with walking aids, and managing their own personal care needs. The lack of control over the level of care they received was a reality for many of them. This reflects the challenges that face the sector with regard to care home management and staffing. It also places the participants in a position where they may be at risk. Upsetting emotions were also evident when the participants described being ignored or not having their needs met. Thus, the paradox for these participants is they have traded their autonomy and dignity for the level of care they require, only to find that care is difficult to achieve for pressured nursing home staff.

Similarly, the paradox of care is reflected in other areas of nursing home life, such as food service and attention to nutrition. While there are strict regulations and a need for compliance with adequate food levels, the experience for the participants was that they had very limited choice and control over preferred food options. It was clear that the system could not provide the type and service of food that they were used to or desired. As Charles says, 'I wouldn't wish it on anyone'. The answers reflected comparisons with the types of food that the older people were used to. The experience of food service indicated that meal times were not be as enjoyable as they were in the participant's previous home life. Mealtimes were described by participants as defining part of the daily structure when they were in their own homes, and most described having to go through a readjustment to acknowledge that this part of the day was possibly not what it used to be:

Well, they haven't got a regular chef here, you know a girl might do the cleaning one day and the next she's in the kitchen cooking the meals. This is the ordinary floor staff cooking the meals. I can imagine what's it's like, they gotta cook for 50–60 people, they just whack it on a plate. To look at it sometimes just puts you off it already. (Leo—one of a couple)

It's not marvellous ... It's a good thing I'm not hungry, but they've got so many to feed, it can't be ... and all the cooking, and the lack of funding ... I wouldn't mind having a hot meal at night instead of the middle of the day, but I believe most nursing homes are like that, hospitals too, so you have to accept that that is the way it is. (Beryl—one of a couple)

I don't like 'em, I don't like 'em. Don't like the flavour. Each meal you don't get a choice. (Charles)

The lack of choice was also identified by participants with regard to routine tasks that affected their care and comfort. All the participants described how they became aware that rules and regulations reflected their new life. Their autonomy was reduced: so too was their ability to experience anything other than the care offered and available. The routine of aged care facility life is such that many tasks have to be completed in a set timeframe and in accordance with regulated standards documented by managers:

Oh, all right, they shower you every morning. That's what I don't like, you don't really need a shower, when you're in bed, in, in a home, you don't really need one every day. Really. I don't have one every day (at home). Now and again, I get jack of it. No, I don't need it. They do that early, I wake up early because I go to bed early, but they get me up and shower me. And dress me. (Nellie)

There are little things that upset you at times, but you've got to expect that. Well, not having a shower until it's getting onto to 10 o'clock, and sometimes it's six o'clock. But that's to be expected 'cos they've got a lot of people to look after. (Odie)

While the care experience for these participants was not always satisfactory, and outside of their control, so too was their ability to engage in personal, meaningful leisure time. Although they describe opportunities to engage in some chosen activities, the reality for the participants is they felt they needed to comply with the rules of the care home and were not free to do what they wanted. As Hyacinth suggests, 'I'm not allowed to':

No, I don't (go to the dining room), they don't really encourage you, so I ... just stay. I could go down, but they bring my meals so ... I just stay. (Beryl—one of a couple)

Oh yes, I can sit here and read me book anytime, all day if I wanted to. I go for a walk all about. I've got to keep walking or otherwise they'll put me to bed. Because I don't want to go to bed. It's terrible to see the people in bed. It's shocking. I don't like that. (Fred)

She (daughter) promised that when I wasn't able to drive myself to church, she would take me. And now she won't, she's got bad shoulders and she won't take me down the street. No, no, they're (staff) not allowed to. No, I would like to be able to walk down to that shop. (Hyacinth)

These participants acknowledged that their ability to participate in familiar activities was limited and they accepted that staff and families were not always able to meet their needs in this area.

This theme clearly illustrates that the majority of participants believed they were living in a world where it was not as easy for them engage in meaningful participation in decision making about what they do in their daily lives. This theme evolved because of the combination of participant's similarities in their understanding of care home governance and their place within this system. This is reflected in their 'instrumental passivity' (Harper Ice, 2002, p. 346) and their transition to interdependence on staff and family members. This finding is in direct contrast to the objectives of new ageing policies of promoting autonomy and healthy ageing (AIHW, 2012c), discussed in Chapter Two, as well as the objectives of the *Aged Care Act 1997*, specifically to 'help those recipients to enjoy the same rights as all other people in Australia'. While the respondents experienced a lack of control in choices, many described their relationships with staff and family as contributing to meaningful life experiences.

## **4.5. Theme two: ‘If you haven’t got that sort of contact, it would be difficult’: Important relationships**

### **4.5.1. Introduction**

The theme that emerged was that maintaining relationships with others was very important to all the participants. They described the close bonds they had with their significant others and the relationships they developed with one or more staff, especially those who spent time with them and got to know them. Some participants discussed problems with continuity of staff and highlighted the importance of family relationships. The reality for the participants was the need to maintain family connections, wanting continuity of carers, craving company and communication, and dealing with living their lives in a public realm. The decision trail for this second theme is presented in Appendix G.

### **4.5.2. Sub-theme 1: Continuity of carers**

The significance of the participants’ relationships with staff is the focus of this sub-theme. However, in all instances this related to relationships with the permanent staff. The older peoples’ experiences with casual staff members were clearly not as positive:

The last 10 days I reckon we were, we were 60–70% agency staff. Yes, a few months, a few months ago one or two agency girls, and I should have reported it, and she came in, and she was looking for (lady X), the lady next door. Ah, ‘Hello (lady X), how are you?’ (said the agency nurse), I said ‘That’s not (lady X)’. ‘Oh, yes, that’s (lady X), here are your tablets.’ I said ‘No, you’re not on your life, you’re not going to give those tablets to her.’ ‘No, no, that’s (lady X).’ She said ‘That’s Room 19’. I said ‘Have a look at the flaming door then’. ‘Oh’, she said ‘I’m awfully sorry.’ I should have reported that. But that sort of thing can happen, you know. ... ah, you see, the regular girls know the quantity what they have. I should have reported that one.” (Leo—one of a couple)

We’ve a lot of agency here, that’s one thing about ... see when you have to take tablets or take medicine, you get used to the same nurse coming in. ... because you get used to the (regular) nurse coming up and she gets used to you, and you, and she knows what you take, otherwise they get all confused especially with the tablets and things like that. You like to

have your own medic-nurse like that. No, I'm quite satisfied because I know I'm right up here (points to her forehead), and I can tell if I don't take this or I don't. This has happened before. Now, look, in this end (of the drawer), I've put them (spare tablets) in here, if anything happened, the tablets didn't come, I've got some, I'm right. (Maude)

These participants described their concerns with being attended to by temporary or casual staff, highlighting the value of relationship continuity between carers and older people. The majority of the respondents believed that care was safer and more meaningful with regular staff. The reality for the participants was that care suffered because of the inability to maintain a personal and informed relationship with daily carers:

Because it is a nursing home, but they're pretty good, they're, you know, some, at the moment we've got agency ones, but they're not so hot. Oh, I don't know, they just have to learn. They were, they are no good, they're, they're the youth of today. Oh, they're no good, hopeless, they're not trained properly, they can't shower you, all they do is just put water all over you, and of course, put no soap on you. Oh, I complained about that one day. (Nellie)

They are very good, but at the moment we are having a lot of extras (agency staff). And it's getting quite a habit. I mean I'm not being selfish I don't think, I mean these sort of people think they know it all, well, I'll give you an instance the other day. We were in the big room and they gave me a tablet, she got a glass out of the kitchen, and there was something in it, I got a very... this dreadful thing in my throat and I couldn't talk and I was choking and she said 'Sort yourself out'. As I said, I had that person, it didn't work and I said to them 'Don't ever give me that girl again.' Yes, there's a lot of that and you've just got to accept it. (Pricilla—one of a couple)

The relationships with regular, caring staff who took time for personal exchanges appear to have a positive effect on living in an aged care facility; however, transient staffing and changes in routines were described by the participants as unsettling and placed the participants in a situation where they felt that their care had to be negotiated. This is a significant challenge for an aged care system that depends on agency staffing to continue. The literature links this to low pay rates for permanent staff and the dominance of documentation taking regular staff away from caring duties (Productivity Commission, 2011a, 128).

The above narratives also highlight the respondents' perception that permanent staff members were more competent than agency staff. The meaning of these experiences was that while there was a degree of concern with their situation, most participants accepted the situation without formal complaint, despite their frustration. As mentioned previously, maintaining meaningful communication with family was also a significant part of being able to cope with facility life. To a degree, such relationships countered the sense of hopelessness they experienced with staffing and care issues.

#### **4.5.3. Sub-theme 2: Relationships with family**

Many participants described the importance of connections with family members and their continued participation in their lives as a very significant part of coping with living in the aged care facility. The experience for some highlighted their changed status from their traditional role of care giver, to a receiver of care:

The position's altered now, mother and daughter are the opposite. She helps me ... for all the years I mothered her. She does all my washing and ironing, she takes it home. She brings them all back and ... colour ... I lose colour, and she says 'Oh Mum, you can't wear that with that', and she puts them all on different hangers with what to wear. What goes with what. (Alice)

For the participants, their changed position in the familial order reinforced their experiences of being dependent living in a care facility. The respondents experienced similarities in their appreciation of family members, even just knowing that they were going to visit or that they were close by:

My wife comes in once every day to make sure I'm all right. Not to say much, right, but to get me out of bed, get me fixed up, in there, oh, hour, two hours a day. (Quentin)

You want your friends and family not too far away. (Beryl—one of a couple)

These connections gave the participants peace of mind and demonstrated that the experience of family visitations was meaningful. It also highlighted for Nellie that visits contributed to 'breaking up' the day, as 'The kids come in, the three boys come in different days, and that takes over.' The level of importance in knowing that family

were around contributed to a positive experience for participants and the act of visiting appeared to give them something to look forward to and cherish. This indicates that family visits were fundamental to their enjoyment of life and were something they highly cherished. This also suggests a lack of meaningful leisure opportunities for some participants, as their stimulation was greatly improved by visitations:

You see now, there's quite a few now, their partners, are, you know, coming in every day, and sort of coming, and they've got someone else to talk to. It makes a difference. (Derek)

For other participants, the significance of visits was linked to feeling safe and secure, as well as being more motivated to interact with others. Participants described the reality of loneliness and losing one's self if they experienced a lack of company and interaction. The effects of lack of interaction and how older people perceive themselves is clear from these participants' experiences:

(Husband) misses his security, that to me is what he misses. In every way. I think he feels very unsafe. I don't really know, I haven't been able to pinpoint it yet, I can just sense it, I can see it, but ah, oh, I mean (son) comes into see us every other day, I mean we are very lucky. Oh yes, if I say to him 'Now son's coming', well, he'll get up and get dressed and do everything. But then on the other hand (if son doesn't visit), he just doesn't want to. Yes, no, as I say, I'm quite happy, I mean, as I said (son) comes and sees us which is a great asset, and then you see I've my other son that I got in (different state) and they come over here. And they write, and they ring me, always ringing me. (Pricilla—one of a couple)

But I think what makes the difference is that we're together sort of thing and we talked things over there, once you're on your own there in a small room eh, you've got no one to visit you, no one to converse with ... you start to fall back into... and you get smaller, smaller and smaller, and in the end you couldn't care less about whether you're alive or dead...Quite happy together, both of us. As long as we can be together, that's the main thing." (Leo—one of a couple)

The reality for couples in the facility is that they are grateful they have each other, but like single participants they still greatly appreciate interactions with family members. It is the comfort of knowing that family are supportive and part of the participant's lives that is important to them. The reality for the participants is that relationships have significant meaning and value within their lives.

Participants who did not have family experienced loneliness as they readily acknowledged the value of others' family visits. Others who had family appreciated that there could be a corresponding loss of identity with a lack of family contact, as 'you get smaller, smaller and smaller and in the end you couldn't care less about whether you're alive or dead' (Leo—one of a couple). Leo lived in the facility with his wife and re-emphasised that as long as they were together, they were happy. The fact of being together reflected the true essence of experiencing the enduring relationship's value.

While family relationships are of utmost importance, the reality for most participants was that they reduced their level of expectations on family as '...you don't expect them much either, they got to live their life themselves. That's the point.' (Quentin). In asking questions such as 'What are some of the best times here?' Participants would describe family visits but also indicated their reduced expectations for frequent or continued visits:

All my family's gone now, bar my own children ...they've got to come from town down here, but he's marvellous, my eldest son. He comes down to make sure I'm all right. But no, I think it's wrong. I feel, ah, they have got their lives to finish. And not to be having to rush out here, not rush, but to come out here and see that I'm all right, and take me out and all that. I feel that they should be free to live the end of their lives also free. (Maude)

cos they're working too, they can't come in all the time, but they come in when they can. I like to see them. (Nellie)

Journal notes indicate that all participants exhibited a sense of sadness about not wanting to place expectations on their children. The participants believed that they were a liability to their family and this made them feel sad. The participants understood that living their lives in a care facility would reduce expectation on their families:

They would be quite willing to have me there, but I don't want to sort of, I have always said that I wouldn't live with my son or my daughter, because I think they have to be by themselves, you know, cos they have family too. (Alice)

And it was time I had to go somewhere and I never expected my children to take me in. (Isabelle)

The reality for participants was that while they relished family visits and placed great importance on these relationships, visits were not frequent. Some participants found it quite hard to talk about family relationships:

My daughter, the ex-wife and granddaughter, grandson I should say, and his wife, but no, they don't come down much, but a little bit, but (silence). (Quentin)

#### **4.5.4. Sub-theme 3: Living in a public realm**

The enduring relationships that participants described with relatives and some staff members clearly played an important role in contributing to their QoL. The respondents' beliefs indicate a critical need for company and closeness with others. It is clear that these relationships are critical for wellbeing and the participants' ability to cope with facility life.

Some participants made sense of living in the aged care facility by developing relationships with other older people residing in the home, which also contributed to a meaningful living experience. The experience for the participants was that they were employing a range of coping mechanisms to assist them in living in the aged care facility and forging relationships that were positive and meaningful. To illustrate this phenomenon, the quotes detailed below indicate that the interactions can be on any level; they all constitute meaningful relationships as experienced by the participants:

You know if I walked down the road, down the passage there, I would say hello to everybody. Or I could just go by, but I don't believe in that. I think if you've having to live with them, just say hello. (Pricilla—one of a couple)

I've got to know them (the other residents) here. Yes it helps with living here, you've got to get to know a few people. Even if you don't know their names, you would never remember them all anyway. But you say hello, they say hello, just get to know them all that way. (Nellie)

Yes, you make friends, you know, I've got a lady at the same table, and she's deaf and blind and I am going blind. Yes, and I just feel that... I

have got something in common. Where I can sort of see what has happened to her. (Alice)

This indicated that the meanings attributed to daily life in the facility are understood by those participants: their belief is that they are able to understand others' experiences. In reassuring others, the participants undertook a process of reciprocal understanding and acknowledgement. It further indicates that they may be more aware of obstacles to fostering relationships and therefore they actively seek to communicate with others:

Yes, and in the other rooms and across the road there when she sings out 'Nurse', yeah. She's all the time doing that and no sooner than the nurse goes out, she's doing it again, she's calling again and the girls get sick of it. She's not bad now, I started to talk to her and she's talkin' to me. We're getting on all right now. I don't yell at her now, I just let her go. (Kitty)

Yes, and I go over there and lecture that one (indicates towards another resident's room). She says 'You'll hit me', I says 'I don't'. She says she can walk. She can't. And then I tell her that nothing can make me more happier to be able see you walk and get around. She says she's in jail and in different places. (Hyacinth)

When we get a new resident down there, I always ask the girls (staff) 'Is she able to talk?' sort of thing. And if they say, 'Oh yes, they're quite good, they are just handicapped physically', sort of thing, I'll go up there and have a natter with them, you know and tell them that they've got a beautiful staff down there, the girls and it makes all the difference. (Leo—one of a couple)

Coping in a communal environment, as opposed to one's own home, brings about many changes and challenges for the participants. The reality was that interacting at any level was important. Although many experienced difficulty coping in the facility, they universally acknowledged that 'getting along' with others was vitally important. Fostering these relationships was something they took on as part of a meaningful participation experience.

#### 4.5.5. Sub-theme 4: More than care

Prompting questions such as, ‘Tell me more about your experiences with the staff’, were used to investigate the participants’ perceptions of care staff. Although most had great praise for the staff, some acknowledged there was often a lack of staffing resources and funding for some care aspects, consistent with investigations into the aged care sector (Productivity Commission, 2011). The participants acknowledged management and social policy issues regarding care delivery; however, the inconsistencies of adequate care appeared to be offset by their relationships, albeit limited, with staff.

This last sub-theme also emerged because of prompting questions such as ‘Tell me some of the things you like about living here?’ The relationships that the older people had with staff were important, considering the participants spent many hours each day with them and were dependent on them for their daily needs. The reality for the residents was that as they became accustomed to facility life, they duly accepted the care that was offered, and were grateful for what they received:

Oh well ... I am used to the staff as I can't do anything on my own now. But they are always there, they don't mind. They are very caring. Often they are short on staff and they have to work harder, sometimes the patients suffer. Some people expect care like having a private nurse and to be completely everywhere, but they can't do that. But they are very kind and very caring. So I was pleased when I got a place, a friendly place and a place where the nurses cared for you, they didn't just do what you asked them to do, they cared for you. I think the care is what I like best about it. I've quite accepted everything. (Beryl—one of a couple)

The participants acknowledged their dependence on the staff. Despite problems with some staff, a consistent message was that, ‘There are certain ones you don't get on with ... you wouldn't get on with everybody anyway.’ (Nellie). It appeared that most functional care needs of the older people were met. However, the underlying feeling of most participants was that they needed to accept there would be issues with staff and to adopt a tolerant attitude:

I get on very well, I can't complain. Oh well, there's some that'll treat you extra good, and some that'll treat you just right, so I can't complain about anything. (Odie)

Well, I get on with most of them, there are some that I don't, ah, two or three that I am not too keen on at all, but it's like everything, I just put up with it. If they're put here to do a job, they're to do it, I mean, that's my opinion. You have to mix with other people (staff) and you have to be patient with people. And if you're patient with other people, you get on ok. (Pricilla—one of a couple)

The reality for most participants was that they wanted to interact and have a good reciprocal relationship with the care staff. Being able to talk with staff was important to all of them, even if, as they stated, it was only for 10 minutes. Most participants perceived that staff were often too busy to spend quality time with them. However, it was clear that the time staff did spend with participants constituted an important aspect of their lives:

You'll get one who will just come and dump everything, your meal and everything in front of you and say nothing or some, they'll come in and talk and carry on, they're, they're a lot different, but, well, you've just got to put up with that. (Nellie)

One of the nurses there, she thinks I'm a Collingwood supporter, that's me gift (hand knitted scarf), she thinks I barrack, I barrack for them too. Makes your day, you know. Here, they're (staff) up and down the passage all the time, they're working admittedly, but you know there's someone there, when you need, which is good though admittedly. Oh no, I couldn't fault them. (Quentin)

Favourite things? Oh well, talking to the staff, and I think that's about it. But, ah, they're very good. Some of the night staff I love, you know. They're lovely, the night staff. (Ruby)

Ruby specifically refers to the night staff and this suggests that the carers who work in the evenings may have more time to spend with her. This indicates that even when staff are under pressure and may not have much time to interact with older people, a brief interaction can create an opportunity for carers and residents to enjoy a relationship beyond just meeting care needs. This may also relate more to daytime staff who, because of their more regimented routine, must complete tasks on time. It

appears that the 'odd 10 minutes to chat' and just knowing that carers were around gave a sense of safety and significantly improved living in the aged care facility.

Some participants described how they had developed close relationships with staff. It appeared that the staff supported them in more ways than just attending to their daily personal care and assistance:

Oh, yes, they (the staff) bring their family in sometimes to meet me.  
(Beryl—one of a couple)

They are friends of ours and they treat us like that, they're company and they don't just take the sheets off and clean up and take off again, they stop and stay here for 10 or 15 minutes, they have a natter with us, they tell us their troubles at home and their experiences. (Derek)

Absolutely yeah, if you haven't got that sort of contact (relationship with the staff) there, it would be difficult. Oh yes, there are some that come in and talk for about 10 minutes and talk about their personal troubles or experiences, or after they have been on holiday, and when they go on holiday, they'll say 'See you in a fortnight'. We get all their stories about their teenage daughters and we say we've been there, done that. That contact the girls have, I reckon, makes all the difference, you know, you've got sort of a family feeling with them. (Leo—one of a couple)

The reality for the participants was that a close connection with staff enabled a reciprocal relationship underpinned by confidence and trust. The personal information shared with the older people can be considered a reciprocal association rather than just a resident/carer relationship. Carers have intimate knowledge of older people; as such, the older people are highly vulnerable. The chance to engage in personal discussions with the carers empowers the older people and creates a more equal basis. As older people have life experience, they are able to understand and appreciate some of the issues or troubles experienced by staff. This may give the older people a chance to give something back to the carers. This constituted a positive experience for the respondents.

It is interesting to note that none of the participants criticised the care provided by regular staff or complained about overall treatment by their carers. This theme indicates that any mixed feelings towards care staff were accepted as part of living in

a facility, with participants sharing similar attitudes of tolerance in exchange for closeness and friendship. The essence of the experience for the participants was that their relationships with staff, for both functional and comfort/companionship needs, was very welcome and contributed to making a positive difference in living in a facility. Although family relationships were highly valued, there was a reduced expectation for visits in some instances. Coping in the facility was an experience of ‘give and take’ where participants respected others in the facility, but there was no indication of any enduring relationships between participants in this study.

## **4.6. Theme three: ‘You make the best of it’: Resigned acceptance**

### **4.6.1. Introduction**

The third theme addresses one of the main objectives of the study, which was to investigate the overall perception of RACF life and how care could be improved. When discussing life in the aged care facility, all participants displayed a resigned acceptance that their life in the facility was finite, and they could not return to their original home life. For most, they had witnessed death in the home, as well as the conditions of the dying, and linked this with their own mortality. While their resigned acceptance of death and their less than ideal life in the home was accepted as a true reflection of their reality, participants still worried about getting frail. However, most understood that while this was sad, they needed to remain positive. The theme reflects a lived experience of dealing with death while making the best of it. The decision trail for this third theme is presented in Appendix H.

### **4.6.2. Sub-theme 1: Mortality**

As discussed in theme 1, the participants invariably acknowledged that they would spend the rest of their lives in the home. It was not necessary to ask prompting questions during the interview regarding the finality of place. Rather, participants willingly broached the subject and spoke fairly freely about dying in the home. The essence of this experience was common across all the participants’ stories as it

constituted a true reflection of how they saw their own lives, and the lives of others: 'You ain't going home.' (Ruby). The reality was that they had made the transition from living at their own home to living out the remainder of their years in the home:

So I haven't got that much longer to live so ... so I'll be alright. Yes, that's what I mean, so I don't worry about that. It's as good as I'll get, and what I could ask for? (Fred)

Oh well ... somewhere to live I suppose. Oh, well, what can you do? (sighs) You can't do anything. You sit in your room on your own... I knew I had to get used to it because I knew I'd be here till they cart me out. (Gerry)

Oh yes, but it's, ah, the place to be if you're not well and your husband can't look after you. Yes, I don't think I'll ever get out of here. I don't think I'll ever get out of here now. (Nellie)

Some of the ladies that come in here after me and they say about going home, and I say 'You're here to stay'. (Ruby)

Acknowledging their inability to go home evoked strong emotions and sadness. The meaning attributed to this particular sub-theme is typified in the quote from Odie:

And then my time was up (in rehabilitation) and I moved up to here, which I'm glad of, but it's too far from home. I'm a little mobilised, I can get around, but I just want to see home, but anyhow, so anyway, we've settled on that, that I'm not coming home. I'm, I'm very, very crook on this. (Odie)

Journal notes taken after this interview with Odie indicated that he was very upset by his situation. The reality for him was indeed a great sense of loss and this was a feeling carried by most participants. Concerns for their own mortality underpinned their existence in the home: they were there because they had no choice and duly accepted their situation. While the reality regarding the finality of place was eventually reconciled by most participants, differences in conceptualising the inevitability of death were apparent, with some participants more readily acknowledging they were prepared for this transition than others:

It (nursing home life) doesn't really worry (me), I know I won't be here that long. (Kitty)

But that's life, 'cos I'm quite happy here. Really. I'll be carried out. (Isabelle)

It's a part of it now, isn't it, we're used to it now, sort of thing. We know we can't go back on our own, on our patch anymore. But, no, you know beforehand when you get here, that it's the last stop, innit? (Leo—one of a couple)

Living with death appeared acceptable to most participants. Their experiences clearly involved living with those dying around them. Some participants expressed sadness in relation to this situation. However, there was a general acceptance that death was inevitable and it '...doesn't affect us' (Leo) as it was part of their lived experience. The reality for the older people was that the home constituted a place for dying and they were intrinsically involved in living with death, which they tolerated:

I was thinking about that the other night when I was awake in me bed, how many would have passed away? Since we were here, and how many are left here that we know? And I reckon there that there would be thirty-odd that's gone. It happens quite often. Sometimes two in a week. Oh, it doesn't affect us. There's quite a few that have passed away, (X) passed away there, (Y) passed away there sort of thing and (Z) laying on the bed there, she doesn't come about the floor anymore. No, no, that doesn't bother us. We're quite settled in now. (Leo—one of a couple)

Last week there was, was three that died. Didn't worry me. (Kitty)

And, you see, yesterday, we had a little service, we lost one of the ladies and we had a little service up there for her yesterday. The funeral, I presume it's today, I don't know, we had a little service for her yesterday. Well, sometimes it affects me, it all depends if I get to know or near to people, you know what I mean? (Ruby)

Reflections on the interview with Ruby conjured up a 'matter-of-fact' response to talking about death as something to be expected, part of everyday life. The obvious understanding for the participants was that death occurred and it was part of the everyday conversations with staff, supporting earlier research in this area (Osterlind et al., 2011, p. 540). The reality for these participants was that they were prepared to accept death. Nevertheless, this still constituted a challenging situation when they were exposed to others dying and this was experienced with some feelings of worry and sorrow.

### 4.6.3. Sub-theme 2: Dual realities

Witnessing a decline in other residents was a difficult experience for most participants, and again gave rise to their own feelings of mortality. It appeared that the meanings ascribed to living in a dying world lay in worrying about their own future in the home, and how they may 'end up':

Well, I don't (relax). I go and tell her to be quiet (refers to another resident yelling) or she might want something, drops something, I'll go and do that. One day, you might be like it yourself. (Hyacinth)

And then afterwards she might (stop incoherent talking), I talked to her last night, I heard her going on, but I think, you never know, you might be like it yourself. (Ethel)

Both Hyacinth and Ethel reflected on their own future because of observing other's conditions. They felt it was important to assist others in these predicaments. They believed they might end up like that themselves, possibly hoping that, in turn, others may help them in the same situation. The meaning they ascribe to these experiences is one of sorrow.

Similarly, other participants understood the predicament of those who were not able to exercise any control over their lives, and this evoked upsetting emotions. Journal reflections for Alice and Gerry indicated a great deal of sadness. It was as though they were re-living the situations when they spoke, and the genuine sorrow was evident. While interviewing I could place myself in the same situation and understood exactly the experience being recalled. Leo reflected on the possibility of losing identity by being institutionalised and understood this particular experience as daunting:

I've seen that here with a lot of people, we've been here over the last 18 months, and we've seen it with a lot of people. They go back in their own little world there and they don't, they stay in their room most of the time and it comes to the point where they're still quite physically to be able to get around in among a group of people to get back into the mainstream of life. I'd imagine so. I can't, I don't know what other people feel like, but in my opinion it would be. If I was in that situation, I don't think I could go that way. (Leo—one of a couple)

I feel that I don't want to be like that. Yes, and I feel that a lot of people just stay in their room. And they don't get out for breakfast at all, and they don't go, sort of thing, outside. And I think that's very sad. (Alice)

But the only thing I think that I get a bit sad about is just seeing the people being fed. And that worries me and I hope it doesn't happen to me and I feel so sorry for them. They can't do anything. (Gerry)

While the participants accepted death as part of aged care facility life, they appeared to be more concerned about the deteriorating health that affected the dying. Aged care facilities are traditionally places where rooms are close together and there are common areas for older people to congregate and freely see other older people. How the older people process this information varies, but it appears that they relate those with deteriorating conditions to their own situation. The lived experience is challenging for some older people and they described their thoughts of, one day, being in a similar situation to other older people with dementia and/or in a palliative state. The reality for the participants was that they could see how others were living and they related to them. They realised that their reaction to these unsettling conditions, and possible future life for themselves, needed to be dealt with positively. This represents an acceptance of their situation.

Many of the participants described a positive attitude as non-negotiable 'Yes. You've got to think positive'. (Isabelle). The majority of respondents believed that to live in the RACF an optimistic and positive outlook was helpful. The participants often described their situation in relation to that of other older people and how they saw the lives compared to them. This theme was common to all participants, highlighting their awareness of their situation. The experience of ageing and becoming more dependent on staff created strong emotions. Despite this, the reality was that they kept a positive outlook on life:

You make the best of it. Well, our attitude is that we've got our whole lives in front of us, innit? (Leo—one of a couple)

Well, I hope I have (a positive attitude). I look at it from all angles, that's what I say. You have to. Otherwise you couldn't live in it. You couldn't live in this environment if you didn't have patience. Give and take, that's what it calls for. Oh heavens, no, it's not an easy world but, then again, you get there. (Ruby)

The reality for Ruby was that there was a necessity of accepting dependence and adapting their lives accordingly. While the participants discussed the aged care system that constrained their autonomy and choices, the majority described how they made the best of it:

Yes, you've got to have a positive attitude, a happy attitude. It does (help). Well, there's a lot of other people worse off in here. When I came in here I was the only one who could get around and walk and talk to people. The others couldn't talk. I just accept it. (Hyacinth)

I am a positive person. I say I realise what the situation is ... there are a lot of trained staff here who know what they're doing and they are very good to me. (Beryl—one of a couple)

The 'glass is half full' approach is actively endorsed by Hyacinth and Beryl as they have accepted that their situation could be worse. Although the participants were living a life that offered reduced choice and autonomy, many said they remained positive, and this constituted their dual reality.

The participants described how they needed to be positive and maintain attitudes conducive to life in the aged care facility. However, some experienced coping through distancing themselves from mainstream aged care facility life, to avoid seeing others who were dying/disabled. This particular experience is discussed next.

#### **4.6.4. Sub-theme: Ageing**

The variety of people who lived in the aged care facilities was a topic of interest for the participants. No one specifically stated that they should be separated from those with dementia or significant frailty, although they did express disillusionment and some adopted avoidance techniques. Most of the participants had a good understanding of the behaviours associated with dementia and were tolerant of older people who had dementia or were in a palliative condition. Being exposed to others frailty and decline was still a negative experience for most participants:

It is upsetting to see people decline. I don't allow myself to get close. And I don't allow myself to get close to anyone. Very few walk out. (Isabelle)

Before, in my lifetime, I was always very sociable. But I've grown more like I'd like to be on my own. I like my visitors, my friends to come in, because a lot of them, most of them (other residents) I think, are a lot younger than me here, and I don't know, maybe because I have seen too much of the dementia and that around (in the home). (Maude)

I sort of, sort of, don't get out into the big room a lot. They said to me would I have my lunch out there when I come here. And I said, I said yes, I'll go out there if they all have their lunch out there in the big room, not all of them. And I went out there a couple of times, but I was sitting with all of those who weren't saying anything, they don't talk, I mean they can't help it. But they've got to be fed. So they feed them out there. Well, I knocked off going out there, I said 'No, I didn't like sitting there. I'd rather have it here on my own.' Yes. It doesn't make me happy seeing all them out there, I feel sorry for them, but I, but I don't like the look of it. No, no, I'm, I'm happy here, apart from that. (Nellie)

The reality for some participants was that they have 'grown more like I'd like to be on my own.' (Maude) and have changed their expectations and behaviours to avoid being in upsetting situations. Disengagement in this sense is phenomenologically understood (Tornstam, 1989, pp. 55-?) and reflects the lives of many of the older people. Changing behaviours give meaning to experiences and, for these participants, represents how they cope with RACF life. For example, Nellie suggests that she is happy with the home apart from witnessing distressing conditions of others. The reality for Nellie is that the distressing conditions are there to stay and cannot be divorced from mainstream RACF life.

The complexity and nature of the aged care system allows a variety of persons to live together, with a very broad range of illness and frailty, endorsed by policies such as ageing-in-place (DHA, 2002, p 4). As such, older people must live in a diversity of conditions and circumstances, and these can become confronting. Due to this, the essence of the experience uncovers many upsetting emotions for those who are ageing and have difficulty in coping with 'a very difficult situation to be in. Sometimes I take it, sometimes I don't' (Pricilla).

As part of aged care facility life, older people are together 24 hours a day and they witness others' suffering and disabilities. Experiencing stress and distress was a reality for many. Upsetting emotions illustrate the phenomenon of living in a communal situation. These feelings, which represent the meaning of their experience, were discussed because of questions such as, 'What are the worst things about living here?' Emotions were also uncovered thorough dialogue relating to other elements of RACF life:

As one of the nurses said to me the other day, and I think it was her son, he had to have his dog put down, he was, he was saying 'They put a dog down when he gets too old or too ill, but these people are left here.' And it's terrible when you've got to have a commode chair here of a night-time here, and you can't get out to the toilet, and they've got to have their bums wiped and everything, oh, and they can't even tell you that they want to go... and no, I reckon it's terrible. (Maude)

But this is it, I'm sure nobody wants, I'm sure you don't, want to finish up in a nursing home. It's just seeing people like that and a lot of them are younger than me, oh yes, which I didn't realise that. (Odie)

Yeah, it does get me down, lying here, thinking things through. I don't know what, there's only me and another two who are normal. All the others are old, have got something the matter with them. Yeah. A lot of them, a lot of them just sleep, sleep all the time. No, no, no. (Kitty)

I didn't think I'd end up in a nursing home, but ... I did, so. Oh, it's quite good. Been pretty good. Oh, occasionally, I get a bit depressed. I don't know (how to get over it), I just have to. Yes, you're here to stay. (Ruby)

During the journey of investigating experiences (van Manen, 1990) the emotions combined to illustrate parts of the participants' lived experience. While these emotions represented a negative experience, it was clear that in this study the participants acknowledged and understood their situation, and they assumed a resigned acceptance that this was their 'lot' in life. Interestingly, no one indicated that they were moved to action to change their conditions. In response to the prompting question, 'What would you do to change this situation?' it was interesting that no one volunteered any options or alternatives.

This theme highlights that, for many older people, their life in the aged care facility was one that they may not have been prepared for. They found adjustment difficult, so they adopted a positive attitude to help them to live in the RACF. The participants described experiencing the illnesses of others and acknowledged that they themselves may face a more frail state in the future. This led them to reflect on their own mortality and remaining years. The essence of the experience for the participants was that they had adopted resigned acceptance of their situation and were living in a situation outside their control.

#### **4.7. Conclusion**

This chapter commenced with a demographic profile of the 18 participants to provide the reader with a context for the emerging themes. Then the meanings inherent in the textual data were discussed, using the themes to organise the participants' voices. Using a phenomenological approach to answer the study question, an understanding of the meaning of the lived experience of older people of care facilities was presented and discussed. Emergent themes using the phenomenological model proposed by van Manen (1990, 1997) provided insight into experiences of living in a residential aged care facility. The analysis was informed by models of data analysis proposed by both van Manen (1990, 1997) and Streubert and Rinaldi Carpenter (2011). From the reflection on and analysis of the narratives, essential themes and sub-themes evolved that uncovered the essence of aged care facility life as lived by these participants. The following is a summary of the themes that emerged, highlighting their salient meanings.

The first theme uncovered how the transition and subsequent daily life in a facility contributed to a loss of autonomy, decision-making abilities and control over their lives. This corresponded with a feeling of loss of identity and a change in their dependence status. While participants were somewhat dependent, they were also compliant with facility life. Care was accepted as the trade-off for their loss of independence, and this is consistent with addressing the first aim of this study. This

theme also highlighted that continuity of care made a difference to their lived experience, reflecting the intention of the second aim.

The second major theme was the importance of relationships. Participants described associations with their family, staff and other older people in the facility. Overall, older people valued time with other people, while accepting that time was often limited. Although most time spent with staff was in a functional capacity, the older people valued any relational interactions. Relationships with family were similarly appreciated, and most of the older people respected the limited time their relatives and children had to spend with them, understanding that they had their own lives to lead. It was important to the older people to maintain those enduring relationships. This theme emerged as a reflection of the resident's descriptions that formed an important part of their lived experience in the aged care facility. The relationships made a significant, positive difference to their lived experience, addressing the second aim of the study, as well as contributing to their QoL, which reflected the third aim.

The third theme highlighted the reality of their acceptance of their own mortality and as witnesses to death and dying in the facility. Although some were fearful of the future, they adopted a positive attitude to cope with distressing situations. The later theme addressed the all three aims of the study and gave an insight into how the overall perception of RACF life was reflected in the participants' experiences, addressing the fourth aim.

The three themes reflect a myriad of aged care facility experiences as lived by the participants. It is these themes that are drawn together in the discussion chapter to provide the major conclusions of this study through the theoretical and philosophical frameworks outlined. The outcomes are compared to what is already known about this topic, discussed in Chapter Two. Further, the implications of these conclusions, as they relate to policy and practice will be suggested.

## **Chapter 5: Conclusions, Discussion and Recommendations**

### **5.1. Introduction**

A detailed data analysis was presented in the previous chapter, resulting in the themes that represented older peoples' experiences of 1) 'You can't do exactly what you want to do': loss of self and control; 2) 'If you haven't got that sort of contact, it would be difficult': valuing important relationships; and 3) 'You make the best of it': resigned acceptance. From these themes, it is possible to draw conclusions that clearly address the aims of the study. The overriding purpose of this phenomenological study was to investigate the lived experiences of older people in high care RACFs. This purpose was underpinned by four aims; which were to investigate the impact that living in a RACF has on the older person's care and experience; to assess those elements of RACF life which made a difference to the older person; to understand the older person's QoL issues, such as, but not limited to, independence, dignity, autonomy, communication, relationships with staff and personal care; and explore their perceptions of their QoL; and to explore the overall perception of RACF life and how care might be improved, from the participants' perspectives. In turn, the discussions surrounding the results may suggest recommendations which could enhance care and contribute to a more positive lived experience.

The conclusions of this study reflect the interrelationships between the aims, the underpinning relevant literature of what is already known about the topic, theoretical philosophy and the results of this study. These will be systematically discussed in this chapter. The implications of these conclusions for policy and practice will then be presented and discussed. This chapter concludes with a discussion of the study's limitations and potential directions for future research that may build on the findings.

## **5.2. Major conclusions**

Three major conclusions of this study are presented and discussed in this chapter. The first major conclusion was that the participants experienced life characterised by limited opportunity to engage in meaningful participation in decision making around those things affecting their lives. This began with the decision to make the transition to a facility and continued during their daily lives. Their lived experience was underpinned by accepting dependency while complying with the facility's governance and subsequently feeling they were losing their identity and autonomy.

The second major conclusion is that it was vitally important for all the participants to have enduring, meaningful relationships with a range of significant others. This is linked to the finding that participants desired friendships with carers and others in the facility, as well as continued meaningful relationships with their families and loved ones. Continuity of carers gave the participants more than just appropriate care; it provided the opportunity to experience enduring relationships that extended beyond physical care requirements; for which they were extremely grateful.

The last conclusion is that the participants were placed in a position of reluctantly accepting their finality of place and experiencing the realities of death and dying in the RACF. While they accepted their own mortality, they realised that they had little option but to accept the finality of their situation. Most participants had reconciled the prospect of death and they all struggled with the conditions of ageing. Participants experienced upsetting emotions and understood that they needed to adopt coping mechanisms, including being positive, to 'deal' with 'a very difficult situation to be in'.

Each of these three conclusions will be presented and discussed in the context of the existing literature, and in relation to the theoretical framework, which was described and discussed in depth in Chapters One and Two.

### **5.3. Conclusions and discussion**

This study sought to investigate the lived experiences of older people in high care RACFs and used phenomenology to gain insights into their perceptions and experiences of facility life. This methodology allowed me to reflect on and represent the experiences as the participants saw them, specifically using the issue of temporality, which assisted in understanding human existence. This connectedness with being and time enabled reflection on the historical and personal experiences of the participants. As a result, three themes emerged that revealed the nature of their life in an aged care facility. These themes were identified using techniques that allowed me to interpret and represent the participants' experiences in a rigorous and trustworthy manner, as described in Chapter Three. A relativist ontology allowed an assumption that the participants' interview responses were a true reflection of their lived experience. The three conclusions indicated that the participants valued important relationships, realised their independence would decline but accepted care as it was offered—albeit with frustration—along with the lack of meaningful participation in decision-making. They also understood death and dying as part of ageing and accepted their situation within the facility. Aspects of their daily lives were clearly reflected in the conclusions of this study, as the participants traded their desire to feel safe and secure for a loss of autonomy and sense of self-determination. However, through relationships within and outside the facility, they found ways to cope with the constraints of their lives and with the looming prospect of death and dying. These conclusions are discussed with reference to the aims of the study, the existing literature and the chosen theoretical framework.

#### **5.3.1. Conclusion one: Lack of meaningful participation in decision making**

The first aim of this study was to investigate the impact that living in a RACF had on the older person's care and experience and the first major conclusion addresses this objective. It also addresses the third aim, which was to understand the older person's QoL issues, such as, but not limited to, independence, dignity, autonomy,

communication, relationships with staff and explore their perceptions of their QoL. 3333The first major conclusion is that the participants had limited opportunity to engage in meaningful participation in decision making around those things affecting their lives. The findings indicate that the respondents felt they had little option but to enter a care facility. They experienced a loss of home life, which reduced their autonomy, independence and sense of identity. They felt they had to sometimes endure sub-optimal care, which they felt affected their dignity and privacy. The participants described a lack of control over decision making and this had a negative effect on their perception of care and experience within the RACF, consistent with Lloyd's suggestion that the preponderance of budget constraints and political pressures in policymaking largely ignore the voices of older people, thus rendering them as a population of dependence, consistent with a negative ageist approach (Lloyd, 2012, p. 136).

As discussed in the literature, adjustment to aged care facility life is closely linked to the older person's ability to take part in the decision making process; a more successful transition is achieved if the older person has a sense of control over the move (Andersson et al., 2007, p. 1,712; Johnson et al., 2010, p. 362). The reality for the participants in this study was that there was little time to consider or choose their new home. They were seldom consulted over the move, which was often urgent. As a result, the participants experienced a lack of autonomy as their choices and preferences were not taken into consideration. Decisions were often made by others, such as family and health professionals. This is exemplified in the literature based on earlier studies that found older people have very limited control over the decision making process, even though policy often infers that their opinion is considered (Bowers et al., 2009, p. 6; Johnson et al., 2010, p. 361).

According to Thein et al. (2011, p. 10) and Shield et al. (2010, p. 573), wellbeing was enhanced for older people if they understood that the move would result in a positive outcome. However, in this study, the participants' interpretation of the move was that while it was necessary, they experienced sadness and homesickness. However, they did all want to relieve family members of the burden of care. They realised their

physical limitations and health problems required care. Popejoy (2008, p. 326) suggests that the acknowledgement of safety and risk issues of remaining at home and available care in a facility contributes to a growing dependence. While the participants in this study realised they needed care, the transition was still difficult to accept. This conclusion suggests that the lack of self-determination contributed to a less than acceptable experience. Clearly, the way in which the decision to move to an aged care facility was managed by the family and/or health care professional, affects the participants' experiences and acceptance of the move. In turn, this affected their QoL. This is wholly supported in the Australian literature by Jilek (2006, p.11), who found older people's feelings were dominated by a sense of disempowerment through entering the world of institutionalisation.

An important theme discussed in Chapter Four, was that the participants in this study acknowledged aged care facility life reduced independence, and contributed to a loss of identity. In part, this evolved because of the participants expressing sorrow and frustration at missing their previous home life, possessions and cherished activities. In the seminal study by Bowers et al. (2009), older participants indicated that personal identity and self-esteem, personal control and autonomy and home and personal surroundings contributed to their perception of a 'good life'. Many of the participants in this study described how hard it was for them to let go of their household contents and the ability to undertake familiar household tasks to move into a single room in an aged care facility. According to Edwards et al. (2003a, p. 40), older people placed significance on possessions and when they have to give them up, they experienced feelings of loss and unhappiness. This led to a reduced sense of autonomy, identity and QoL. As described in the literature, Australia's aged care system is dominated by regulations that contribute to a reduced sense of identity, limiting older persons' ability to retain items and maintain significant activities. This lack of decision-making ability is constrained by a number of policy controls.

A loss of identity has also been associated with a loss of wellbeing (Ward et al., 2012, pp. 15–16). This has had a significant impact on the participant's experience of RACF life. In reviewing the literature, the importance of autonomy and preserving choice for

improving QoL and wellbeing is clear (Brownie & Horstmansdorf, 2012, p. 780; Edwards et al., 2003, p. 34; Kane et al., 2005, p. 2,076). As discussed by Anderberg and Burglund (2010, p. 66) and Robison et al. (2011, p. 283), older people attributed importance to having control over their daily living activities. In this study, the participants lamented, 'I am so used to doing everything, sort of thing, for myself. And I have had that taken away from me. (Alice)'. All the participants talked about desiring to do what they wanted, such as going for a walk, cooking, sewing, enjoying the company of pets or just pottering around. Instead, they all described a lack of independence and choice over these once-cherished activities. Moreover, most of their activities were confined to those operated by the facility. It appeared that some of these had little value for the participants, who would have preferred doing other more meaningful things, such as cooking, sewing or gardening. This represents a loss in opportunity for an enriched QoL (Edwards et al., 2003a, p. 40). It also indicates that, while facilities advocate person-centred care and provision of a 'home-like' experience (National Care Homes Research and Development Forum, 2007), the reality was that, due to current models of care, participants experienced reduced autonomy and independence (Fay & Owen, 2012, 35). These conclusions are consistent with those of Perron (2008, p. 15) who suggests that dissatisfaction occurs with loss of personal freedom. Brownie and Horstmanshof (2012, pp. 779, 873) found that opportunities for older persons in RACFs to exercise their basic human rights regarding their sense of identity and self-esteem were constrained by their living environment.

The literature suggests that lack of choice and control and maintenance of dignity and privacy affects the lives of those living in a RACF (Edwards et al., 2003b, p. 34; Kane et al., 2005, p. 2,076). In this study, some participants indicated that they disliked asking for help; this represented a loss of dignity, privacy and independence. 'I was too embarrassed to ring it (bell)' (Maude). Out of frustration waiting for assistance (or boredom), some participants took themselves to the toilet or went for a walk, contrary to the safety policies of the care home. The participants realised they may get into trouble or suffer a fall, but were willing to accept this as a consequence of exercising their autonomy.

Participants acknowledged their decline in health and physical abilities, but were concerned that this should not affect their privacy and dignity. In some instances, based on limited spaces in aged care facilities, some female participants had to share a bathroom with a male resident in the adjoining room. In all instances the female participants in this study found this unacceptable. Resident privacy impacts on QoL, and it is severely affected if a sense of dignity and privacy is not maintained (Bowers et al., 2009, p. 38). It is clear in this study that the participants indicated their level of privacy was reduced and their dignity was compromised in a variety of ways. This is consistent with the findings of Robison et al. (2011, p. 279), who suggest that care practices can compromise privacy and dignity. The conclusions are also in direct contrast to the objectives of the UN Principles of Older Persons (UN, 1991) which include supporting the dignity of older people, and also the objectives of the *Aged Care Act 1997* (DHA, 2012g), aiming to protect the human rights and wellbeing of aged care services recipients.

Robison et al. (2011, p. 282) also suggests that polite, respectful treatment by staff, and having their modesty protected all contribute to maintaining older persons' dignity. Perceived and experienced adverse behaviour may reflect a negative view of older people as being a burden (Nay & Garrett 2009, p. ix) and also indicates an ageist attitude. This is supported in the literature by Reyna et al., (2007, p. 50), who see dependence reinforced by staff assuming a negative stereotypical approach to care-giving.

The literature concerning participatory research with older people indicates that QoL is influenced by the level and quality of personal care, comfort and support (Bowers et al., 2009, p. 47; Horner, 2005, pp. 148, 151;). In this study, the participants described feeling like a burden, as staff appeared hurried and under pressure when attending to their needs. This is consistent with the findings of Horner (2005, p. 148), who found that older people did not want to be rushed though ADLs. Tuckett (2005) noted similar findings regarding service provision in facilities being dominated by a culture of 'doing for', rather than 'being with'. It is also indicative of increasing

dependency levels in aged care (Robinson & See, 2010, p. 1), which reduces the time afforded older people in care and comfort, consistent with the findings of Gibson et al. (2002, p. 2). Richardson and Bartlett (2009, p. 28) suggest that QoL for the older person is reduced because of this situation.

In this study, reduced autonomy and independence was exemplified by a loss of control over voicing concerns. Some participants felt they may suffer reprisals because of speaking out, and others described having no control over any decision making. This contrasts to the Charter of Rights, which states that older people should be able to live without discrimination or victimisation and without being obliged to feel grateful to those providing care and accommodation (DHA, 2007). Despite the well documented conclusions surrounding loss of identity and independence, many participants in this study indicated that while they felt they were cared for and were safe and secure in the aged care facility, this was at the expense of their autonomy. The practices of the care home meant that the older people in this study felt dependent; this is supported in the literature by Harper Ice (2002, p. 36) who noted older people became the victims of a 'learned helplessness and instrumental passivity', which promoted dependency and discouraged independence (Harper Ice, 2002, p. 346).

This suggests a negative view of ageing (Bowling et al., 2003, p. 270). Even though this perspective is changing (Rowe & Kahn, 1997, p. 145), the conclusions of this study indicate an entrenched dependency model (Fay & Owen, 2012, p. 35). Participants experienced ageist attitudes by care staff, consistent with the findings of Reyna et al. (2007, p. 50) and Minechiello et al. (2000, p. 262). A counter discourse to ageist attitudes and a negative dependency model is promoted by increasing older persons' relational autonomy and interdependence. The conclusions in this study indicate that while the participants accepted that their level of autonomy, choice and control were reduced, they also recognised that they received necessary care, and that they were interdependent.

The findings indicate that the participants in this study were aware of the need for rules and regulations and the challenges that face the aged care system, which sometimes restricted their autonomy and influenced the quality of care in the facility. The literature expressly indicates that care is subject to the dominance of political and economic agendas that principally disregard the rights and voices of the older person and deal negatively with disparities of care provision (Lloyd, 2012, p. 136). This conclusion is also representative of a medical care model, within which processes affecting health care intervention are dominated by professional perspectives and institutional management (Wan et al., 2010, p. 6), rather than the concerns, preferences and desires of the end user. It is contrary to endeavours, through social policy and service provision, to change concepts of ageing to a model of care that is more person-centred and humanistic (Edwards et al., 2003b, p. 33). It appears that the endeavours of Australian health policy to encourage more healthy ageing are not replicated in this conclusion, as individual preferences are not a major part of the transition process; this reflects a lack of understanding of older persons' experiences (Streubert, 2011, p. 4). This conclusion highlights one of the challenges of the current aged care system, to enable greater levels of choice, improvements and responsiveness (Ansell, Davey & Vu 2012, p. 13; Productivity Commission, 2011a). It appears that this can only occur with participatory involvement by users of that system explicating their experiences and expectations. This is consistent with a phenomenological view of understanding aged care facility life and the opportunities to explore possibilities for a more positive experience for end users.

### **5.3.2. Conclusion two: Importance of enduring and meaningful relationships**

The main aim of the study was to investigate the lived experiences of older people in high care RACFs. The second important conclusion of the study was that it was vitally important for all the participants to have enduring, meaningful relationships with a range of significant others. This is clearly evident in the findings, especially with respect to theme two, which reflected the participants' experience of wanting continuity of staffing relationships, depending on family for help and support, having empathy with other older people and appreciating friendships with staff. This

conclusion addresses the second and third aims of the study, which were to investigate those elements of RACF life that made a difference and to understand the older person's QoL issues, such as, but not limited to, independence, dignity, autonomy, communication, relationships with staff and personal care; and explore their perceptions of their QoL. Being able to maintain relationships made a significant difference on their ability to live in the RACF. This is reinforced in the literature, which indicates that QoL is always influenced by relationships with significant others (Carpenter, 2002, p. 286; Edwards et al., 2003a, p. 40; Robison et al., 2011, p. 280), and that meaningful relationships are an important element for older people in their vision of a 'good life' (Bowers et al., 2009; Ward et al., 2012). The conclusion also partially responds to the first aim, which was to investigate the impact that living in a RACF has on the older person's care and experience. In this study, the participants' experience of receiving adequate care was affected by inconsistency of regular carers.

As discussed in Chapter Two, De Bellis (2010), Castle and Engberg (2007) and Castle and Anderson (2011) suggest that quality of care and QoL in RACFs are affected by staff numbers, level of education, qualifications and stability. In this study, the participants saw a lack of consistent carers as problematic. They understood that they were entering the aged care facility to receive the care they needed. However, due to the extended use of casual or agency staff, the participants were not always able to form a consistent relationship with those who provided their care.

Australian researchers Edwards et al. (2003a, p. 40) found older people trusted familiar staff to provide required care, which increased their QoL. The participants in this study felt that non-regular staff did not always know what to do, evident in mistakes with medication and misidentifying residents: this evoked feelings of despair and dissatisfaction. Consistent with a phenomenological stance, the participants experienced disenchantment and frustration caused by care they described as less than adequate, and they craved consistent relationships with carers. As discussed in Chapter Two, Cook and Brown-Wilson (2010, p. 24) found that relational interactions and social exchanges enabled staff to acknowledge personal preferences. However, older persons residing in RACFs can receive indifferent care if such relationships are

compromised. The meaning attributed by the participants to the experience of being cared for by a range of casual staff was one of being disregarded and marginalised, and this severely affected their QoL.

As discussed in the literature, Harrington and Swan (2003, p. 366) and Han et al. (2005, 10–11) suggest that decreased staff turnover and reduced use of agency staff improves quality of care and life for older people. The reality for the participants in this study is that a lack of ability to form consistent relationships with staff has affected their care and QoL. De Bellis (2010, p. 101), and Seblega et al. (2010, p. 341) suggested that a downward trend in qualified staffing levels (Productivity Commission, 2011a), as well as increasing administrative duties, often led to a reduced quality of care, also affecting the recruitment of staff to care for older people. This issue appears symptomatic of problems associated with the funding of the health care system, as discussed in Chapter Two. As highlighted in Chapter Two, increasing job dissatisfaction led to high attrition rates (Yu, Qui & Crooks, 2006, p. 570). The impacts of regulatory controls and budgetary constraints (Perry et al., 2011, p. 2,140) have led to a reliance on agency staff, ultimately resulting in a reduced and more fragmented level of personalised care. This is consistent with research into barriers for nursing staff in delivering high-quality person-centred care and is contrary to the objective of providing services within a psychosocial, person-centred model of care (O'Dwyer, 2013, p. 234).

As discussed in Chapter Two, participatory research concerning successful ageing by Horner (2005) and Horner and Boldy (2008), found the elements of communication and interaction with staff and family as fundamental elements contributing to QoL. Further, Hall et al. (2011), Robison et al. (2011, p. 280), Thein et al. (2011, p. 14), and Tseng and Wang (2001) found that participants valued continued and high frequency of family interactions and friendships as significant contributors to older persons' satisfaction, wellbeing and QoL. This is consistent with the experience of participants in this study, who valued ongoing relationships with family and friends, and has been previously discussed regarding the older person's reliance on family during transition to a RACF. This is supported by Keefe and Fancey (2000, p. 240),

who found older persons' QoL was influenced by their desire to maintain the same quality of relationships with family where their intimate knowledge enhanced their identity and purpose, similar to their situation before moving to the aged care facility.

As discussed in the literature, due to current trends in life course such as more family members in the paid workforce, there are fewer family carers for older relatives. Modernisation theory posits that the nature of the relationships within families and the responsibility of caring for older people has changed (Moody, 2006, p. 7), resulting in more older people going into care facilities rather than staying with family. The reality for the participants in this study is that they too experienced a reduced status in society, based on their dependence (Lloyd, 2012, p. 173). This is consistent with the deficit model of ageing. In this study, participants accepted the role reversal of care, where their once-held responsibility as family head had changed. This concurs with functionalist disengagement theory (Cummins & Henry, 1961), which is phenomenologically understood through disengagement. While the participants experienced a reduced ability to be involved in physical activities or reciprocate exchanges, they attached great meaning to being active in relationships with family and friends, consistent with the active ageing approach advocated by activity theory (Neugarten, 1964, p. 194).

Further, the meanings participants attached to care and comfort from family and friends affected their lived experience. They valued meaningful relationships and this was understood to be an important aspect of their daily lives that gave them comfort and security. This represents a change in perspectives in later life, where the participants reflected on important issues represented by non-material activities and reality is defined by value-laden relationships. This is consistent with the phenomenological geotranscendence theory of conceptualising ageing (Tornstam, 1994; Wang, 2011). The conclusion shows that relationships with family represented a true reflection of life satisfaction and this made a difference while living in the RACF.

The literature has shown that the aged care system is characterised by continued growth of community care-based services and deinstitutionalisation (DHA, 2011; DHA, 2012f; Palmer & Short, 2000, p. 298), enabling older people to be cared for within their own home for as long as possible (Alzheimer's Australia, 2010a, p. iv). These policy initiatives are not without their problems and reflect a real challenge for policy makers as they become increasingly unviable (Angus & Nay, 2003, p. 130), and result in an overwhelming burden on family caregivers (Rowland, 2012, p. 195). The reality for this study's participants was that family members could not look after them. Participants felt they would have been a burden on their families, as they understood the pressures and responsibilities of their relatives' own lives. Participants in this study, while valuing relationships with family, readily acknowledged that their relatives were also ageing, were busy and 'had their own lives to lead', which explains why they accepted family visits were possibly not as frequent as they would like.

Older people in RACFs may experience a loss in closeness and intimacy with family members once they move into a residential care facility. This was not evident in this study; rather, the participants craved time with family and actively sought to maintain these continuing intimate relationships as a fulfilling part of their lives. The experience of a reduced QoL due to social isolation is a concern affecting older people (Parmenter & Cruickshank, 2010, pp. 62–63), which was evident in this study.

In researching the perspectives of older people, Bowling et al., (2003), Harris et al. (2008) found good social relationships, engaging in social roles and activities and the social environment were essential elements to maintaining a good QoL. The participants in this study understood that, to live in the facility, it was beneficial and positive for them to maintain good relationships with others. The issues surrounding living in a public domain, discussed by Fiveash (1998, p. 169) found that older people reported a dehumanising situation in having little privacy. Bowers et al. (2009, p. 8) found older people had little control over public and private areas of their lives when they lived in a RACF. This is consistent with the findings of this study that the public nature of facility life reduced privacy for participants and made the opportunity to

develop and maintain personal relationships vitally important. Accepting and living with others in the facility represented a true reality for the participants, as the meanings they attached to this experience were that they were with people in similar positions and, to ‘get along’, it was necessary to forge relationships.

As discussed in Chapter Two, social contact inside the facility is highly appreciated as older people gain valuable support from their peers, which helps to maintain a more positive outlook (Carpenter, 2002, p. 287; Robison et al., 2011, p. 280). Most of the participants in this study had a keen desire to form relationships and empathise with others. It appeared that maintaining and forming positive relationships with others assisted them to make sense of living in the aged care facility. The reality for the participants was that the lived experience of assimilating with others in a public world required ‘give and take’. In this study, some of the participants assisted and supported others with a clear sense of empathy. This suggests that the participants have a degree of independence, where the little assistance they gave to others contributed to their productive ability, their sense of fulfilment and wellbeing (Gibson & Singleton, 2012, p. 32).

As discussed in the literature, the physical environment contributing to social interactions was a major issue in determining good QoL (Horner, 2005; Bowers et al., 2009). However, Fleming, Crookes and Sum (2008, p. 298), Moore et al. (2011, p. 416) and Tsai and Tsai (2008, p. 1,919) found limitations in social interactions due to the structure of the physical environment, the physical separation of older people or the lack of staff to facilitate interaction with others. In this study, the participants also described barriers to interaction, such as limitations in mobility and not being allowed to walk around unless assisted by a staff member. This reflects budgetary constraints on providing positive environmental design outcomes and adequate staffing levels (Fleming et al., 2008, p. 298).

The literature found an overemphasis on aged care facility staff providing technical services and completing documentation rather than nurturing social contact with and between older persons (De Bellis, 2010, p. 119; Productivity Commission, 2011). In

this study, most of the participants felt that staff provided essential care, but did not have time to assist them in walking around or engaging in meaningful social activities. This indicates the participants would have liked staff to devote more time to supporting social activities; this is an important finding, as they clearly craved company and wanted to make friends within the facility. Horner (2005, p. 152) has suggested that access to social activities is critical for wellbeing. It is evident that, while there were formal organised activities available, the activities were not always meaningful to the participants, nor was their input sought in determining what social activities were offered (Edwards et al., 2003a, p. 40). The essence of the experience for these participants suggests a level of disengagement, which is contrary to the objectives of successful ageing (Neugarten, 1964, p. 194). Most participants in this study described how they simply missed home and, regardless of the company within the aged care facility, the loss of their previous life could not be replaced.

The literature has shown that older people experience greater wellbeing in the case of having meaningful relationships with staff (Bowers et al., 2009; Bowling et al., 2003; Carpenter, 2002; Healey-Odgen & Austin, 2011; Horner, 2005; Huber et al., 2011). In this study, the participants clearly wanted to be involved in relationships with staff who interacted positively with them, and who they had come to know. The reality for the participants was that they wanted more than just a functional relationship with staff, as social connections were highly valued. The participants described very limited opportunities to engage with highly pressured staff with task-orientated work, consistent with the nature of aged care service delivery in facilities (De Bellis, 2010, pp. 161–162). Participants acknowledged that the staff was busy. Some of the participants experienced a less than satisfactory level of wellbeing through a lack of meaningful relationships with staff, and were subject to receiving care-as-service rather than care-as-comfort, based on a dependant relationship of care (Bowers et al., 2001, p. 539; Carpenter, 2002, pp. 286–287).

As discussed in the literature, older people appreciated friendship and empathy from staff and valued close relationships and intimacy as an expression of positive care (Bowers et al., 2001, p. 539). The participants in this study craved closeness and

familiarity with staff, and many felt that the staff were their friends, feeling that they could confide in them and express personal choices for care. The participants' reality was that they had trouble with creating and maintaining meaningful relationships with staff, especially considering time constraints, limited permanent staff members and regular use of casual or agency staff. This suggests that participants gained more from their relationships with the regular staff, which allowed the development of trust and more personalised care.

As discussed in the literature, Cook and Brown-Wilson (2010, p. 28) found personal exchanges and the sharing of experiences and information allowed reciprocal benefits. However, the literature also suggested that the ability for older people to engage in social reciprocity (Brownie & Horstmanshof, 2012) is constrained by the controls surrounding the operation of facility life, limiting interaction time between staff and older people. The results of this study indicate that some participants were able to engage in limited reciprocal relationships with staff. The essence of the experience of fostering meaningful relationships with staff creates a greater sense of wellbeing for the participants, and this made a substantial difference to living in the facility.

Some older people in this study suggested that they only got along with certain members of staff and there were some staff members who would only undertake care duties as required. This is consistent with research by Carpenter (2002, p. 288), who found that perceptions by staff of older people in their care may influence the amount and quality of care received, and affect the opportunity for social relationships. As discussed in the literature, pressured workloads, under-resourcing (Minichiello et al., 2000, p. 262) and a lack of education (Reyna et al., 2007, p. 54) renders older people vulnerable to ageist attitudes from staff, where dependency is the focus of the care relationship. The meanings attributed by participants to this behaviour from care staff included being made to feel dependent and requiring submission. The participants in this study reported that interactions with staff were not always positive, as staff were often hurried and didn't have the time for social interaction outside their duties.

Foley (2010, p. 19), De Bellis (2010, pp. 100, 101) and *National Seniors Australia* by Access Economics (2010) have all reported that sub-optimal residential care policies, facilitating a lack of workforce investment, has affected quality of care, with a corresponding impact on resident QoL (Castle & Anderson, 2011, p. 545; Han et al., 2005, pp. 10–11; Harrington & Swan, 2003, p. 366). The issue of increasing staff numbers and creating a climate of greater stability would give staff more opportunities to spend time with older people, resulting in improved relationships between staff and older people. This issue was explored by Castle and Engberg (2007, p. 1,845), and was a common theme mentioned by the older people in this study. This critical issue represents a significant challenge for policy makers to appreciate more personal care provision in-service delivery. It is clear that the preferences of older people are not always taken into account in daily facility care. The reality for the participants is that they experienced a lack of wellbeing due to the lack of engagement in more meaningful interactions with care staff, with a subsequent reduction in the level of care and comfort. The findings of this study are not consistent with the *Older People Charter of Rights and Responsibilities*, which states that older people should be treated with respect and accepted as individuals, and have individual preferences taken into account (CoA, 2007).

This study concludes that older people's QoL is affected by the quality of relationships that they have with a range of significant others, such as family members, friends, staff and other older people. The participants in this study realised the importance of these social contacts, as they made a substantial difference to their lived experience.

The next conclusion relates to older people dealing with the challenging behaviours of other residents, as well as living with death and dying, in the aged care facilities.

### **5.3.3. Conclusion three: Resigned acceptance**

The last conclusion addresses all the study's aims. It is clear that the impact of living in the facility has elicited strong emotions for the participants and this has evolved

from their experience of living with death and dying. There were few elements of RACF life that the participants felt made a positive difference to them, and it appeared that optimism had to come from within, rather than the facility creating a positive experience for them. Subsequently, their QoL was affected and they felt that there was little hope of improvement and they accepted their life, albeit reluctantly and with reservations.

This finding indicates that the participants were aware of their own frailty and mortality and of the need to come to terms with their life in the aged care facility. This concurs with the findings of Kane et al. (2003) and Wan et al. (2010, pp. 11–12) that QoL is always affected by the environment within which the older person lives, along with the factors that influence their living conditions, including adjustment and mental attitude to the challenges of aged care facility life. Some circumstances affecting comfort and safety, such as the challenging behaviours of other residents associated with dementia and participants witnessing the conditions of the dying, were evident in the stories of these participants.

The literature suggests that for the transition to an aged care facility to be successful, older people must have a sense of being able to deal with potential challenges (Shield et al., 2010, p. 573) and have the coping skills required for adjustment (Andersson et al., 2007, p. 1,713). These findings were borne out in this study, with many of the participants experiencing apprehension on entering the facility. As the choice was generally not their own, they were unprepared for the changes associated with RACF life. This conclusion signifies that most participants had difficulty accepting their understanding of RACF life.

Aged care policy similarly advocates that the majority of older people will require care until they die (DHA, 2011). This is supported in statistics suggesting that once older people move into care facilities, they die in care (Gelfand, 2006, p. 17) rather than back in the community or in a hospital. The older people in this study understood that they would end their days in the RACF; however, for them the finality of place and its connection to their own mortality was a logical progression of life.

This realisation that they would live out their days in the facility was not immediate or automatic, as the participants needed to reconcile their own mortality with their inability to go back 'home' or to reverse their situation. For some, the concept was very difficult to accept. Further, participants understood that once they entered the facility there were no other options (Alzheimer's Australia, 2010a, p. iv; DHA, 2011). In fact, the aged care system reinforces the inevitability of death in a facility by its hierarchical care system, which is based on care needs dictated by progressive frailty, ultimately leading to the highest level of care available. This situation also reflects a dependency model of care that concentrates on older people's weaknesses in preparation for death (Nay & Garrett, 2009) and similarly reflects a deficit perspective that emphasises social and physical decline (Cummins & Henry, 1961).

For others, the realisation that their final stage of life would be in a RACF was accepted. It represented their understanding of being-in-the-world in terms of death; both their own and others. As discussed in Chapter Two, the nature of aged care means that the conditions of dying or the suffering associated with other frailties or disabilities are generally visible to those older people living in the facility (MacKinley, 2012, p. 26). This was apparent in the upsetting feelings described by the participants, who experienced situations where they saw others lying in bed unable to communicate, being fed by others and expressing pain. The experience of witnessing the suffering of others was confronting, affecting the participants' lived experience and their QoL. While they attributed meaning to the RACF as a place for the dying, seeing others' dignity being compromised when staff performed their duties with the doors open or witnessing others' debilitating conditions in communal areas reflected the true essence of their understanding of mortality.

According to MacKinley (2012, p. 26) the care of the dying should, if possible, remain private and hidden from others in the facility to preserve dignity and reduce distress. This suggests the experience of dying in a RACF could be improved with more dignity-centred care practices (Jeong et al., 2011b, p. 166). The literature also indicates that the preferences of dying older people are not always known to staff, and

the dying are subject to routine end-of-life care, provided by the facility (Gjerberg et al., 2011, p. 42; Tuckett, 2007, pp. 130, 133). Some of the participants in this study saw what it was like to be dying; the reality for them was that they identified with the dying and saw themselves in the same situation in the future. The impact of these experiences on the participants was significant and indicates that dying is not separate from the unsettling process of dying. The experience for the participants' perspectives reflected a lack of personally orientated care for the dying, especially in terms of respect and dignity. This is inconsistent with literature advocating that personally orientated care contributes to a more positive end-of-life experience and to less anguish for the dying and others in the facility. This may be a reflection of the ability of care staff to respond to this particularly sensitive issue, given the intensification of dependency levels in care and the staffing pressures in RACFs (Andrews-Hall, Howe & Robinson, 2007; Chalmers et al., 2002, p. 30). This ultimately reduces personal care and comfort, an important aspect of QoL.

The dying individual's desire to die, rather than accept prolonged life, is sometimes overlooked at the expense of their autonomy, and in deference to family wishes. This study found that some participants did not want to have their lives extended and wanted to die with dignity. Further, one participant experienced abhorrence of witnessing the depressing elements of aged care facility life, such as the deteriorating physical and mental conditions of the dying. That experience of being-in-the-world evoked true feelings of not wanting to be in that particular world.

The literature suggests that while there is an obvious connection between death and RACF life, there is a general reluctance to discuss factors surrounding death with older people in the facility (Osterlind et al., 2011, pp. 540–541). Living with death appeared to be more acceptable than living with dying, for the participants in this study. It was interesting that the participants spoke openly about living with others dying. In contrast to the literature, participants indicated that they spoke openly to staff about those who died or who were about to die. Their experiences of living with death reflected the reality of mortality. While it was a confronting part of lived

experience in the RACF, participants accepted death, but preferred not to witness the conditions of the dying.

As discussed in the literature, the stability and presence of more qualified staff who accept responsibility for quality of care relieves the pressure otherwise felt by unqualified staff (Kayser-Jones et al., 2003, p. 82). In this study, it appeared not to matter whether the staff were qualified or unqualified—the participants wanted assistance to deal with the prospect of death and with others who displayed agitated and intrusive behaviours. In essence, their experience of intrusions and lack of privacy evoked distress and anxiety. While some participants felt confident in dealing with fellow older people's challenging behaviours, they desired more assistance from the staff. This placed the participants in a position where they felt that they should not have to endure such impositions. However, as stated in the literature, it reflects the inability of care homes to manage the complexities of challenging behaviours within an ageing-in-place scenario (Rosewarne, 2001, p. 119). This includes adapting the environment to cope with increasing and more diverse requirements, and employing an effective staff skill mix to cope with a range of complex needs. The participants' reality in this study indicated a less than optimal QoL experience. This is reflected in the literature where Bowers et al. (2009, p. 38) suggests that successfully meeting privacy, warmth and safety needs, are essential for wellbeing.

As discussed in the literature, Bowling et al. (2003) found that having a positive psychological outlook on life contributed to QoL. Clare et al. (2008, pp. 716–717) found that even though the situation of ageing and living with others with dementia was difficult and distressing, older people often managed to find ways of accepting the situation with constructive ways of coping, such as being positive and retaining a sense of self. Participants saw what it is like for others 'to lose identity'. The reality for the participants was that while they lived with many negative experiences, they understood they needed to develop coping strategies to remain positive. This contributed to their understanding of the need to accept their circumstances by remaining positive. This was an element of understanding that made a difference in their lives in the RACF, consistent with addressing the second aim. This is also

consistent with a view of successful ageing where a positive psychological outlook is essential for wellbeing (Rowe & Kahn, 1997). The essence of the participants' experience was that they accepted reduced choice and autonomy in return for the care they received. However, the literature discusses, staying strong and hiding vulnerability (Anderberg & Berglund, 2010, pp. 66–67) to maintain some control was a necessary coping skill and this is reflected in this study. This is not ideal. However, despite all the negative aspects of living in a RACF, the participants chose to maintain a positive perspective on life. The literature suggests that sub-optimal residential aged care policies create substandard levels of care provision (De Bellis, 2010, p. 200) and do not fulfil the objective of providing a home-like environment (Bowers et al., 2009), essential for a good QoL. The implications of ageing and the care conditions of the RACF did not reflect a home life environment for the participants. As such, they adopted a range of coping mechanisms to deal with the reality of RACF life. While the objective of care facilities was to create a positive experience for older persons living in the RACF, acknowledging a humanistic, person-centred model of care (Edwards et al., 2003b), the reality was that the participants had to create their own positive experiences, or more specifically, make a negative experience tolerable.

As discussed in Chapter Two, aged care facilities provide long-term care for older people with significant physical and cognitive disabilities, with chronic illness and its associated conditions, and with complex palliative care needs (Robison et al., 2011, p. 275). The physical environment in which this takes place influences quality of care, QoL, autonomy and independence for these older people (Kayser-Jones et al., 2003, p. 79; Moore et al., 2011, p. 416). Many of these authors add that the symptoms of dementia are a major risk factor affecting the environment. Along with the changing demographics of aged care facilities, where increasing numbers of older people have dementia, facilities are faced with more complex care issues (AIHW, 2007; Willemsse, Smit, de Lange & Pot, 2011; Rosu & Millar, 2004, p. 1). The study participants' reality was that the facilities in which they resided were unable to manage the overwhelming multifaceted nature of care provision. This resulted in participants being in the unenviable position of having to accept living in the RACF while changing their behaviours to cope with the situation.

Participants understood that they needed coping skills to deal with the challenging behaviours of other residents, such as withdrawing from certain areas of the RACF, not engaging in activities or not becoming close to others. According to Tsai and Tsai (2008, p. 1,918), older people considered their own mortality within the facility. This raised the question of whether they wanted to pursue friendships with others in the facility and risk the grief involved when a friend dies, or whether it was better to remain remote. Despite this, the majority of the participants in this study stated that they did not want to be separated from those with dementia. There was agreement that the conditions and unsettling behaviours of other were 'part of life' in the RACF. This is consistent with the findings of Clare et al. (2008, p. 717). Their research concluded that older people in RACFs tried to retain a sense of pride in themselves and their life, to appreciate the chance to review their life, to feel that achievements were still possible and to sense that they were managing well despite their limitations, while feeling empathy for those less well off. This suggests that the participants developed their own coping mechanisms to deal with challenges and frustrations while remaining positive.

The last conclusion illustrates the meanings attributed to the experiences of the participants, reconciling their mortality, witnessing death and dying, coping with distressing emotions and behaviours and trying to remain positive to cope with life in the RACF. It highlights what life is like in a RACF, and reveals the resoluteness of participants' understanding of the need to adapt and accept the conditions of ageing with which they live. It is important to note that the meanings they attributed to these conditions did not evoke anger, although many described their experience as sad. This may well be representative of older people's ability to transcend their limited once-held views of life to accept inconsistencies, and assume increasingly lenient views of right and wrong (Tornstam, 2005). This is not to imply that they accept, or should accept, a lower QoL nor less personalised and meaningful experiences. Instead, this suggests that the important issues have changed for older people; there is more focus on non-material relationships and accepting the changes associated with ageing.

#### **5.3.4. Summary of the conclusions**

This study has attempted to portray the lived experience of older persons in RACFs, with the results and conclusions underpinned by the philosophical framework of phenomenology. The participants' experiences are discussed in this chapter and the conclusions of this study represent 'What it is like to be'. The conclusions depict the inherent meanings uncovered through investigating the experience as they have described it, and are interpreted here as a true reflection of their life. Consistent with a phenomenological approach, the conclusions have been discussed within the ambit of my own understanding of being-in-the-world (van Manen, 1990) and the interpretation of the texts represents my understandings of the participants' perceptions of reality. To understand how something is lived, I as the researcher, have investigated the experience, uncovered essential and incidental themes and found meaning through describing the phenomenon as it was told to me. I have maintained a strong dedication to the phenomenon of lived experience of older people living in RACFs by remaining orientated to the singularity of the experience and immersing the interpretation and analysis with the facts and going from the themes back to the whole text. The participants' interviews were about being-in-the-world and reflected the essence of their experience as being not separate from their own origin, where temporality played a large part in my understanding of their reality.

Participants in this study lived with others and experienced their environment. Each person interprets their own reality when confronted with unfamiliar situations. The participants' reality was that their experiences evoked feelings of sadness and frustration as they grappled with a loss of decision-making abilities and autonomy, as they craved meaningful relationships, and reconciled their own mortality within the RACF environment. Their feelings are represented in this chapter to show how they made meaning and understood RACF life. In this study, it is clear that the aged care system and the conditions of a RACF direct what an older person living there should 'be'. This demonstrates how policy and practice dominates the lives of older people in a RACF as they become more dependent and live with a sense of loss. Their experiences are conditioned by their own sense of vulnerability, compounded by a

lack of voice to express disillusionment, fight for personal care or exercise their rights. Their feelings are therefore dominated by sorrow, tempered with a drive to remain positive.

These findings have drawn on phenomenology as both the philosophical framework and methodology of this study, to describe the participants' life experiences in a RACF. The conclusions contribute to understanding their experiences within a framework that demonstrates the reality of 'what it is like to be' in a RACF.

#### **5.4. Implications for policy and practice**

As discussed in Chapter One, effective policy and practice to manage population ageing is a universal challenge for the world community, with the decline in the number of workers relative to dependent older people (Weiner, 2009, p. 12). Correspondingly, there is a significant challenge for governments to provide effective and efficient health care (Beard et al., 2011, p. 7). The OECD suggested a number of reforms designed to soften the impact of ageing on public finances, such as future planning to fund health and aged care services (OECD, 2009). Societies have experienced massive economic and social changes over the years that have been accommodated by largely unplanned adjustments to existing patterns of behaviour in kinship relations, working life status and expenditure on health, especially aged care. For example, the once traditional household where younger adults cared for their ageing parents within the home has almost disappeared in western society. An ageing society causes changes to social and economic relationships where expansion of aged care services through state support reflects changes in family dynamics, increased confidence in using aged care facilities and the growing pressure for sustainable aged care provision (Fernandez & Forder, 2010, p. 714; Tolson et al., 2011, p. 184).

Health care policies in most developed countries have already been subject to change, development and renegotiation as a reaction to greater numbers of ageing people in society. Irvine and Kroeger, (2010, p. 164) suggest that the Australian health care system needs to deal with multiple challenges in quality service delivery in aged care

and, according to the Productivity Commission (2011a), reforms in the area of aged care and health in Australia are essential. Critical issues, such as the partnership between public and private support, will have to be identified and managed through policy. Some of these issues of concern (according to research into the Australian health care industry as it relates to aged care) include divided responsibilities, factional political responsibilities, budgetary pressures, an unstable workforce and an ageing population with increasingly complex needs (Healy, 2011, p. 77; Gupta & Harding, 2007a, p. 9). Given this background, the effectiveness of aged care provision can only be reliably improved within the aged care needs if considered within the perspective of the totality of services.

This study has described the lived experience of the participating older people. Certainly, the changing definition of familial responsibilities was raised by participants, and their understanding of the issues contributed to their acceptance of aged care facility life as a part of ageing, due to ill health and frailty. Policy issues include continuing reliance on public support for care provision and formalising and refining broad policy initiatives required to reflect changes in familial support and the needs of older people.

According to Stabile and Greenblatt (2010, p. 21), providing universal health care across the lifespan requires radical changes in policy. Residential care and government finance provide support of a specialised, professional kind that family members are simply unable to provide. This is critical for the wellbeing of older people in aged care facilities. Older people in this study realised that they could only get the care they needed within the aged care facility environment. The quality of this care is regulated by user rights charters, policies and appeals options, such as the *Older People Charter of Rights and Responsibilities*. However, as this study noted, the participants traded their autonomy, choice and dignity in return for the care they received. The reasons for this are complex, but include the pressure on staff having sufficient time or professional skills to deliver the level of care that older people desired. This suggests that future macro and micro policy reform should be explored to address these issues.

According to Stauner (2008, p. 206), policy reform to allow flexibility in pension schemes and flexible working arrangements for those families wanting to care for ageing relatives while working would be beneficial. In relation to this study, some participants indicated that their sons or daughters were too busy working to care for them or they worked too far away and could not visit as often. This negatively affected opportunities for social contact and significant relationships with family members. Moreover, some participants said that while it was not their choice to go to an aged care facility, they understood the necessity, as there was no one else who could look after them. Policy for the provision of older peoples' care could be developed with a view to providing options for working caregivers, to enable those in employment to maintain their employment but also continue to provide support for older family members both at home or in the aged care facility (Christensen et al., 2009, p. 1,205). Such a policy initiative would clearly have a financial cost. However, this could be offset by the reduced numbers of those requiring placement in an aged care facility. Similarly, policy could provide support options for informal caregivers through the continued growth of shared care approaches between the state, community and family. This would mean that, in Australia for example, more defined and autonomous roles could be developed between the various levels of government providers and independent persons, which would alleviate duplication of services and provide greater certainty for users. Further, this could include improved benefits and monetary assistance to informal carers. Other options, such as private long-term care insurance schemes, may be beneficial to support policy reform. This strategy appears to provide options for the older people in the UK and the USA, enabling people to plan for and fund their future care (Hogan, 2004, p. 29; Park & Werner, 2011, p. 783; Weiner, 2009, p. 17).

With the increasing demand for aged care facilities, wellbeing is a major issue for the older people themselves, their families and health care providers (Parmenter & Cruickshank, 2010, pp. 62–63; Robison et al., 2011, p. 280). Policy should draw on research into the experience and needs of older people and, based on the conclusions of this and earlier studies, should support older people's social interactions, greater

levels of care and self-determination, and mechanisms to better manage those with dementia in aged care facilities. Reports by the CoA (2007, p. 9) suggest government policy and planning is based on projected resident populations; therefore inconsistencies between policy and the actual experiences of older people are to be expected. The results of this study certainly contribute to the body of knowledge to inform policy development in this area. Policy changes should consider research findings relating to older people's experience of aged care facility life and their perceptions of care. Similarly, participants in this study indicated, through their experience of reduced autonomy, that greater self-determination was very important to them. While the future planning for aged care is very important, it is equally imperative to ensure services also meet the needs of current aged care facility older people.

As discussed in Chapter Two, quality improvement policies require regular audits and checks on aged care facilities in Australia. As such, the accreditation system tends to focus on the physical requirements of aged care facilities, rather than personal needs assessment, affecting QoL (Rosewarne, 2001, p. 118). It is therefore critical that aged care facilities are held accountable for more than just routine care. As Courtney et al. (2007, pp. 87–89) discuss, formalised accreditation processes in residential aged care only partially address quality assessment. According to Richardson and Bartlett (2009, pp. 28, 30) the current process also increases dependency levels and results in fewer low care placements being available. Certainly, the Productivity Commission (2011a, pp. 115–116) has reported that the accreditation system, along with the ACFI, focus on, and promote, dependence. De Bellis (2010, p. 102) has reported that funding models promoting dependency and ageing-in-place have major implications, as many low care places were allocated to older persons requiring high care (DHA, 2012c, p. 32). The current ACIF (DHA, 2013, p. 1) in its attempt to provide an overall care profile for allocation of funds, has been developed within a professional model. There appears to be a lack of participatory research into its design. Indeed, the DHA (2013) suggests that the ACIF is not intended as an inclusive assessment package. It is suggested that participatory research with end users would facilitate a more comprehensive list of domains.

The funding allocations and accreditation process should be based on a more humanistic appreciation of care, and this can be achieved by reviewing and implementing research recommendations based on the lived experience of older people in aged care facilities and implementing them into regulation and accreditation requirements. Indeed, in their response to the Productivity Commission's inquiry into aged care, the Australian Nurses Federation suggested that a national education programme for assessor training be implemented, which may assist in adequate provision of aged care (Thomas & Chaperon, 2010, pp. 4, 27). It also appears that the level of documentation to achieve funding should be reduced as it detrimentally affects the care of older people with time taken away from care staff to fulfil the objective of fund-based evidentiary paperwork. This represents a challenge to the government to incorporate research-based findings, such as those identified in this study, which could assist in informing broader policies.

The literature suggests that many families want more information on procedures and a better understanding of the lines of authority as well as facility policies (Russell & Forman, 2000; Russell & Foreman, 2002, p. 147). Older people clearly rely on relatives and friends to act on their behalf to provide comfort. Aged care facility administrators could adapt the options of ageing-in-place: older people and families could discuss future plan choices in consultation, with minimal disruption for moving at each stage of progressive illness and immobility. This is consistent with the objectives of advance care planning and advance care directives discussed in the literature by Jeong et al. (2010, 2011a, & 2011b). The aged care system and ageing-in-place in the community is dependent on informal carers for success (Productivity Commission 2011a, p. 235). Policies, including better remuneration, reimbursements and carers' leave entitlements, along with greater recognition of community care, would be vital for the continuance of this care in the community. This may require more flexible models of care to be sympathetic to individual circumstances.

The current funding model would need to support the opportunities for increased comfort and wellbeing for older people, and the culture of the aged care facility would

need to encourage resident-oriented care, rather than mere adherence to the regulatory requirements that drive the daily operations facility. While this latter factor is a compulsory requirement under the *Aged Care Act*, RACFs would be able to provide a more humanistic model of care to facilitate QoL if regulatory requirements actively reflected the needs of older people and were not just driven by a culture of risk aversion (Fernandez & Forder, 2010, pp. 713–714).

Policy shifts in aged care management in Australia in the early 1970s resulted in the proliferation of unqualified workers and lower pay rates for qualified nursing staff (Willis et al., 2009, p. 89); clearly this has affected quality of care. Qualified staff do most of the work and relieve pressure on unqualified staff (Kayser-Jones et al., 2003, p. 82). Currently, nurses and carers in aged care settings are among the poorest paid in Australia (Payscale Australia, 2012). Government lobbying for parity of remuneration with acute care colleagues could increase pay rates and status for aged care workers. This would provide an incentive for qualified staff to remain and more staff to seek employment in aged care facilities. This may contribute to more adequate staffing of aged care services, which would ultimately improve wellbeing for older people. Further, reliance on agency staff would decrease, and this would greatly improve the ‘gaps’ in care that the older people spoke of in their narratives. This is supported by researchers such as De Bellis (2010, p. 10), and Castle and Engberg (2007, p. 1823) as well as Donohue (2011, p. 3), who suggested that older people’s QoL could be improved with greater staff training and more permanent staff. However, in the current context of a global nursing shortage, this recommendation is not without challenges.

Other policy incentives could include continuing education and in-service programmes for nursing staff who currently work in the aged care sector. Again, this would require the allocation of additional funding. Residential care facilities would need to develop a culture of ongoing improvement in staff education and skills, and the appropriate flexibility in their employment conditions to allow staff leave for study and potentially even consider fee reimbursement. The recognition of care workers would be improved because of higher qualifications and, with an increase in

status, the attractiveness of work in the aged care sector may increase. Connected to this option is the responsibility of health worker regulators (for example the registering bodies and course accreditors) who should insist that extensive coursework content and clear competency standards are incorporated into aged care and nursing qualifications.

At a local level, to ensure older people get appropriate, personalised care whereby health that is personally tailored whilst the culture of care facilities changes to respond to policy whilst still retaining a home like environment (Graham et al., 2013), one recommended change would be the provision of a separate unit for dementia in those facilities where older people who have dementia and those who are cognitively able share common areas. In these places, dementia-specific philosophies and models could then be incorporated into care. Although depending on the size and staffing of the aged care facility, this could result in less staffing for those older people who are not cognitively impaired. However, such a change may also allow the environment to be better orientated towards QoL for those older people with dementia with options such as sensory rooms, direction signs and pictures indicating facilities like toilets, as suggested by Moore et al. (2011). Such initiatives in practice may foster a more enjoyable and comfortable environment for cognitively able older people who are subject to the behaviours of older people with dementia. This was a conclusion of this study, where older people actively withdrew from some elements of aged care facility life to avoid having to cope with dementia-related behaviours.

In summary, the suggestions for how this study could inform policy and practice have highlighted the need for a review of aged care services funding, to not only accommodate increasing demand, but also provide more resident-centred care, allow end user contributions for policymaking and better rates of pay and professional development opportunities for staff. The inquiry by the Productivity Commission (2011) has reviewed the aged care system and user group contributions, and further reform is proposed in the *Living Longer. Living Better Package* (CoA, 2012), which will comprise amendments to the *Aged Care Act 1997* (DHA, 2012b). The success of

the objective to implement consumer-directed care principles into the aged care system is a matter for future debate.

## **5.5. Limitations**

Limitations for research include reflection on issues of objectivity and the interaction between the researcher and the issue or phenomenon observed. The research methods in this study needed to address the following limitation, inherent in phenomenology (Cohen, Kahn & Steeves, 2000, p. viii). Qualitative research, such as this study, is not designed to provide general findings, as this would not be consistent with the aims. Thus, this study employs dialogical openness, open mindedness and open heartedness, which is appropriate for investigating older people's perceptions of life (Gerber & Moyle, 2004, p. 44). The sample size involved 18 aged care facility older people across five aged care facilities. Therefore, the findings in this study are not universal. However, this was not the study's aim; rather, it sought to gain an in depth understanding of the lived experience of aged care facility life.

Another limitation was that the interviews did not capture the experiences of those older people with dementia or who were more cognitively impaired, nor did it capture differences between ethnic groups. Again, this was not an aim of this study, as the study was time limited and unfunded, precluding the inclusion of these specific populations. However, this area could be part of further research expanding on the findings of this study.

A further limitation relates to levels of physical and mental frailty that may have resulted in quite different perceptions of their experiences and may have influenced their narratives. However, a variety of experiences was needed to gain insight into how older people experience aged care facility life. Further, some older people were interrupted by staff or visitors while being interviewed and this may have disturbed their train of thought. In this study, the older people's narratives were accepted as a true reflection of their perceptions of aged care facility life.

I approached this study with some assumptions. These included that aged care facilities would be willing to engage with this research topic; that there would be many older people willing and able to participate; that all participants would be able to complete the interview(s); that all nominated interviewees would be through purposive sampling; and that the study would need to be done over stages. A key influence on interpreting findings is to accept limitations and assumptions, and to employ an interpretive theoretical approach that encompasses reflection on such issues, such as espoused by van Manen (1990). This was dependant on my own interpretation and on the historical context and temporality that existed regarding those concepts.

## **5.6. Recommendations for further research**

The first major conclusion was that older people experienced decreased autonomy and a lack of meaningful participation in decision making over issues affecting their lives. Further research into assessing independent opportunities for older people, such as having choice and control over individual elements of aged care facility life (for example their bed times or showering times) may indicate the elements over which they could retain control. In turn, this would promote a greater level of autonomy for the older people, which may influence their care options and provide a degree of independence similar to when they were at home. While there has been much research on quality of care in aged care facilities, research into the effect of the level of care and its impact on independence from end users themselves could inform care providers regarding greater personally orientated care provision. Participatory research into more humanistic elements of aged care facility life (Bowers et al., 2009; Horner, 2005; Ward, Barnes & Gahagan, 2012) resulted in clarifying significant elements relating to personal care and older people's QoL.

The second major conclusion of this study is that older people valued relationships with others. Visits from family and friends provided social connectedness with the 'outside world' and kept older people up-to-date with their previous home life. Further, relationships with other older people and staff were significant aspects of

their enjoyment of the facility. However, some barriers in forging these relationships existed. Further research into aged care facility policies of visiting practices could ascertain if these areas could be improved to promote more friendly and open visiting opportunities. Additionally, those barriers, such as the physical layout of the facility and the need for staff assistance to enable older people to mobilise, communicate and participate in activities could be researched as they relate to improved social contact prospects, especially in relation to meaningful activities. Observational and interview-based studies could clarify the main elements conducive to, or are barriers against, social contact.

The third major conclusion is the participants' resigned acceptance of aged care facility life and adopted coping mechanisms to deal with the unsettling experiences relating to dealing with those older people with demanding behaviours or who were dying. Further research into how the behaviours of older people with dementia affect those who are cognitively able, as well as on other older people with dementia, may identify behaviours that could be moderated to allow a more congenial environment. Further, research into the use of diversionary and sensory activities and the success of reducing demanding behaviours could create possible intervention practices in the aged care facility. This could be achieved through observations and interviews.

Continued research into policy areas could benefit the provision of aged care through government and private (including NFP) providers. Areas for large research projects could include ageing and the financial incentives and saving for future long-term care including insurance, superannuation saving, the ageing labour market and productivity, flexible employment and incentives. Similarly, an evaluation of education and training for carers and a review of pay rates for carers are all important determinants of coping with the ageing population. The influence of political, social and economic trends on ageing requires investigation about how dynamic processes affect the provision of aged care. This could be researched using a large longitudinal survey. To capture the diversity of outcomes for older people, an exploration of the broad range of trends in the ageing sector would be beneficial.

Further research is also needed to determine if the findings of this study reflect the experiences of older people in other facilities. Following this, a survey could be undertaken to determine how older people would like to see their environment adapted to provide more personally oriented care. Any new studies could use a larger and more representative sample to reach a deeper understanding of the experience of residential aged care. As QoL for aged care facility older people is multidimensional, it may be useful to research older people's perspectives on the dimensions of QoL (for example the physical environment and staffing issues identified in this study may be of concern to other older people) so a larger study could explore these dimensions. Older people's perceptions when exploring QoL are fundamental in appreciating the lived experience and the potential for improvements that may reflect more personally oriented care. Future approaches to regulating and improving the quality of care in residential aged care should acknowledge older people's views on QoL. Mechanisms to facilitate consumer empowerment will enable older people to play an increasingly active role in quality development (OECD, 2005). This reflects a growing recognition of the importance of including resident's voices in determining quality in residential aged care.

Any research into lived experience from a QoL perspective informs the public about the needs of older people and can add to a growing awareness of QoL issues affecting the older people in aged care facilities. Acknowledgement of problems and improvements can be made through government policy, task forces, current awareness programs and specific organisations set up to monitor and provide advice about ageing, such as Alzheimer's Australia and Aged Care Australia. Government policy could provide greater funding for those organisations to extend research and draw on completed research study outcomes to adopt recommendations as proposed. The new legislative amendments to the *Aged Care Act 1997* may indeed provide opportunities for greater participatory involvement by user groups and end users such as those older people already living in RACFs. Future research could involve a study surrounding the operation of the new changes and its impact on care in RACFs.

## 5.7. Conclusion

This chapter has presented the conclusions and findings of this study that sought to explore the lived experiences of older people within aged care facilities. The theoretical framework of phenomenology was used in this study to assist in understanding the findings. The study findings have been presented as three conclusions that have been discussed in relation to QoL and in the context of the available literature regarding aged care. The implications of the conclusions and the value of the theoretical framework for policy and practice changes have been discussed, followed by opportunities for further research. Suggestions have been made for research that could explore the areas of specific impact on older people's QoL. This approach allows consideration of the quality of care aspects inherent in aged care facility care provision, policy initiatives as well as the more humanistic elements, which were more important to this group of older people, such as social relationships, security and affection.

Finally, this study set out to explore the lived experience of older people in aged care facilities and while it is acknowledged that the findings of this study cannot explain the experiences of older people generally, the conclusions can assist in expanding knowledge about residential aged care. I wish to thank the older people who so willingly gave their time for this study. It has been the intention throughout this thesis to tell the older people's stories in a credible and plausible way and it is hoped that the findings will resonate with others in similar situations. One key outcome of this study is to raise awareness of the experiences of older people living in aged care facilities. This was underpinned by four aims, which were to investigate the impact that living in a RACF has on the older person's care and experience; to assess those elements of RACF life which made a difference to the older person; to understand the older person's QoL issues, such as, but not limited to, independence, dignity, autonomy, communication, relationships with staff and explore their perceptions of their QoL; and to explore the overall perception of RACF life and how care might be improved, from the participants' perspectives.

Finally, this study reinforces the value of hearing the stories of older people as a means of informing policy and practice in the aged care context. The final determination of whether this has been achieved rests with the readers of this work.

## References

ABS. (2009a). *Disability, ageing and carers, Australia: Summary of findings* (Cat. no. 4430.0). Retrieved from [http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/9C2B94626F0FAC62CA2577FA0011C431/\\$File/44300\\_2009.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/9C2B94626F0FAC62CA2577FA0011C431/$File/44300_2009.pdf)

ABS. (2009b). *National health survey: Summary of results, 2007–2008* (Reissue, cat. no. 4364.0). Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4364.0Explanatory%20Notes12007-2008%20%28Reissue%29>

ABS. (2010a). *Deaths* (Cat. no. 3302.0). Retrieved from <http://www.ausstats.abs.gov.au/>

ABS. (2010b). *Measures of Australia's progress, 2010* (Cat. no. 1370.0). Retrieved from [http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1370.0~2010~Chapter~Burden%20of%20disease%20\(4.1.6.4\)](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1370.0~2010~Chapter~Burden%20of%20disease%20(4.1.6.4))

ABS. (2010c). *Population by age and sex, Australian states and territories, Jun 2010* (Cat. no. 3201.0). Retrieved from <http://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/3201.0?>

ABS. (2012a). *Causes of death, Australia, 2010* (Cat. no. 3303.0). Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3303.02010?OpenDocument>

ABS. (2012b). *Deaths, Australia, 2011* (Cat. no. 3302.0). Retrieved from <http://abs.gov.au/ausstats/abs@.nsf/Latestproducts/3302.0Main%20Features62011?opendocument&tabname=Summary&prodno=3302.0&issue=2011&num=&view=>

ABS. (2012c). *Life tables, states, territories and Australia, 2009–2011* (Cat. no. 3302.0.55.001). Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3302.0.55.0012009-2011?OpenDocument>

Aboderin, I. (2004). Modernisation and ageing theory revisited: Current explanations of recent developing world and historical Western shifts in material family support for older people. *Ageing and society*, 24(1), 29-50.

Access Economics. (2010). The future of aged care in Australia, September 2010. A public policy discussion paper prepared for National Seniors Australia. Barton, ACT: National Seniors Australia. Retrieved from [http://www.nationalseniors.com.au/icms\\_docs/Future\\_of\\_Aged\\_Care\\_Report.pdf](http://www.nationalseniors.com.au/icms_docs/Future_of_Aged_Care_Report.pdf)

Adams, J. M. & White, M. (2004). Biological ageing: A fundamental, biological link between socio-economic status and health? *European Journal of Public Health*, 14(3), 331–334.

Adams, K. B., Sanders, S. & Auth, E. A. (2004). Loneliness and depression in independent living retirement communities: Risk and resilience factors. *Aging & Mental Health*, 8(6), 475–485.

Aged Care Act, § 2.1 (1997). Retrieved from [http://www.austlii.edu.au/au/legis/cth/consol\\_act/aca199757/s2.1.html](http://www.austlii.edu.au/au/legis/cth/consol_act/aca199757/s2.1.html)

Aged Care Crisis. (2010a). *Care issues*. Retrieved from <http://www.agedcarecrisis.com/>

Aged Care Crisis. (2010b). *Productivity Commission inquiry: Caring for older Australians*. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0008/102140/sub433.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0008/102140/sub433.pdf)

ACSAA. (2012). *Accreditation overview*. Retrieved from <http://www.accreditation.org.au/accreditation/accreditationoverview/>

AIHW. (2008). *Residential aged care in Australia 2006–07: A statistical overview* (Aged care statistics series no. 26, cat. no. AGE 56). Retrieved from <http://www.aihw.gov.au/publications/index.cfm/title/10589>

AIHW. (2009). *Residential aged care in Australia 2007–08: A statistical overview* (Aged care statistics series no. 28, cat. no. AGE 58). Retrieved from <http://www.aihw.gov.au/publication-detail/?id=6442468253>

AIHW. (2010a). *Australia's health 2010: The twelfth biennial health report of the Australian Institute of Health and Welfare* (Australia's health series no. 12, cat. no. AUS 122). Retrieved from <http://www.aihw.gov.au/publication-detail/?id=6442468376&libID=6442468374>

AIHW. (2010b). *Residential aged care in Australia 2008–09: A statistical overview* (Aged care statistics series no. 31, cat. no. AGE 62). Retrieved from <http://www.aihw.gov.au/publication-detail/?id=6442472446>

AIHW. (2011a). *Residential aged care in Australia 2009–10: A statistical overview* (Aged care statistics series no. 35, cat. no. AGE 66). Retrieved from <http://www.aihw.gov.au/publication-detail/?id=10737419861>

AIHW. (2011b). Tracking the growth path to ageing and aged care. *Access*, 29. Retrieved from <http://www.aihw.gov.au/access/201103/feature/ageing-and-aged-care.cfm>

AIHW. (2012a). *Ageing*. Retrieved from <http://www.aihw.gov.au/ageing/>

AIHW. (2012b). *Ageing in place*. Retrieved from <http://www.aihw.gov.au/ageing-in-place/>

AIHW. (2012c). *Australia's aged care system*. Retrieved from <http://www.aihw.gov.au/aged-care/options/>

AIHW. (2012d). *Health expenditure Australia 2010–11* (Health and welfare expenditure series no. 47, cat. no. HWE 56). Retrieved from <http://www.aihw.gov.au/publication-detail/?id=10737423009>

AIHW. (2012e). *Permanent resident, 30 June 2011*. Retrieved from <http://www.aihw.gov.au/aged-care-data-cube/?id=10737422979>

AIHW. (2012f). *Residential aged care in Australia 2010–11: A statistical overview* (Aged care statistics series no. 31, cat. no. AGE 62). Canberra, Australia: AIHW. Retrieved from <http://books.google.com.au/books?id=xtM292fRVTsC&printsec=frontcover#v=onepage&q&f=false>

AIHW. (2012g). *Services and places, 30 June 2011* [Data set]. Retrieved from <http://www.aihw.gov.au/aged-care-data-cube/?id=10737422980>

- AIHW. (2012h). *Health expenditure Australia 2010-11. Health and welfare expenditure series no. 47*. Retrieved from <http://www.aihw.gov.au/publication-detail/?id=10737423009>
- Ajjawi, R. & Higgs, J. (2007). Using hermeneutic phenomenology to investigate how experienced practitioners learn to communicate clinical reasoning. *Qualitative Report*, 12(4), 612–638. Retrieved from <http://www.nova.edu/ssss/QR/QR12-4/ajjawi.pdf>
- Alzheimer's Australia (2010a). *Caring places: Planning for aged care and dementia 2010–2050* (Vol. 1). Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0010/102304/sub446.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0010/102304/sub446.pdf)
- Alzheimer's Australia. (2010b). *Submission to the Productivity Commission Inquiry: Caring for older Australians*. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0012/100362/sub079.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0012/100362/sub079.pdf)
- Anderberg, O. & Berglund, A.-L. (2010). Elderly persons' experiences of striving to receive care on their terms in nursing homes. *International Journal of Nursing Practice*, 16(1), 64–68. doi:10.1111/j.1440-172X.2009.01808.x
- Andersen, M. L. & Taylor, H. F. (2008). *Sociology: Understanding a diverse society* (4th ed.). Belmont, CA: Thompson Wordsworth.
- Andersson, I., Pettersson, E. & Sidenvall, B. (2007). Daily life after moving into a care home—experiences from older people, relatives and contact persons. *Journal of Clinical Nursing*, 16(9), 1712–1718. doi:10.1111/j.1365-2702.2007.01703.x
- Andrews-Hall, S., Howe, A. & Robinson, A. (2007). The dynamics of residential aged care in Australia: 8-year trends in admission, separations and dependency. *Australian Health Review*, 31(4), 611–622.

Andrews, F. M. & Withey, S. B. (1976). *Social indicators of well-being: Americans' perceptions of life quality*. New York, NY: Plenum Press.

Angus, J. & Nay, R. (2003). The paradox of the Aged Care Act 1997: The marginalisation of nursing discourse. *Nursing Inquiry*, 10(2), 130–138. doi:10.1046/j.1440-1800.2003.00164.x

Annells, M. (1996). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research*, 6(3), 379–393. doi:10.1177/104973239600600306

Ansell, C., Davey, E. & Vu, H. (2012). *Australian cost of residential aged care research: Service costs in modern residential aged care services*. Retrieved from [http://www.grantthornton.com.au/files/cost\\_of\\_care\\_research\\_120201.pdf](http://www.grantthornton.com.au/files/cost_of_care_research_120201.pdf)

Armitage, A. (1950). Rene Descartes (1596–1650) and the early Royal Society. *Notes and Records of the Royal Society*, 8(1), 1–19.

Australian Nursing Federation. (2013). *A snapshot of residential aged care* (Fact sheet 4). Canberra, Australia: Author. Retrieved from [http://www.anf.org.au/pdf/Fact\\_Sheet\\_Snap\\_Shot\\_Aged\\_Care.pdf](http://www.anf.org.au/pdf/Fact_Sheet_Snap_Shot_Aged_Care.pdf)

Ball, J., Ford, P. & Smith, V. (2005). Working in care homes: A survey. *Nursing Standard*, 20(6), 41–46.

Banerjee, S., Samsi, K., Petrie, C. D., Alvir, J., Trelgia, M., Schwam, E. M. & del Valle, M. (2009). What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *International Journal of Geriatric Psychiatry*, 24(1), 15–24. doi:10.1002/gps.2090

Banks, M., Bauer, J., Graves, N. & Ash, S. (2010). Malnutrition and pressure ulcer risk in adults in Australian health care facilities. *Nutrition*, 26(9), 896–901.

doi:10.1016/j.nut.

2009.09.024

Barrett, P., Hale, B. & Gauld, R. (2012). Social inclusion through ageing-in-place with care? *Ageing and Society*, 32(3), 361–378. doi:10.1017/S0144686X11000341

Bashir, M., Tanvir Afzaal, M. & Azeem, M. (2008). Reliability and validity of qualitative and operational research paradigm. *Pakistan Journal of Statistical and Operational Research*, 4(1), 35–45.

Bass, S. (2007). The emergence of the golden age of social gerontology? *Gerontologist*, 40(3), 408-412.

Bass, S. (2009). Toward an integrative theory of social gerontology. In V. L. Bengtson, D. Gans, N. M. Putney & M. Silverstein (Eds), *Handbook of theories of aging* (2nd ed., pp. 347–374). New York, NY: Springer.

Beard, J. R., Biggs, S., Bloom, D. E., Fried, L. P., Hogan, P., Kalache, A. & Olshansky, S. J. (Eds). (2011). *Global population ageing: Peril or promise?* Geneva, Switzerland: World Economic Forum.

Begg, S., Vos, T., Barker, B., Stevenson, C., Stanley, L. & Lopez, A. D. (2007). *The burden of disease and injury in Australia 2003* (Cat. no. PHE 82). Retrieved from <http://www.aihw.gov.au/publication-detail/?id=6442467990>

Bengtson, V. L., Gans, D., Putney, N. M. & Silverstein, M. (Eds) (2009a). *Handbook of theories of aging* (2nd ed.). New York, NY: Springer.

Bengtson, V. L., Gans, D., Putney, N. M. & Silverstein, M. (2009b). Theories about age and aging. In V. L. Bengtson, D. Gans, N. M. Putney & M. Silverstein (Eds), *Handbook of theories of aging* (2nd ed., pp. 3–24). New York, NY: Springer.

Berglund, H. (2007). Researching entrepreneurship as a lived experience. In H. Neergaard & J. P. Uhløi (Eds), *Handbook of qualitative research methods in entrepreneurship research* (pp. 75–96). Cheltenham, England: Edward Elgar.

Bigby, C. (2003). *Ageing with a lifelong disability: A guide to practice, program and policy issues for human services professionals*. London, England: Jessica Kingsley.

Biggs, S. (2012). Toward critical narrativity: Stories of ageing in contemporary social policy. In G. Boulton-Lewis & M. Tam (Eds), *Active ageing, active learning: Issues and challenges* (pp. 89–102). Dordrecht, The Netherlands: Springer Science + Business Media.

Blattner, W. D. (1999). *Heidegger's temporal idealism*. Cambridge, England: Cambridge University Press.

Bloom, D. E. & Canning, D. (2008). Global demographic change: Dimensions and economic significance. *Population and Development Review*, 34(Suppl.), 17–51.

Bokel, H. (2007). *Parliamentary Assembly, Council of Europe. Working Papers 2007 Ordinary Session (second part) 16–10 April 2007*, (111). Strasbourg, France: Council of Europe Publishing.

Borowski, A., Encel, S. & Ozanne, E. (Eds). (1997). *Ageing and social policy in Australia*. Cambridge, England: Cambridge University Press.

Boulton-Lewis, G. & Tam, M. (Eds) (2012). *Active ageing, active learning: Issues and challenges*. Dordrecht, The Netherlands: Springer Science + Business Media.

Bowers, B., Fibich, B. & Jacobson, N. (2001). Care-as-service, care-as-relating, care-as-comfort: Understanding nursing home residents' dimensions of quality. *Gerontologist*, 41(4), 539–545. doi:10.1093/geront/41.4.539

Bowers, H., Clark, A., Crosby, G., Easterbrook, L., Macadam, A., MacDonald, R., ... Smith, C. (2009). *Older people's vision for long-term care*. Retrieved from <http://www.jrf.org.uk/publications/older-people-vision-long-term-care>

Bowling, A. (2005). *Measuring health: A review of quality of life measurement scales* (3rd ed.). Maidenhead, England: Open University Press.

Bowling, A. (2009). *Research methods in health: Investigating health and health services* (3rd ed.). Maidenhead, England: Open University Press.

Bowling, A., Gabriel, Z., Dykes, J., Dowding, L. M., Evans, O., Fleissig, A., ... Sutton, S. (2003). Let's ask them: A national survey of definitions of quality of life and its enhancement among people aged 65 and over. *International Journal of Aging & Human Development*, 56(4), 269–306. doi:10.2190/BF8G-5J8L-YTRF-6404

Bradburn, N. M. & Caplovitz, D. (1965). *Reports on happiness: A pilot study on behaviour related to mental health*. IL: Aldine.

Braithwaite, J., Makkai, T. & Braithwaite, V. (2007). *Regulating aged care: Ritualism and the new pyramid*. Cheltenham, England: Edward Elgar.

Briggs, D., Courtney, M., Cormack, M., Smith, R. & Sadler, P. (2004). Health care financing: Australian and international perspectives. In M. Courtney & D. Briggs (Eds), *Healthcare financial management* (pp. 1–17). Sydney, Australia: Elsevier Mosby Australia.

Brown, S. L., Brown, M. R. & Penner, L. A. (2012). *Moving beyond self-interest: Perspectives from evolutionary biology, neuroscience, and the social sciences*. New York, NY: Oxford University Press.

Brownie, S. & Horstmanshof, L. (2012). Creating the conditions for self-fulfilment for aged care residents. *Nursing Ethics*, 19(6), 777–786. doi:1177/0969733011423292

Bruen, W. (2005). Policy update: Aged care in Australia: past, present and future. *Australasian Journal on Ageing*, 24(3), 130–133. doi:10.1111/j.1741-6612.2005.00109.x

Bryant, C. D. (Ed.) (2003). *Handbook of death and dying* (Vol. 1). Thousand Oaks, CA: SAGE.

Bryman, A. (2012). *Social research methods* (4th ed.). Oxford, England: Oxford University Press.

Burch, R. (1990). Phenomenology, lived experience: Taking a measure of the topic. *Phenomenology + Pedagogy*, 8, 130–160.

Burns, L. R., Bradley, E. H. & Weiner, B. J. (2012). *Shortell and Kaluzny's health care management: Organisation, design and behavior* (6th ed.). New York, NY: Delmar Cengage Learning.

Buys, L. & Millar, E. (2012). Active ageing: Developing a quantitative multidimensional measure. In G. Boulton-Lewis & M. Tam (Eds), *Active ageing, active learning: Issues and challenges* (pp. 103–120). Dordrecht, The Netherlands: Springer Science + Business Media.

Byrne, G. J. & Neville, C. (2010). *Community mental health for older people*. Sydney, Australia: Churchill Livingstone Elsevier.

Caelli, K., Ray, L. & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2(2), 1–13.

Cahill, S. & Diaz-Ponce, A. M. (2011). 'I hate having nobody here. I'd like to know where they all are': Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? *Aging & Mental Health*, 15(5), 562–572. doi:10.1080/13607863.2010.551342

Calasanti, T. M. & Slevin, K. F. (2001). *Gender, social inequalities, and aging*. Walnut Creek, CA: AltaMira Press.

Campbell, A., Converse, P. E. & Rodgers, W. L. (1976). *The quality of American life: Perceptions, evaluations, and satisfactions*. New York, NY: Russell Sage Foundation.

Cantril, H. (1965). *The pattern of human concerns*. New Brunswick, NJ: Rutgers University Press.

Cape, R. D. & Gibson, S. J. (1994). The influence of clinical problems, age and social support on outcomes for elderly persons referred to regional aged care assessment teams. *Australian and New Zealand Journal of Medicine*, 24(4), 378–385. doi:10.1111/j.1445-5994.1994.tb01465.x

Carp, F. M. (2000). *Elder abuse in the family: An interdisciplinary model for research*. New York, NY: Springer.

Carpenter, B. D. (2002). Family, peer, and staff social support in nursing home patients: Contributions to psychological well-being. *Journal of Applied Gerontology*, 21(3), 275–293.

Casey, E. & Martens, L. (Eds) (2007). *Gender and consumption: Domestic cultures and the commercialisation of everyday life*. Aldershot, England: Ashgate.

Castle, N. G. & Anderson, R. (2011). Caregiver staffing in nursing homes and their influence on quality of care: Using dynamic panel estimation methods. *Medical Care*, 49(6), 545–552. doi:10.1097/MLR.0b013e31820fbca9

Castle, N. G. & Engberg, J. (2007). The influence on staffing characteristics on quality of care in nursing homes. *Health Services Research*, 42(5), 1822–1847. doi:10.1111/j.1475-6773.2007.00704.x

Chalmers, J. M., Carter, K. D., Fuss, J. M., Spencer, A. J. & Hodge, C. P. (2002). Caries experience in existing and new nursing home residents in Adelaide, Australia. *Gerodontology*, 19(1), 30–40. doi:10.1111/j.1741-2358.2002.00030.x

Chapelhow, C., Crouch, S., Fisher, M. & Walsh, A. (2005). *Uncovering skills for practice: Foundations in nursing and health care*. Cheltenham, England: Nelson Thornes.

Cheal, J. (2010). 'Quack, quack. Get out of town': Is neuro-linguistic programming a science or a pseudo-science? Retrieved from <http://www.gwiztraining.com/NLP%20&%20Science.pdf>

Cheek, J. & Ballantyne, A. (2001). Moving them on and in: The process of searching for and selecting an aged care facility. *Qualitative Health Research*, 11(2), 221–237. doi:10.1177/104973201129119064

Cheek, J., Ballantyne, A., Byers, L. & Quan, J. (2007). From retirement village to residential aged care: What older people and their families say. *Health & Social Care in the Community*, 15(1), 8–17. doi:10.1111/j.1365-2524.2006.00646.x

Chi, I., Mehta, K. K. & Howe, A. L. (Eds). (2001). *Long-term care in the 21st century: Perspectives from around the Asia-Pacific Rim*. Binghamton, NY: Haworth Press.

Christensen, K., Doblhammer, G., Rau, R. & Vaupel, J. W. (2009). Ageing populations: The challenges ahead. *Lancet*, 374, 1196–1208. doi:10.1016/S0140-6736(09)61460-4

Clare, L., Rowlands, J., Bruce, E., Surr, C. & Downs, M. (2008). The experience of living with dementia in residential aged care: An interpretative phenomenological analysis. *Gerontologist*, 48(6), 711–720. doi:10.1093/geront/48.6.711

Clark, E. & McCann, T. (2009). The aged care sector: Residential and community care. In E. Willis, L. Reynolds & H. Keleher (Eds), *Understanding the Australian health care system* (pp. 83–94). Sydney, Australia: Churchill Livingstone Elsevier.

Clark, J. (2008). Philosophy, understanding and the consultation: A fusion of horizons. *British Journal of General Practice*, 58(546), 58–60. doi:10.3399/bjgp08X263929

CoA. (2006). *Aged care assessment and approval guidelines*. Retrieved from [http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA25774C001857CACA256F19000F3C96/\\$File/acaag.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA25774C001857CACA256F19000F3C96/$File/acaag.pdf)

CoA. (2007). *National program guidelines for the Home and Community Care Program*. Retrieved from [http://www.health.wa.gov.au/hacc/docs/pg\\_npg.pdf](http://www.health.wa.gov.au/hacc/docs/pg_npg.pdf)

CoA. (2012). *Living longer. Living better*. Retrieved from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-aged-care-reform-measures-toc>

Cochran, C. E., Mayer, L. C., Carr, T. R., Cayer, N. J., Mckenzie, M. J. & Peck, L. R. (2012). *American public policy: An introduction*. Boston, MA: Wadsworth Cengage Learning.

Coffey, A. A. & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: SAGE.

Cohen, L., Manion, L. & Morrison, K. (2000). *Research methods in education* (5th ed.). London, England: RoutledgeFalmer.

Cohen, M. Z. (1987). A historical overview of the phenomenologic movement. *Journal of Nursing Scholarship*, 19(1), 31–34. doi:10.1111/j.1547-5069.1987.tb00584.x

Cohen, M. Z. (2000). Introduction. In M. Z. Cohen, D. L. Kahn & R. H. Steeves, *Hermeneutic phenomenological research: A practical guide for nurse researchers* (pp. 1–12). Thousand Oaks, CA: SAGE.

Cohen, M. Z. & Omery, A. (1994). Schools of phenomenology: Implications for research. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 136–153). Thousand Oaks, CA: SAGE.

Cohen, M. Z., Kahn, D. L. & Steeves, R. H. (2000). *Hermeneutic phenomenological research: A practical guide for nurse researchers*. Thousand Oaks, CA: SAGE.

Colaizzi, P. F. (1978). Psychological research as a phenomenologist views it. In R. S. Valle & M. King (Eds.), *Existential phenomenological alternatives for psychology* (pp. 48-71). New York, NY: Oxford University Press.

Commission on Funding of Care and Support. (2011). *Fairer care funding: The report of the Commission on Funding of Care and Support*. Retrieved from [http://www.ilis.co.uk/uploaded\\_files/dilnott\\_report\\_the\\_future\\_of\\_funding\\_social\\_care\\_july\\_2011.pdf](http://www.ilis.co.uk/uploaded_files/dilnott_report_the_future_of_funding_social_care_july_2011.pdf)

Cook, G. & Brown-Wilson, C. (2010). Care home residents' experiences of social relationships with staff. *Nursing Older People*, 22(1), 24–29.

Cook, I. G. & Halsaw, J. (2011). *Aging in comparative perspective: Processes and policies*. New York, NY: Springer Science + Business Media.

Cooney, A., Murphy, K. & O'Shea, E. (2009). Resident perspectives of the determinants of quality of life in residential care in Ireland. *Journal of Advanced Nursing*, 65(5), 1029–1038. doi:10.1111/j.1365-2648.2008.04960.x

Courtney, M. & Briggs, D. (2004). *Health care financial management*. Sydney, Australia: Mosby Elsevier.

Courtney, M., Boldy, D. & Moyle, W. (2009). Measuring and supporting quality of life. In R. Nay & S. Garratt (Eds), *Older people: Issues and innovations in care* (3rd ed., pp. 351–371). Sydney, Australia: Churchill Livingstone Elsevier.

Courtney, M., O'Reilly, M. T., Edwards, H. & Hassall, S. (2007). Development of a systematic approach to assessing quality within Australian residential care facilities: The Clinical Care Indicators Tool. *Australian Health Review*, 31(4), 582–591.

Crisp, J. & Taylor, C. (2008). *Potter and Perry's fundamentals of nursing* (3rd ed.). Sydney, Australia: Mosby Elsevier.

Crombie, A., Disler, P. & Threlkeld, G. (2009). Ageing in rural areas. In R. Nay & S. Garrett (Eds), *Older people issues and innovations in care* (3rd ed., pp. 42–59). Sydney, Australia: Churchill Livingstone Elsevier.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London, England: SAGE.

Crowell, S. (2002). The Cartesianism of phenomenology. *Continental Philosophy Review*, 35(4), 433–454. doi:10.1023/A:1023974008594

- Crowell, S. (2013). *Normativity and phenomenology in Husserl and Heidegger*. Cambridge, England: Cambridge University Press.
- Csordas, T. J. (Ed.). (1994). *Embodiment and experience: The existential ground of culture and self*. Cambridge, England: Cambridge University Press.
- Cubit, K. A. & Meyer, C. (2011). Aging in Australia. *Gerontologist*, 51(5), 583–589. doi:10.1093/geront/gnr082
- Cumming, E. & Henry, W. E. (1961). *Growing old: The process of disengagement*. New York, NY: Basic Books.
- Cutcliffe, J. R. & McKenna, H. P. (2004). Expert qualitative researchers and the use of audit trails. *Journal of Advanced Nursing*, 45(2), 126–135. doi:10.1046/j.1365-2648.2003.02874.x
- Daly, J., Speedy, S. & Jackson, D. (2004). *Nursing leadership*. Sydney, Australia: Churchill Livingstone Elsevier.
- Dannefer, D. & Phillipson, C. (Eds). (2010). *The SAGE handbook of social gerontology*. London, England: SAGE.
- Davies, D. & Dodd, J. (2002). Qualitative research and the question of rigor. *Journal of Qualitative Health Research*, 12(2), 279–289. doi:10.1177/104973230201200211
- Davies, S. & Heath, H. (2007). Quality of care. In Help the Aged, *My home life: Quality of life in care homes; A review of the literature* (pp. 30–41). London, England: Author. Retrieved from <http://www.scie.org.uk/publications/guides/guide15/files/myhomelife-litreview.pdf>
- De Bellis, A. (2010). Australian residential aged care and the quality of nursing care provision. *Contemporary Nurse*, 35(1), 100–113. Retrieved from

<http://search.informit.com.au/documentSummary;dn=521537847131038;res=IELHEA>

De Bellis, A., Mosel, K., Curren, D., Prendergast, J., Harrington, A. & Muir-Cochrane, E. (2011). Education on physical restraint in dementia care: A review of the literature. *Dementia*. Advance online publication. doi: 10.1177/1471301211421858.

Demetriades, J. E., Kolodner, R. M. & Christopherson, G. A. (Eds) (2008). *Person-centered health records: Toward health people*. New York, NY: Springer Science + Business Media.

K. & Lincoln, Y. S. (Eds.) (2003a). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds), *Strategies of qualitative enquiry* (2nd ed., pp. 1–45). Thousand Oaks, CA: SAGE.

Denzin, N. K. & Lincoln, Y. S. (Eds) (2003b). *Strategies of qualitative enquiry* (2nd ed.). Thousand Oaks, CA: SAGE.

Denzin, N. K. & Lincoln, Y. S. (2011a). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds), *The SAGE handbook of qualitative research* (4th ed., pp. 1–20). Thousand Oaks, CA: SAGE.

Denzin, N. K. & Lincoln, Y. S. (Eds) (2011b). *The SAGE handbook of qualitative research* (4th ed.). Thousand Oaks, CA: SAGE.

Department of Ageing and Life Course, WHO (2012). *Knowledge transition framework for ageing and health*. Geneva, Switzerland: WHO. Retrieved from [http://www.who.int/ageing/publications/knowledge\\_translation.pdf](http://www.who.int/ageing/publications/knowledge_translation.pdf)

Department of Families, Housing, Community Services and Indigenous Affairs. (2009). *Australian Social Policy No. 8*. Canberra, Australia: CoA. Retrieved from [http://www.fahcsia.gov.au/sites/default/files/documents/05\\_2012/asp-8.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/05_2012/asp-8.pdf)

DHA. (2002a). *Ageing in place: A guide for providers of residential aged care*. Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/F80E9639A83FCC27CA256F19000FF586/\\$File/aip\\_broc.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/F80E9639A83FCC27CA256F19000FF586/$File/aip_broc.pdf)

DHA. (2002b). *Ageing in place: Quality care for older Australians* [Pamphlet]. Canberra, Australia: Commonwealth of Australia. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/F80E9639A83FCC27CA256F19000FF586/\\$File/aip\\_book.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/F80E9639A83FCC27CA256F19000FF586/$File/aip_book.pdf)

DHA. (2006). *Resident Classification Scale*. Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/7D7E680F025258EECA2572D7007BC130/\\$File/finlrep.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/7D7E680F025258EECA2572D7007BC130/$File/finlrep.pdf)

DHA. (2007a). *Accommodation bond*. Retrieved from <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-finance-strength.htm>

DHA. (2007b). Department of Health and Ageing (DHA). (2008). *Aged Care Funding Instrument (ACFI) training program*. Canberra, Australia: CoA.

DHA. (2007c). *Fees and charges*. Retrieved from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-rescare-costs.htm>

DHA. (2008a). Department of Health and Ageing (DHA). *Evaluation of the impact of accreditation on the delivery of quality of care and quality of life to residents in Australian Government subsidised residential aged care homes—Final report*. Retrieved from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-iar-final-report.htm>

DHA. (2008b). *Guide to changes to the regulatory framework for aged care*. Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/75A3796E08F4B81BCA257523007D16B3/\\$File/legislat%20guide.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/75A3796E08F4B81BCA257523007D16B3/$File/legislat%20guide.pdf)

DHA. (2008c). The aged care accreditation system. In *Evaluation of the impact of accreditation on the delivery of quality of care and quality of life to residents in Australian Government subsidised residential aged care homes—Final report*. Retrieved from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-iar-final-report.htm~ageing-iar-final-report-4.htm>

DHA. (2008d). The regulatory framework for residential aged care in Australia. In *A Literature review and description of the regulatory framework*. Retrieved from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-iar-review-framework.htm~ageing-iar-review-framework-3.htm>

DHA. (2009). *Help with aged care homes*. Retrieved from <http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/High-level%20care> Department of Health and Ageing

DHA. (2011). *Community Packaged Care*. Canberra, Australia: CoA. Retrieved from <http://www.cpcguidelines.health.gov.au/wp-content/uploads/CommunityPackagedCareGuidelines.pdf>

DHA. (2012a). *2011–12 report on the operation of the Aged Care Act 1997*. Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/content/A5B5FF6D485AA146CA257AC3001C6B98/\\$File/AgedCareACT-booklet.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/A5B5FF6D485AA146CA257AC3001C6B98/$File/AgedCareACT-booklet.pdf)

DHA. (2012b). *Aged Care Act 1997—Principles*. Retrieved from <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-legislat-aca1997-prindex.htm>

DHA. (2012c). *Aged Care Funding Instrument (ACFI)*. Retrieved from <http://www.medicareaustralia.gov.au/provider/aged-care/acfi.jsp>

DHA. (2012d). *Compulsory reporting guidelines for approved providers of residential aged care*. Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/C9DCCE683D372150CA2573020008C89B/\\$File/CR%20guidelines%20for%20APs.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/C9DCCE683D372150CA2573020008C89B/$File/CR%20guidelines%20for%20APs.pdf)

DHA. (2012e). *National Respite for Carers Program (NRCP) and other Australian Government support for carers* (Information sheet no. 5). Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/content/BE2F5B83D6C5512ACA256F5E0016BB00/\\$File/Info-Sheet-05-SEPT12.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/BE2F5B83D6C5512ACA256F5E0016BB00/$File/Info-Sheet-05-SEPT12.pdf)

DHA. (2012f). Outcome 6: Rural health. In *Australian Government 2012–13 health and ageing portfolio budget statements* (pp. 157–162). Retrieved from [http://www.health.gov.au/internet/budget/publishing.nsf/content/2012-13\\_Health\\_PBS\\_sup1/\\$File/2.06\\_Outcome\\_6.pdf](http://www.health.gov.au/internet/budget/publishing.nsf/content/2012-13_Health_PBS_sup1/$File/2.06_Outcome_6.pdf)

DHA. (2012g). Proposed amendments to the Aged Care Act 1997 [Web log post]. Retrieved from <http://agedcarereform.govspace.gov.au/proposed-amendments-to-the-aged-care-act-1997-released-for-public-comment/>

DHA. (2012h). *Residents charter of rights and responsibilities*. Retrieved from <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-resicharter.htm>

DHA. (2012i). *The ACFI and .* Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/Department of Health F4DC4192EE23 5386CA25740C000555E6/\\$File/03\\_The\\_ACFI\\_and\\_Aged\\_Care\\_Workers.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/Department%20of%20Health%20F4DC4192EE235386CA25740C000555E6/$File/03_The_ACFI_and_Aged_Care_Workers.pdf)

DHA. (2013). *Aged Care Funding Instrument: User guide.* Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/4DCD6B1B6814A833CA257AEF00073C89/\\$File/ACFI-User-Guide-Feb2013.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/4DCD6B1B6814A833CA257AEF00073C89/$File/ACFI-User-Guide-Feb2013.pdf)

Diekelmann, N. L. (Ed.) (2002). *First, do no harm: Power, oppression, and violence in healthcare.* London, England: University of Wisconsin Press.

Donohue, M.-A. T. (2011). Nursing workload and the impact of technology. *New Jersey Nurse, 41*(2), 2–4.

Dowd, J. J. (1975). Aging as exchange: A preface to theory. *Journal of Gerontology, 30*(5), 584–594. doi:10.1093/geronj/30.5.584

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies, 44*(1), 131–142. doi:10.1016/j.ijnurstu.2005.11.026

Drew, N. (1993). Reenactment interviewing: A methodology for phenomenological research. *Journal of Nursing Scholarship, 25*(4), 345-351.

Dreyfus, H. L. (1996). The current relevance of Merleau-Ponty's phenomenology of embodiment. *Electronic Journal of Analytic Philosophy, 4*(Spring). Retrieved from <http://ejap.louisiana.edu/ejap/1996.spring/dreyfus.1996.spring.html>

Dreyfus, H. L. & Wrathall, M. A. (Eds) (2009). *A companion to phenomenology and existentialism.* Chichester, England: Blackwell.

Dreyfus, H.L. (2012). Introductory essay: The mystery of the background qua background. In Z. Radman (Ed.) *Knowing without thinking: Mind, action, cognition and the phenomenon of the background* (pp. 1-12). New York, NY: Palgrave Macmillan.

Earle, V. (2010). Phenomenology as research method or substantive metaphysics? An overview of phenomenology's uses in nursing. *Nursing Philosophy*, *11*(4), 286–296. doi:10.1111/j.1466-769X.2010.00458.x

Easterby-Smith, M., Thorpe, R. & Jackson, P. (2008). *Management research* (3rd ed.). London, England: SAGE.

Edwards, H. E., Courtney, M. D. & O'Reilly, M. T. (2003b). Involving older people in research to examine quality of life in residential aged care. *Quality in Ageing*, *4*(4), 38–43. doi:10.1108/14717794200300027

Edwards, H., Gaskill, D., Sanders, F., Forster, E. M., Morrison, P., Fleming, R. M., ... Chapman, H. (2003a). Resident-staff interactions: A challenge for quality aged care. *Australasian Journal on Ageing*, *22*(1), 31–37.

Embree, L. (2001). The continuation of phenomenology: A fifth period? *Indo-Pacific Journal of Phenomenology*, *1*(1). Retrieved from <http://www.ajol.info/index.php/ipjp/article/view/65712/53400>

Fakhri, K. (2011). Quality of life in the nursing homes in Jordan: Perspectives of residents. *Care Management Journals*, *12*(4), 169-182.

Faunce, T. A. (2007). *Who owns our health?* Sydney, Australia: UNSW Press.

Fay, R. & Owen. C. (2012). 'Home' in the aged care institution: Authentic or ersatz? *Procedia—Social and Behavioral Sciences*, *35*, 33–43. doi:10.1016/j.sbspro.2012.02.060

Fernández, J.-L. & Forder, J. (2010). Equity, efficiency, and financial risk of alternative arrangements for funding long-term care systems in an ageing society. *Oxford Review Economic Policy*, 26(4), 713–733. doi:10.1093/oxrep/grq036

Finch, J. (2004). *Evaluating mental health services for older people*. Abingdon, England: Radcliffe.

Findlay, R. A. (2003). Interventions to reduce social isolation amongst older people: Where is the evidence? *Ageing and Society*, 23(5), 647–658. doi:10.1017/S0144686X03001296

Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology & Practice*, 3(1), 6–25.

Fiveash, B. (1998). The experience of nursing home life. *International Journal of Nursing Practice*, 4(3), 166–174. doi:10.1046/j.1440-172X.1998.00062.x

Fleming, R., Crookes, P. A. & Sum, S. (2008). *A review of the empirical literature on the design of physical environments for people with dementia*. Sydney, Australia: Primary Dementia Collaborative Research Centre, University of New South Wales and HammondCare. Retrieved from [http://ro.uow.edu.au/cgi/viewcontent.cgi?article=3923&context=hbspapers&sei-redir=1&referer=http%3A%2F%](http://ro.uow.edu.au/cgi/viewcontent.cgi?article=3923&context=hbspapers&sei-redir=1&referer=http%3A%2F%2F)

Fleming, R., Gaidys, U. & Robb, Y. (2003). Hermeneutic research in nursing: Developing a Gadamerian-based research method. *Nursing Inquiry*, 10(2), 113–120. doi:10.1046/j.1440-1800.2003.00163.x

Flowers, P. (2009). *Research philosophies: Importance and relevance* (Issue 1). Retrieved from <http://www.networkedcranfield.com/cell/Assignment%20Submissions/research%20philosophy%20-%20issue%201%20-%20final.pdf>

Foley, E. (2010). Aged care funding: Heading in the right direction. *Australian Nursing Journal*, 17(11), 19.

Fontana, A. & Frey, J. H. (2000) The interview: From structured questions to negotiated text. In N. K. Denzin & Y. S. Lincoln (Eds), *Handbook of qualitative research* (2nd ed., pp. 645–672). London, England: SAGE.

Formosa, M. (1997, May). *From dependence to interdependence*. Paper presented at the Seminar Malta Ageing Forum (III) of the United Nations International Institute on Ageing, Malta. Retrieved from <http://www.um.edu.mt/pub/formosam7.html>

Foundation for Effective Markets and Governance. (2011). *Comment on the 2011 Productivity Commission draft, 'Caring for Older Australians'*. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0009/108747/subdr679.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0009/108747/subdr679.pdf)

Friis, L. K. & Harder, I (2010). Nursing home residents' experience of life in a nursing home. *Danish Journal of Nursing*, 110(11), 48–52.

Furness, S. (2007). Promoting control and interdependence for those living in care homes by establishing 'friends of care home' groups. *Quality in Ageing and Older Adults*, 8(3), 24–31. doi:10.1108/14717794200700018

Gabriel, Z. & Bowling, A. (2004). Quality of life from the perspectives of older people. *Ageing and Society*, 24(5), 675–691. doi:10.1017/S0144686X03001582

Gadamer, H. G. (1960/1989). *Truth and method* (1960). London: Sheed and Ward.

Ganley, R. (2009). Carer payment recipients and workforce participation. *Australian Social Policy*, 8, pp. 35–83. Retrieved from [http://www.fahcsia.gov.au/sites/default/files/documents/05\\_2012/asp-8.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/05_2012/asp-8.pdf)

Gasson, S. (2004). Rigor in grounded theory research: An interpretive perspective on generating theory from qualitative field studies. In M. E. Whitman & A. B. Woszczyński, *The handbook of information systems research* (pp. 79–102). Hershey, PA: Idea Group.

Gatrell, C. (2008). *Embodying women's work*. Maidenhead, England: Open University Press.

Gattuso, S. & Bevan, C. (2000). Mother, daughter, patient, nurse: Women's emotion work in aged care. *Journal of Advanced Nursing*, 31(4), 892–899. doi:10.1046/j.1365-2648.2000.01360.x

Geanellos, R. (2000). Exploring Ricoeur's hermeneutic theory of interpretation as a method of analysing research texts. *Nursing Enquiry*, 7(2), 112–119. doi:10.1046/j.1440-1800.2000.00062.x

Gelfand, D. E. (2006). *The aging network: Programs and services* (6th ed.). New York, NY: Springer.

Gerber, R. & Moyle, W. (2004). The role of theory in health research. In V. Minichiello, G. Sullivan, K. Greenwood & R. Axford (Eds), *Handbook of research methods for nursing and health science* (pp. 32–55). Frenchs Forest, Australia: Pearson Education Australia.

Gerritsen, D. L., Steverink, N., Ooms, M. E. & Ribbe, M. W. (2004). Finding a useful conceptual basis for enhancing the quality of life of nursing home residents. *Quality of Life Research*, 13(3), 611–624.

Giacomini, M. (2010). Theory matters in qualitative research. In I. Bourgeault, R. Dingwall & R. de Vries (Eds), *The SAGE Handbook of qualitative methods in health research* (pp. 125–156), London, England: SAGE.

Gibson., D, Rowland, F., Braun, P. & Angus, P. (2002). *Ageing in place: Before and after the 1997 aged care reforms* (AIHW Bulletin 1, cat. no. AUS 26). Canberra, Australia: AIHW. Retrieved from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453152>

Gibson, H. J. & Singleton, J. F. (Eds) (2012). *Leisure and ageing: Theory and practice*. Champaign, IL: Human Kinetics.

Gibson, M. C., Carter, M. W., Helmes, E. & Edberg, A.-K. (2010). Principles of good care for long-term care facilities. *International Psychogeriatrics*, 22(Special issue 7), 1072–1083. doi:10.1017/S1041610210000852

Gilleard, C. & Higgs, P. (2000). *Cultures of ageing: Self, citizen and the body*. Harlow, England: Prentice Hall-Pearson Education.

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, 28(2), 235–260. doi:10.1163/156916297X00103

Gjerberg, E., Førde, R. & Bjørndal, A. (2011). Staff and family relationships in end-of-life nursing home care. *Nursing Ethics*, 18(1), 42–53. doi:10.1177/0969733010386160

Glucksmann, M. (2006). Developing an economic sociology of care and rights. In L. Morris (Ed.), *Rights: Sociological perspectives* (pp. 55–72). Abingdon, England: Routledge.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. New York, NY: Doubleday.

Goldstein, J. R. (2009). How populations age. In P. Uhlenberg (Ed.), *International handbook of population aging* (pp. 7–18). Dordrecht, The Netherlands: Springer Science + Media.

Grace, S. & Ajjawi, R. (2010). Phenomenological research: Understanding human phenomena. In: J. Higgs, N. Cherry, R. Macklin & R. Ajjawi (Eds), *Researching practice: A discourse on qualitative methodologies* (pp. 197–208). Rotterdam, The Netherlands: Sense.

Graham, J., Wing, S., Wadhams, K., & Worden, M. (2013). Staff Perspectives and Perceptions of the Culture Change Movement: A Closer Look at Person Centered Care and the Eden Alternative in Long Term Care Facilities.

Graneheim, U. H. & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112.

Gray, L. (2001). *Two year review of aged care reforms*. Canberra, Australia: Commonwealth of Australia. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/7F5FE29B6C33B870CA256F19000F1EBE/\\$File/finalrep.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/7F5FE29B6C33B870CA256F19000F1EBE/$File/finalrep.pdf)

Gray, M. & Heinsch, M. (2009). Ageing in Australia and the increased need for care. *Ageing International*, 34(3), 102–118. doi:10.1007/s12126-009-9046-3

Grbich, C. (Ed.) (2004). *Health in Australia: Sociological concepts and issues* (3rd ed.). NSW, Australia: Pearson/Longman.

Gruin, G., Veroff, J. J. & Feld, S. (1960). *Americans view their mental health: A nationwide interview survey*. New York, NY: Basic Books.

Guba, E. G. (Ed.). (1990). *The paradigm dialog*. Newberry Park, CA: SAGE.

Guba, E. G. & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: SAGE.

Gupta, A. & Harding, A. (2007a). Introduction and overview. In A. Gupta & A. Harding (Eds), *Modelling our future: Population ageing health and aged care* (pp. 1–40). Bingley, England: Emerald.

Gupta, A. & Harding, A. (Eds) (2007b). *Modelling our future: Population ageing health and aged care*. Bingley, England: Emerald.

Haddock, A. & Macpherson, F. (Eds) (2008). *Disjunctivism: Perception, action, knowledge*. Oxford, England: Oxford University Press.

Haesler, E., Bauer, M. & Nay, R. (2006). Factors associated with constructive staff-family relationships in the care of older adults in the institutional setting. *International Journal of Evidence-Based Health Care*, 4(4), 288–336.  
doi:10.1111/j.1479-6988.2006.00053.x

Hall, S., Opio, D., Dodd, R. H. & Higginson, I. J. (2011). Assessing quality of life in older people in care homes. *Age and Ageing*, 40(4), 507–516.  
doi:10.1093/ageing/afr027

Hally, M. B. (2009). *A guide for international nursing students in Australia and New Zealand*. Sydney, Australia: Churchill Livingstone Elsevier.

Halpern, E. S. (1983). *Auditing naturalistic inquiries: The development and application of a model* (Unpublished doctoral dissertation). Bloomington, IN: Indiana University. Retrieved from

- Hamilton, S. D. & Menezes, F. M. (2011). Embedded incentives in the funding arrangements for residential aged care in Australia. *Economic Papers*, 30(3), 326–340. <http://onlinelibrary.wiley.com/doi/doi:10.1111/j.1759-3441.2011.00125.x>
- Han, G. S., Madison, J. & Chandler, M. (2005). Australian residential aged care: Skills mix and funding post 1997. *Geriatrics*, 23(1), 5–11.
- Harman, D. (2003). The free radical theory of aging. *Antioxidants & Redox Signaling*, 5(5), 557–561. doi:10.1089/152308603770310202
- Harper Ice., G. (2002). Daily life in a nursing home: Has it changed in 25 years? *Journal of Aging Studies*, 16(4), 345–359. doi:10.1016/S0890-4065(02)00069-5
- Harrington, C. & Swan, J. H. (2003). Nursing home staffing, turnover, and case mix. *Medical Care Research and Review*, 60(3), 366–392. doi:10.1177/1077558703254692
- Harris, D. K. & Benson, M. L. (2006). *Maltreatment of patients in nursing homes: There is no safe place*. Binghamton, NY: Haworth Pastoral Press.
- Harris, N., Wenham, K., & Grootjans, J. (2008). Resident identified issues shaping wellbeing in retirement and aged living and care facilities. *Geriatrics*, 26(1), 5.
- Harwood, J. (2007). *Understanding communication and aging: Developing knowledge and awareness*. Thousand Oaks, CA: SAGE.
- Havinghurst, R. J. (1961). Successful aging. *The Gerontologist*, 1(1), 8–13. <http://gerontologist.oxfordjournals.org/content/1doi:10.1093/geront/1.1.8>
- Healey-Ogden, M. J. & Austin, W. J. (2011). Uncovering the lived experience of well-being. *Qualitative Health Research*, 21(1), 85–96. doi:10.1177/1049732310379113

Healy, J. (2011). *Improving health care safety and quality: Reluctant regulators*. Farnham, England: Ashgate.

Healy, J., Sharman, E. & Lokuge, B. (2006). *Australia: Health system review* (Health systems in transition, J. Healy Ed., vol. 8, no. 5). Copenhagen, Denmark: WHO Regional Office for Europe. Retrieved from [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0007/96433/E89731.pdf](http://www.euro.who.int/__data/assets/pdf_file/0007/96433/E89731.pdf)

Heidegger, M. (1962). *Being and time*. New York, NY: Harper & Row. (Original work published 1927)

Heidegger, M. (1977). *Basic writings* (D. F. Krell Ed.). New York, NY: HarperCollins.

Heidegger, M. (1996). *Being and time: A translation of Sein und Zeit* (J. Stambaugh, Trans.). Albany, NY: State University of New York Press. (Original translated work published 1953)

Hellstrom, Y., Persson, G. & Hallberg, I. R. (2004). Quality of life and symptoms among older people living at home. *Journal of Advanced Nursing*, 48(6), 584–593. doi:10.1111/j.1365-2648.2004.03247.x

Henderson, E. J. & Caplan, G. A. (2008). Home sweet home? Community care for older people in Australia. *Journal of the American Medical Directors Association*, 9(2), 88–94. doi:10.1016/j.jamda.2007.11.010

Henningsen, N. & McAlister, M. (2011). Paradigm shift: Shaping policy to meet the needs of our aging population. *Healthcare Papers*, 11(1), 20–24 & 86–91.

Hjaltadóttir, I. & Gústafsdóttir, M. (2007). Quality of life in nursing homes: Perception of physically frail elderly residents. *Scandinavian Journal of the Caring Sciences*, 21(1), 48–55. doi:10.1111/j.1471-6712.2007.00434.x

Hogan, W. P. (2004). *Review of pricing arrangements in residential aged care: Final report*. Canberra, Australia: CoA. Retrieved from [http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA25774C001857CACA256F18005083CC/\\$File/full\\_report.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA25774C001857CACA256F18005083CC/$File/full_report.pdf)

Holloway, I. (Ed.) (2005). *Qualitative research in health care*. Maidenhead, England: Open University Press.

Holloway, I. & Wheeler, S. (2010). *Qualitative research in nursing and health care* (3rd ed.). Chichester, England: Wiley-Blackwell.

Holmes, D. & Ramirez, M. (2003). Models for individuals with Alzheimer disease: Beyond the special care framework. In A. S. Weiner & J. L. Ronch (Eds), *Culture change in long-term care* (pp. 175–182). Binghamton, NY: Haworth Social Work Practice Press.

Holtkamp, C. C. M., Kerkstra, A., Ribbe, M. W., Van Campen, C. & Ooms, M. E. (2000). The relation between quality of co-ordination of nursing care and quality of life in Dutch nursing homes. *Journal of Advanced Nursing*, 32(6), 1364–1373. doi:10.1046/j.1365-2648.2000.01626.x

Horner, B. & Boldy, D. P. (2008). The benefit and burden of ‘ageing-in-place’ in an aged care community. *Australian Health Review*, 32(2), 356–365. doi:10.1071/AH080356

Horner, B. J. (2005). *The impact and influence of change in a residential aged care community: An action research study* (Doctoral dissertation ). Retrieved from

[http://espace.library.curtin.edu.au/R?func=dbin-jump-full&local\\_base=gen01-era02&object\\_id=16052](http://espace.library.curtin.edu.au/R?func=dbin-jump-full&local_base=gen01-era02&object_id=16052)

Hornsby, J. (2008). A disjunctive conception of acting for reasons. In A. Haddock & F. Macpherson (Eds.), *Disjunctivism: Perception, action, knowledge* (pp. 244–261). Oxford, UK Oxford, England: Oxford University Press.

Hothersall, S. & Bolger, J. (Eds.) (2010). *Social policy for social work, social care and the caring professions: Scottish perspectives*. Farnham, England: Ashgate.

Huber, M., Knottnerus, J. A., Green, L., Horst, H. V. D., Jadad, A. R., Kromhout, D., ... & Smid, H. (2011). How should we define health? *BMJ*, 343.  
doi:10.1136/bmj.d4163

Husserl, E. (1969). *Ideas: General introduction to pure phenomenology* (W. R. Boyce Gibson Trans.). London, England: Allen & Unwin. (Original work published 1931)  
Husserl, E. (1973). *Logical investigations* (J. N. Findlay Trans.). London, England: Routledge.

Husserl, E. (1980). *Phenomenology and the foundations of the sciences: Third book; Ideas pertaining to a pure phenomenological philosophy* (T. E. Klein & W. E. Pohl Trans.). The Hague: Martinus Hijhoff. (Original work published 1952)

Husserl, E. (1999). *The idea of phenomenology* (L. Hardy Trans.). Dordrecht, The Netherlands: Kluwer Academic. (Original work published 1970)

Hyde, M., Wiggins, R. D., Higgs, P. & Blane, D. B. (2003). A measure of quality of life in early old age: The theory, development and properties of a needs satisfaction model (CASP-19). *Aging & Mental Health*, 7(3), 186–194.  
doi:10.1080/1360786031000101157

Irvine, S. J. & Kroeger, K. (2010). An ICT solution for medical care to residents in residential aged care facilities. *Health Information Management Journal*, 39(1), 41–45.

Jackson, D., Mannix, J. & Daly, J. (2003). Nursing staff shortages: Issues in Australian residential aged care. *Australian Journal of Advanced Nursing*, 21(1), 42–46.

Jay, M. (2009). The lifeworld and lived experience. In H. L. Dreyfus & M. A. Wrathall (Eds), *A companion to phenomenology and existentialism* (pp. 91–104). Chichester, England: Blackwell.

Jeong, S. S.-Y., Higgins, I. & McMillan, M. (2010). The essentials of advance care planning for end-of-life care for older people. *Journal of Clinical Nursing*, 19(3–4), 389–397. doi:10.1111/j.1365-2702.2009.03001.x

Jeong, S. S.-Y., Higgins, I. & McMillan, M. (2011a). Experiences with advance care planning: Older people and family members' perspective. *International Journal of Older People Nursing*, 6(3), 176–186. doi:10.1111/j.1748-3743.2009.00201.x

Jeong, S. S.-Y., Higgins, I. & McMillan, M. (2011b). Experiences of advance care planning: Nurses' perspective. *International Journal of Older People Nursing*, 6(3), 165–175. doi:10.1111/j.1748-3743.2009.00200.x

Jilek, R. (2006). The lived experience of men entering residential aged care. *Geriaction*, 24(2), 5–13.

Johnson, B. & Christensen, L. (2010). *Educational research: Qualitative, quantitative, and mixed approaches* (4th ed.). Thousand Oaks, CA: SAGE.

- Johnson, R., Popejoy, L. L. & Radina, M. E. (2010). Older adults' participation in nursing home placement decisions. *Clinical Nursing Research*, 19(3), 358–375. doi:10.1177/1054773810372990.
- Jones, A. (2001). Absurdity and being-in-itself. The third phase of phenomenology: Jean-Paul Sartre and existential psychoanalysis. *Journal of Psychiatric and Mental Health Nursing*, 8(4), 367–372. doi:10.1046/j.1365-2850.2001.00405.x
- Jopp, D. S. & Schmitt, M. (2010). Dealing with negative life events: Differential effects of personal resources, coping strategies, and control beliefs. *European Journal of Ageing*, 7(3), 167–180. doi:10.1007/s10433-010-0160-6
- Joppe, M. (2000). *The research process*. Retrieved from <http://www.ryerson.ca/~mjoppe/rp.htm>
- Kalache, A., Barretto, S. M. & Keller, I. (2005). Global ageing: The demographic revolution in all cultures and societies. In M. L. Johnson (with V. L. Bengtson, P. G. Colman & T. B. L. Kirkwood) (Eds), *The Cambridge handbook of age and ageing* (pp. 30–46). Cambridge, England: Cambridge University Press.
- Kane, R. A. (2001). Long-term care and a good quality of life: Bringing them closer together. *Gerontologist*, 41(3), 293–304. doi:10.1093/geront/41.3.293
- Kane, R. A., Kling, K. C., Bershadsky, B., Kane, R. L., Giles, K., Degenholtz, H. B., ... Cutler L. J. (2003). Quality of life measures for nursing home residents. *Journals of Gerontology: Series A*, 58(3), M240–M248. doi:10.1093/gerona/58.3.M240
- Kane, R. L., Rockwood, T., Hyer, K., Desjardins, K., Brassard, A., Gessert, C. & Kane, R. (2005). Rating the importance of nursing home residents' quality of life. *Journal of the American Geriatrics Society*, 53(12), 2076–2082. doi:10.1111/j.1532-5415.2005.00493.x

- Kant, I. (1965). *Critique of pure reason* (N. K. Smith Trans.). New York, NY: St Martin's Press. (Original work published 1929)
- Kayser-Jones, J., Schell, E., Lyons, W., Kris, A. E., Chan, J. & Beard, R. L. (2003). Factors that influence end-of-life care in nursing homes: The physical environment, inadequate staffing, and lack of supervision. *Gerontologist*, 43(2), 76–84.
- Keefe, J. & Fancey, P. (2000). The care continues: Responsibility for elderly relatives before and after admission to a long term care facility. *Family Relations*, 49(3), 235–244.
- Keleher, H. (2009). Primary health care system. In E. Willis, L. Reynolds & H. Keleher (Eds), *Understanding the Australian health care system* (pp. 33–44). Sydney, Australia: Churchill Livingstone Elsevier.
- Kelley, E. & Hurst, J. (2006). *Health care quality indicators project: Conceptual framework paper* (OECD Health Working Papers No. 23, DELSA/JEA/WD/HWP[2006]3). Paris, France: OECD. Retrieved from <http://www.oecd.org/els/healthpoliciesanddata/36262363.pdf>
- Kendig, H. & Browning, C. (2010). A social view on healthy ageing: Multi-disciplinary perspectives and Australian evidence. In D. Dannefer & C. Phillipson (Eds), *The SAGE Handbook of Social Gerontology* (pp. 459–471). London, England: SAGE.
- Kendig, H. & Duckett, S. (2001). *Australian directions in aged care: The generation of policies for generations of older people* (Australian Health Policy Institute commissioned paper series 2001/5). Sydney, Australia: Australian Health Policy Institute at the University of Sydney.

- Khader, F. (2011). Quality of life in the nursing homes in Jordan: Perspectives of residents. *Care Management Journals*, 12(4), 149–162. doi:10.1891/1521-0987.12.4.169
- Koch, S., Hunter, P. & Nair, K. (2009). Older people in acute care. In R. Nay & S. Garrett (Eds), *Older people: Issues and innovations in care* (3rd ed., pp. 153–167). Sydney, Australia: Churchill Livingstone Elsevier.
- Koch, T. (1994). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19(5), 976–986. doi:10.1111/j.1365-2648.1994.tb01177.x
- Koch, T. (1995). Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21(5), 827–836. doi:10.1046/j.1365-2648.1995.21050827.x
- Koch, T. & Harrington, A. (1998). Reconceptualizing rigour: The case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882–890. doi:10.1046/j.1365-2648.1998.00725.x
- Koch, T., Power, C. & Kralik, D. (2006). Exploring longevity with Australian centenarians. *Geriaction*, 24(4), 5–14.
- Kockelmans, J. J. (1994). *Edmund Husserl's phenomenology*. West Lafayette, IN: Purdue University Press.
- Krysik, J. L. & Finn, J. (2013). *Research for effective social work practice* (3rd ed.). New York, NY: Routledge.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: SAGE.

Lagergren, M. (2007). A simulation model concerning future needs for long-term care of elderly persons in Sweden. In A. Gupta & A. Harding (Eds), *Modelling our future: Population ageing health and aged care* (pp. 281–296). Bingley, England: Emerald.

Laidlaw, K. & Knight, B. G. (Eds) (2008). *Handbook of emotional disorders in later life: Assessment and treatment*. Oxford, England: Oxford University Press.

Laing, R. D. (1971). *The politics of the family and other essays*. London, England: Tavistock.

LaPierre, T. A. & Hughes, M. E. (2009). Population ageing in Canada and the United States. In P. Uhlenberg (Ed.), *International handbook of population aging* (pp. 191–230). Dordrecht, The Netherlands: Springer Science + Media.

Larsen, P. D. (2013). Chronicity. In I. M. Lubkin & P. D. Larson, *Chronic illness: Impact and intervention* (8th ed., pp. 3–20). Burlington, MA: Jones & Bartlett Learning.

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 21–35.

Lawn, C. (2006). *Gadamer: A guide for the perplexed*. London, England: Continuum International.

Lewin, G., Carville, K., Newall, N., Phillipson, M., Smith, J. & Prentice, J. (2003). Determining the effectiveness of implementing the AWMA ‘Guidelines for the Prediction and Prevention of Pressure Ulcers’ in Silver Chain, a large home care agency stage 1: baseline measurement. *Primary Intention*, 11(2), 57–72.

Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: SAGE.

Lincoln, Y. S., Lynham, S. A. & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & Y. S. Lincoln (Eds), *The SAGE handbook of qualitative research* (4th ed., pp. 97–128). Thousand Oaks, CA: SAGE.

Lindlof, T. R. & Taylor, B. C. (2011). *Qualitative communication research methods* (3rd ed.). Thousand Oaks, CA: SAGE.

Lindseth, A. & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145–153. doi:10.1111/j.1471-6712.2004.00258.x

Llewellyn, G., Sullivan, G. & Minichiello, V. (2004). Sampling in qualitative research. In V. Minichiello, G. Sullivan, K. Greenwood & R. Axford, R. (Eds), *Handbook of research methods for nursing and health science* (3rd ed., pp. 210–241). Frenchs Forest, Australia: Pearson Education Australia.

Lloyd, L. (2004). Mortality and morality: Ageing and the ethics of care. *Ageing and Society*, 24(2), 235–256. doi:10.1017/S0144686X03001648

Lloyd, L. (2012). *Health and care in ageing societies: A new international approach*. Bristol, England: Policy Press.

Lloyd, L. & Cameron, A. M. (2005). Significant life events: Developing knowledge for care at the end of life in old age. *Journal of Integrated Care*, 13(3), 34–39. doi:10.1108/14769018200500024

Lopez, K. A. & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, 14(5), 726–735. doi:10.1177/1049732304263638

Lowes, L. & Prowse, M. A. (2001). Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies*, 38(4), 471–480. doi:10.1016/S0020-7489(00)00080-8

Lubkin, I. M. & Larsen, P. D. (2013). *Chronic illness: Impact and intervention* (8th ed.). Burlington, MA: Jones and Bartlett Learning.

McCall, S. (1975). Quality of life. *Social Indicators Research*, 2, 229–248.

MacKenzie, S. (2003). Implementing the Eden alternative in Australia. In A. S. Weiner & J. L. Ronch (Eds), *Culture change in long-term care* (pp. 325–345). Binghamton, NY: Haworth Social Work Practice Press.

MacKinley, E. (2012). *Palliative care, ageing and spirituality: A guide for older people, carers and families*. London, England: Jessica Kingsley.

McMurray, A. & Clendon, J. (Eds) (2011). *Community health and wellness: Primary health care in practice* (4th ed.). Sydney, Australia: Churchill Livingstone Elsevier.

Macnee, C. L. & McCabe, S. (2008). *Understanding nursing research: Reading and using research in evidence-based practice* (2nd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

McNiff, J. (2013). *Action research: Principles and practice* (3rd ed.). Abingdon, England: Routledge.

McVey, P. K. (2011). *A palliative approach for people with declining health living in hostel accommodation: The state of play* (Doctoral dissertation, University of Sydney). Retrieved from <http://hdl.handle.net/2123/8141>

- Maggs-Rapport, F. (2001). 'Best research practice': In pursuit of methodological rigour. *Journal of Advanced Nursing*, 35(3), 373–383. doi:10.1046/j.1365-2648.2001.01853.x
- Marquardt, G. & Schmiege, P. (2009). Dementia-friendly architecture: Environments that facilitate wayfinding in nursing homes. *American Journal of Alzheimer's Disease & Other Dementias*, 24(4), 333–340. doi:10.1177/1533317509334959
- Mason, R. & Faulkenbury, G. D. (1978). Aspirations, achievements and life satisfactions. *Social Indicators Research*, 5(2), 133–150.
- Mead, G. H. (2009). *Works of George Herbert Mead: Volume 1. Mind, self, and society from the standpoint of a social behaviourist* (C. W. Morris Ed.). London, England: University of Chicago Press. (Original work published 1937)
- Meleis, A. I. (2012). *Theoretical nursing: Development and progress* (5th ed.). Philadelphia, PA: Walters Kluwer Health/Lippincott Williams & Wilkins.
- Merleau-Ponty, M. (1962) *Phenomenology of perception* (C. Smith Trans.). Delhi, India: Narendra Prakash Jain. (Original work published 1945)
- Merleau-Ponty, M. (1964). *The primacy of perception and other essays on phenomenological psychology, the philosophy of art, history, and politics* (J. Edie Ed.). Evanston, IL: Northwestern University Press.
- Merson, M. H., Black, R. E. & Mills, A. J. (Eds) (2004). *International public health: Diseases, programs, systems, and policies*. Sudbury, MA: Jones and Bartlett.
- Mertens, D. M. & Ginsberg, P. E. (Eds) (2009). *The handbook of social research ethics*. Thousand Oaks, CA: SAGE.

Millar, C. A. (2009). *Nursing for wellness in older persons* (5th ed.). Philadelphia, PA: Wolters Kluwer Health/ Lippincott, Williams and Wilkins.

Mills, A. J. & Ranson, M. K. (2004). The design of health systems. In M. H. Merson, R. E. Black & A. J. Mills (Eds), *International public health: Diseases, programs, systems, and policies* (2nd ed., pp. 513–552). Sudbury, MA: Jones and Bartlett.

Minichiello, V. & Coulson, I. (Eds) (2005). *Contemporary issues in gerontology: Promoting positive ageing*. Sydney, Australia: Allen & Unwin.

Minichiello, V., Browne, J. & Kendig, H. (2000). Perceptions and consequences of ageism: Views of older people. *Ageing and Society*, 20(3), 253–278.

Minichiello, V., Sullivan, G., Greenwood, K. & Axford, R. (Eds) (1999). *Handbook of research methods in health sciences*. Melbourne, Australia: Addison, Wesley, Longman.

Minogue, V. (2008). Carer and user service perspectives on affective disorders in older adults. In S. Curran & J. P. Wattis (Eds), *Practical management of affective disorders in older people: A multi-professional approach* (pp. 217–229). Abingdon, England: Radcliffe.

Moates, A. (2005). The rural urban health divide. *Chisholm Health Ethics Bulletin*, 11(1), 4–7.

Mohammadi, N. (2008). *A hermeneutic phenomenological inquiry into the lived experience of Muslim patients in Australian hospitals* (Doctoral dissertation, University of Adelaide). Retrieved from <http://hdl.handle.net/2440/47562>

Moody, H. R. (2006). *Aging: Concepts and controversies* (5th ed.). Thousand Oaks, CA: Pine Forge Press.

- Moore, K. J., Hill, K. D., Robinson, A. L., Haines, T. P., Haralambous, B. & Nitz, J. C. (2011). The state of physical environments in Australian residential aged care facilities. *Australian Health Review*, 35(4), 412–417. doi:10.1071/AH10932
- Moran, D. (2005). *Edmund Husserl: Founder of phenomenology*. Cambridge, England: Polity Press.
- Morrissey, M. B. (2011). Phenomenology of pain and suffering at the end of life: A humanistic perspective in gerontological health and social work. *Journal of Social Work in End-Of-Life & Palliative Care*, 7(1), 14–38. doi:10.1080/15524256.2011.548045
- Morse, J. M. (2005). A review committee’s guide for evaluating qualitative proposals. *Qualitative Health Research*, 13(6), 883–851. doi:10.1177/1049732303255367
- Nancy, J.-L. (2008). The being-with of being-there. *Continental Philosophy Review*, 41(1), 1–15. doi:10.1007/s11007-007-9071-4
- Seniors Australia. (2010). *The future of aged care in Australia*. Retrieved from [http://www.nationalseniors.com.au/icms\\_docs/Future\\_of\\_Aged\\_Care\\_Report.pdf](http://www.nationalseniors.com.au/icms_docs/Future_of_Aged_Care_Report.pdf)
- Nay, R. (1995). Nursing home residents’ perceptions of relocation. *Journal of Clinical Nursing*, 4(5), 319–325. doi:10.1111/j.1365-2702.1995.tb00030.x
- Nay, R. & Garrett, S. (Eds) (2009). *Older people: Issues and innovations in care* (3rd ed.). Sydney, Australia: Churchill Livingstone Elsevier.
- Neergaard, H. & Uihøi, J. P. (Eds) (2007). *Handbook of qualitative research methods in entrepreneurship research*. Cheltenham, England: Edward Elgar.
- Neugarten, B. L. (1964). *Personality in middle and late life: Empirical studies*. New York, NY: Atherton Press.

New aged care award cuts pay. (2010). *Lamp*, 67(1), 28–29. Retrieved from [http://www.payscale.com/research/AU/Job=Registered\\_Nurse\\_\(RN\)/Hourly\\_Rate](http://www.payscale.com/research/AU/Job=Registered_Nurse_(RN)/Hourly_Rate)

Newacheck, P. W. & Benjamin, A. E. (2004). Intergenerational equity and public spending. *Health Affairs*, 23(5), 142–146. doi:10.1377/hlthaff.23.5.142

O'Dwyer, C. (2013). Official conceptualizations of person-centered care: Which person counts? *Journal of Aging Studies*, 27(3), 233–242. doi:10.1016/j.jaging.2013.03.003

O'Reilly, M., Courtney, M. & Edwards, H. (2007). How is quality being monitored in Australian residential aged care facilities? A narrative review. *International Journal for Quality in Health Care*, 19(3), 177–182. doi:10.1093/intqhc/mzm002

OECD. (2005). *Long-term care for older people*. Paris, France: Author.

OECD. (2006). *Projecting OECD health and long-term care expenditures: What are the main drivers* (Economics Department Working Papers no. 477, ECO/WKP[2006]5). Paris, France: OECD. Retrieved from <http://www.oecd.org/tax/publicfinanceandfiscalpolicy/36085940.pdf>

OECD. (2011). *Help wanted? Providing and paying for long term care*. Paris, France: Author. Retrieved from <http://www.oecd.org/els/healthpoliciesanddata/47884889.pdf>

Ormel, J., Lindenberg, S., Steverink, N. & Vonkorff, M. (1997). Quality of life and social production functions: A framework for understanding health effects. *Social Science & Medicine*, 45(7), 1051–1063. doi:10.1016/S0277-9536(97)00032-4

Österlind, J., Hansebo, G., Andersson, J., Ternstedt, B.-M. & Hellström, I. (2011). A discourse of silence: Professional carers reasoning about death and dying in nursing homes. *Ageing and Society*, 31(4), 529–544. doi:10.1017/S0144686X10000905

Owen, T. & National Care Homes Research and Development Forum (Eds) (2007). *My home life: Quality of life in care homes*. London, England: Help the Aged.

Retrieved from

<http://www.scie.org.uk/publications/guides/guide15/files/myhomelife.pdf>

Palmer, E. & Eveline, J. (2012). Sustaining low pay in aged care work. *Gender, Work & Organization*, 19(3), 245-275. doi:10.1111/j.1468-0432.2010.00512.x

Palmer, G. R. & Short, S. D. (2000). *Health care and public policy: An Australian analysis* (3rd ed.). Melbourne, Australia: Macmillan.

Palmore, E. B., Branch, L. & Harris, D. K. (Eds) (2005). *Encyclopaedia of ageism*. Binghamton, NY: Haworth Pastoral Press.

Park, H.-A., Murray, P. & Delaney, C. (Eds). (2006). *Consumer-centered computer-supported care for healthy people: Proceedings of NI2006*. Amsterdam, The Netherlands: IOS Press.

Park, J. & Werner, R. M. (2011). Changes in the relationship between nursing home financial performance and quality of care under public reporting. *Health Economics*, 20(7), 783–801. doi:10.1002/hec.1632

Parmenter, G. & Cruickshank, M. (2010). Visiting at rural Australian residential aged care facilities: A review of the literature. *Asia Pacific Journal of Health Management*, 5(1), 62–67.

Patel, K. & Rushefsky, M. (2006). *Health care politics and policy in America* (3rd ed.). Armonk, NY: M. E. Sharpe.

Pearson, A., Nay, R. & Taylor, B. (2004). Relatives' experience of nursing home admissions: Preliminary study. *Australasian Journal on Ageing*, 23(2), 86–90. doi:10.1111/j.0141-6790.2004.02701007\_1.x

Pemberton, M. & Hampton, S. (2011). Why are bedsores not being prioritized in nursing care? Or bedsore neglect is a result of reduction education and resources. *British Journal of Nursing*, 20(15 Suppl.), S26–S28.

Perek-Bialas, J., & Schippers, J. J. (2013). Economic gerontology: Older people as consumers and workers. In *Old Age In Europe* (pp. 79-96). Springer Netherlands.

Pernecky, T. & Jamal, T. (2010). (Hermeneutic) phenomenology in tourism studies. *Annals of Tourism Research*, 37(4), 1055–1075. doi:10.1016/j.annals.2010.04.002

Perron, R-L. (2008). *Determining predictors of nursing home admission and sub-populations of skilled nursing facility residents using the Medicare Current Beneficiary Survey (MCBS)* (Doctoral dissertation, University of Maryland). Retrieved from <http://gradworks.umi.com/33/16/3316082.html>

Perry, B. (2009). *More moments in time: Images of exemplary nursing*. Edmonton, Canada: Athabasca University Press.

Perry, L., Bellchambers, H., Howie, A., Moxey, A., Parkinson, L., Capra, S. & Byles, J. (2011). Examination of the utility of the Promoting Action on Research Implementation in Health Services framework for implementation of evidence based practice in residential aged care settings. *Journal of Advanced Nursing*, 67(10), 2139–2150. doi:10.1111/j.1365-2648.2011.05655.x

Phillipson, C. (2009). Reconstructing theories of aging: The impact of globalization on critical gerontology. In V. L. Bengtson, D. Gans, N. M. Putney & N. Silverstein (Eds), *Handbook of theories of aging* (2nd ed., pp. 615–628). New York, NY: Springer.

Podneiks, E. (2006). Social inclusion: An interplay of the determinants of health—New insights into elder abuse. In M. J. Mellor & P. Brownell (Eds), *Elder abuse and mistreatment: Policy, practice, and research* (pp. 57–80). Binghamton, NY: Haworth Press.

Polit, D. & Taranto Beck, C. (2014). *Essentials of nursing research: Appraising evidence or nursing practice* (8th ed.). Philadelphia, PA: Wolters Kluwer/Lippincott Williams & Wilkins.

Polkinghorne, D. (1983). *Methodology for the human sciences: Systems of inquiry*. Albany, NY: State University of New York Press.

Poon, L. W. & Cohen-Mansfield, J. (Eds) (2011). *Understanding well-being in the oldest-old*. Cambridge, England: Cambridge University Press.

Popejoy, L. L. (2008). Adult protective services use for older adults at the time of hospital discharge. *Journal of Nursing Scholarship*, 40(4), 326–332. doi: 10.1111/j.1547-5069.2008.00246.x

Priest, S. (2002). *Merleau-Ponty*. London, England: Routledge.

Prieto-Flores, M.-E., Forjaz, M.-J., Fernández-Mayoralas, G., Rojo-Perez, F. & Martinez-Martin, P. (2011). Factors associated with loneliness of noninstitutionalized and institutionalized older adults. *Journal of Aging and Health*, 23(1), 177–194. doi:10.1177/0898264310382658

Productivity Commission. (2005). *Economic implications of an ageing Australia: Productivity Commission research report*. Canberra, Australia: CoA. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0006/13587/ageing1.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0006/13587/ageing1.pdf)

Productivity Commission. (2008). *Trends in aged care services: Some implications; Productivity Commission research paper*. Canberra, Australia: CoA. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0004/83380/aged-care-trends.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0004/83380/aged-care-trends.pdf)

Productivity Commission. (2009). *Annual review of regulatory burdens on business: Social and economic infrastructure services: Productivity Commission research report*. Canberra, Australia: CoA. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0003/91344/social-economic-infrastructure.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0003/91344/social-economic-infrastructure.pdf)

Productivity Commission. (2011a). *Caring for older Australians: Productivity Commission report; Overview* (No. 53). Canberra, Australia: CoA. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0016/110932/aged-care-overview-booklet.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0016/110932/aged-care-overview-booklet.pdf)

Productivity Commission. (2011b). *Disability care and support: Productivity Commission inquiry report; Overview and recommendations* (No. 54). Canberra, Australia: CoA. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0014/111272/disability-support-overview-booklet.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0014/111272/disability-support-overview-booklet.pdf)

Radman, Z. (Ed.) (2012). *Knowing without thinking: Mind, action, cognition and the phenomenon of the background*. New York, NY: Palgrave Macmillan.

Rapport, F. (2005). Hermeneutic phenomenology: The science of interpretation of texts. In I. Holloway (Ed.), *Qualitative research in health care* (pp. 125–146). Maidenhead, England: Open University Press.

Ray, M. A. (1994). The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 117–133). Thousand Oaks, CA: SAGE.

- Reeves, S., Albert, M., Kuper, A. & Hodges, B. D. (2008). Why use theories in qualitative research? *BMJ*, 337, a949. doi:10.1136/bmj.a949
- Reinhardt, U. E., Hussey, P. S. & Anderson, G. F. (2004). U. S. health care spending in an international context. *Health Affairs*, 23(10), 10–25.
- Reyna, C., Goodwin, E. J. & Ferrari, J. R. (2007). Older adult stereotypes among care providers in residential care facilities: Examining the relationship between contact, education, and ageism. *Journal of Gerontological Nursing*, 33(2), 50–55.
- Richardson, B. & Bartlett, H. (2009). The impact of ageing-in-place policies on structural change in residential aged care. *Australasian Journal on Ageing*, 28(1), 28–31. doi:10.1111/j.1741-6612.2008.00325.x
- Richie, J. & Lewis, J. (Eds) (2003). *Qualitative research practice: A guide for social science students and researchers*. London, England: SAGE.
- Riley, M., Johnson, M. E. & Foner, A. (1972). *Ageing and society vol.3: A Sociology of age stratification*. New York, NY: Russell Sage Foundation.
- Robinson, A. & See, C. (2010). *The need for a whole of organization approach to change in residential aged care by delivering an innovative and mentor based RACF clinical placement program underpinned by a positive organisational culture*. Hobart, Australia: University of Tasmania. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0018/101484/sub231.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0018/101484/sub231.pdf)
- Robison, J., Shugrue, N., Reed, I., Thompson, N., Smith, P. & Gruman, C. (2011). Community-based versus institutional supportive housing: Perceived quality of care, quality of life, emotional well-being, and social interaction. *Journal of Applied Gerontology*, 30(3), 275–303. doi:10.1177/0733464810369810.

- Robson, C. (2002). *Real world research: A resource for social scientists and practitioner researchers* (2nd ed.). Oxford, England: Blackwell.
- Rodgers, B. L. (2005). *Developing nursing knowledge: Philosophical traditions and influences*. Philadelphia, PA: Lippincott, Williams & Wilkins.
- Rosewarne, R. (2001). Australian approaches to resident classification and quality assurance in residential care. In I. Chi, K. K. Metha & A. L. Howe (Eds). *Long-term care in the 21st century: Perspectives from around the Asia-Pacific Rim* (pp. 117–120) Binghamton, NY: Haworth Press.
- Rosu, C. & Millar, N. A. (2004). *Nursing home admission decision-making: Working age residents' perspective*. Paper presented at the 132nd Annual Meeting of the APHA (American Public Health Association), Washington DC. Abstract retrieved from [http://apha.confex.com/apha/132am/techprogram/paper\\_85876.htm](http://apha.confex.com/apha/132am/techprogram/paper_85876.htm)
- Rowe, J. W. & Kahn, R. L. (1997). Successful aging. *Gerontologist*, 37(4), 433–440. doi:10.1093/geront/37.4.433
- Rowland, D. T. (2012). *Population ageing: The transformations of societies*. Dordrecht, The Netherlands: Springer Science + Media.
- Rowlands, D. (2008). HealthConnect: A health information network for all Australians. In J. E. Demetriades, R. M. Kolodner & G. A. Christopherson (Eds), *Person-centered health records: Toward healthpeople* (pp. 242–258). New York, NY: Springer Science + Business Media.
- Russell, G. M. & Kelly, N. H. (2002). Research as interacting dialogic processes: Implications for reflexivity. *Forum: Qualitative Social Research*, 3(3). Retrieved from <http://ojs-test.cedis.fu-berlin.de/fqs-test/index.php/fqs/article/view/831/1807>

Russell, H. & Foreman, P. (2000). *Facilitating family involvement in a residential care facility*. Lincoln Gerontology Centre and Villa Maria Society. Bundoora, Victoria: Latrobe University.

Russell, H. & Foreman, P. E. (2002). Maintaining a relationship with a family member in a nursing home: The role of visitor. *Journal of Family Studies*, 8(2), 147–164. doi:10.5172/jfs.8.2.147

Ryan, A. K. & Willits, F. K. (2007). Family ties, physical health, and psychological well-being. *Journal of Aging and Health*, 19(6), 907–919. doi:10.1177/0898264307308340

Ryan, K. (2007). *Palliative care for an ageing population: A rural model? Or, 'For whom the bell tolls'* (Doctoral dissertation). Retrieved from <http://vuir.vu.edu.au/1482/1/Ryan.pdf>

Sadala, M. L. A. & de Camargo Ferreira Adorno, R. (2002). Phenomenology as a method to investigate the experience lived: A perspective from Husserl and Merleau Ponty's thought. *Journal of Advanced Nursing*, 37(3), 282–293. doi:10.1046/j.1365-2648.2002.02071.x

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27–37. Retrieved from <http://pdfs.journals.lww.com/advancesinnursingscience/1986/04000/>

Sankaran, S., Cartwright, C., Kelly, J., Shaw, K. & Soar, J. (2010). Leadership of non-profit organizations in the aged care sector in Australia. In *Proceedings of the 54th Meeting of the International Society for the Systems Sciences*. Retrieved from <http://journals.iss.org/index.php/proceedings54th/article/view/1414>

Santamaria, N., Carville, K., Prentice, J., Ellis, I. K., Ellis, T., Lewin, G., ... Bremner, A. (2009). Reducing pressure ulcer prevalence in residential aged care: Results from phase II of the PRIME Trial. *Wound Practice & Research*, 17(1), 12–24.

Schultz, R. & Monin, J. K. (2012). The costs and benefits of informal caregiving. In S. Brown, R. Brown & L. Penner. *Moving beyond self-interest: Perspectives from evolutionary biology, neuroscience, and the social sciences* (pp. 178–198). New York, NY: Oxford University Press.

Schutz, A. (1967). Walsh, G. & Lerner, F. Trans. *The phenomenology of the social world*. London, England: Heinemann. (Original work published 1932).

Seblega, B. K., Zhang, N. J., Unruh, L. Y., Breen, G.-M., Paek, S. C. & Wan, T. T. H. (2010). Changes in nursing home staffing levels, 1997 to 2007. *Medical Care Research & Review*, 67(2), 232–246. doi:10.1177/1077558709342253

Sheppard, K. G. (2008). *Depressive symptoms among culturally deaf adults* (Doctoral dissertation, University of Arizona). Retrieved from <http://books.google.com.au/books?id=ghCo3Km4J3wC&printsec=frontcover&dq=inauthor:%22Kate+G.+Sheppard>

Shield, R. R., Wetle, T., Teno, J., Miller, S. C. & Welch, L. C. (2010). Vigilant at the end of life: Family advocacy in the nursing home. *Journal of Palliative Medicine*, 13(5), 573–579. doi:10.1089/jpm.2009.0398

Snape, D. & Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 1-23). London, UK: SAGE Publications.

Smythe, E. & Spence, D. (2012). Re-viewing literature in hermeneutic research. *International Journal of Qualitative Methods*, 11(1), 12–25. Retrieved from <http://ejournals.library.ualberta.ca/index.php/IJQM/article/view/6484/13578>

Snape, D. & Spencer, L. (2003). The foundations of qualitative research. In J. Richie & J. Lewis (Eds), *Qualitative research practice: A guide for social science students and researchers* (pp. 1–23). London, England: SAGE.

Soccio, D. J. (2010). *Archetypes of wisdom: An introduction to philosophy* (7th ed.). Belmont, CA: Wadsworth Cengage Learning.

Spencer, L. (2005). Delivery of care for older people. In V. Minichiello & I. Coulson (Eds), *Contemporary issues in gerontology: Promoting positive ageing* (pp. 190–214). Sydney, Australia: Allen & Unwin.

Speziale, H. J. S. (2002). Evaluating qualitative research. In G. LoBiondo-Wood & J. Haber, *Nursing research: Methods, critical appraisal and utilization* (5th ed., pp. 165–182). St Louis, MO: Mosby. Retrieved from <http://books.google.com.au/books?id=uS9tAAAAMAAJ&q=Nursing+research:+Methods,+critical+appraisal,+and+utilization+5th&dq=Nursing+research:+Methods,+critical+ap>

Spinelli, E. (1989). *The interpreted world: An introduction to phenomenological psychology*. London, England: SAGE.

Spurling, L. (1977). *Phenomenology and the social world: The philosophy of Merleau-Ponty and its relation to the social sciences*. London, England: Routledge & Kegan Paul.

Stabile, M. & Greenblatt, J. (2010). *Providing pharmacare for an aging population: Is prefunding the solution?* (IRPP Study no. 2). Retrieved from [http://www.irpp.org/pubs/IRPPstudy/IRPP\\_Study\\_no2.pdf](http://www.irpp.org/pubs/IRPPstudy/IRPP_Study_no2.pdf)

Stahl, B. C. (2007). Ontology, life-world, and responsibility in IS. In Sharman, R., Kishore, R. & Ramesh, R. (Eds), *Ontologies: A handbook of principles, concepts and*

*applications in information systems* (pp. 143–169). New York, NY: Springer Science + Business Media. doi:10.1007/978-0-387-37022-4\_6

Stauner, G. (2008). The future of social security systems and demographic change. *European View*, 7(2), 203–208. doi:10.1007/s12290-008-0052-8

Steeves, H. P. (2006). *The things themselves: Phenomenology and the return to the everyday*. Albany, NY: State University of New York Press.

Stewart, D. & Mickunas, A. (1990). *Exploring phenomenology: A guide to the field and its literature*. Athens, OH: Ohio University Press.

Stolt, R., Blomqvist, P. & Winblad, U. (2011). Privatization of social services: Quality differences in Swedish elderly care. *Social Science & Medicine*, 72(4), 560–567. doi:10.1016/j.socscimed.2010.11.012

Streubert, H. J. (2011). Philosophy and theory: Foundations of qualitative research. In H. J. Streubert & D. Rinaldi Carpenter (Eds), *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed., pp. 1–17). Philadelphia, PA: Wolters Kluwer Health/Lippincott, Williams & Wilkins.

Streubert, H. J. & Rinaldi Carpenter, D. (Eds) (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott, Williams & Wilkins.

Streubert Speziale, H. J. & Rinaldi Carpenter, D. (2007). *Qualitative research in nursing. Advancing the Humanistic Imperative* (4th ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott, Williams & Wilkins.

Takeuchi, R., Hatano, Y. & Yamasaki, M. (2011). The influence of different exercise intervention programs on changes in quality of life and activity of daily living levels among geriatric nursing home residents. *Journal of Physical Therapy Science*, 23(1), 133–136.

Tanner, D. & Harris, J. (2008). *Working with older people*. New York, NY: Routledge.

Tappen, R. M. (2011). *Advanced nursing research: From theory to practice*. Sudbury, MA: Jones and Bartlett Learning.

Taylor, B. & Francis, K. (2013). *Qualitative research in the health sciences: Methodologies, methods and processes*. Abingdon, England: Routledge.

Taylor, M. (2003). Dealing with death: Western philosophical strategies. In C. D. Bryant (Ed.), *Handbook of death and dying* (Vol. 1, pp. 24–33). Thousand Oaks, CA: SAGE.

Taylor, R. (2011). *Ageing, health and innovation: Policy reforms to facilitate healthy and active ageing in OECD countries*. London, England: International Longevity Centre. Retrieved from <http://www.globalcoalitiononaging.com/v2/data/uploads/documents/ilc-uk-ihp.pdf>

Taylor, S., Foster, M. & Fleming, J. (Eds) (2008). *Health care practice in Australia: Policy, context and innovations*. Melbourne, Australia: Oxford University Press.

Teddlie, C. & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Thousand Oaks, CA: SAGE.

Teresi, J. A., Holmes, D. & Ory, M. G. (2000). The therapeutic design of environments for people with dementia: Further reflections and recent findings from

the National Institute on Aging Collaborative Studies of Dementia Special Care Units. *Gerontologist*, 40(4), 417–421. doi:10.1093/geront/40.4.417

Thein, N. W., D'Souza, G. & Sheehan, B. (2011). Expectations and experience of moving to a care home: Perceptions of older people with dementia. *Dementia*, 10(1), 7–18. doi:10.1177/1471301210392971

Themessl-Huber, M., Hubbard, G. & Munro, P. (2007). Frail older people's experiences and use of health and social care services. *Journal of Nursing Management*, 15(2), 222–229. doi:10.1111/j.1365-2834.2007.00726.x

Thomas, L. (2008). Aged Care Funding Instrument (ACFI)—Sorting out fact from fiction. *Australian Nursing Journal*, 16(2), 23. Retrieved from <http://search.informit.com.au/documentSummary;dn=245315420608492>

Thomas, L. & Chaperon, Y. (2010). *Initial submission to the Productivity Commission inquiry—Caring for older Australians*. Canberra, Australia: Australian Nursing Federation. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0007/102220/sub327.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0007/102220/sub327.pdf)

Thomas, L. E. & Eisenhandler, S. A. (Eds) (1994). *Aging and the religious dimension*. Westport, CT: Auburn House.

Thomas, W. H. (1996). *Life worth living: How someone you love can still enjoy life in a nursing home; The Eden Alternative in action*. Acton, MA: VanderWyk & Burnham.

Tolson, D., Rolland, Y., Andrieu, S., Aquino, J. P., Beard, J., Benetos, A., ... Morley, J. E. (2011). International Association of Gerontology and Geriatrics: A global agenda for clinical research and quality of care in nursing homes. *Journal of the American Medical Directors Association, 12*(3), 184–189.

doi:10.1016/j.jamda.2010.12.013

Tornstam L. (1989). Gero-transcendence: A reformulation of the disengagement theory. *Aging, 1*(1), 55–63. doi:10.1007/BF03323876

Tornstam, L. (1994). Gero-transcendence: A theoretical and empirical exploration. In L. E. Thomas & S. A. Eisenhandler (Eds), *Aging and the religious dimension* (pp. 203–226). Westport, CT: Auburn House.

Tornstam, L. (2005). *Gerotranscendence: A developmental theory of positive aging*. New York, NY: Springer.

Tresolini, C. P. & Pew-Fetzer Task Force (1994). *Health professions education and relationship-centered care: Report of the Pew-Fetzer Task Force on Advancing Psychosocial Health Education*. San Francisco, CA: Pew Health Professions Commission. Retrieved from <http://rccswmi.org/uploads/PewFetzerRCCreport.pdf>

Tsai, H.-H. & Tsai, Y.-F. (2008). A temporary home to nurture health: Lived experiences of older nursing home residents in Taiwan. *Journal of Clinical Nursing, 17*(14), 1915–1922. doi:10.1111/j.1365-2702.2007.02240.x

Tseng, S.-Z. & Wang, R.-H. (2001). Quality of life and related factors among elderly nursing home residents in Southern Taiwan. *Public Health Nursing, 18*(5), 304–311. doi:10.1046/j.1525-1446.2001.00304.x

Tuckett, A. G. (2005). Residents' rights and nurses' ethics in the Australian nursing home. *International Nursing Review, 52*(3), 219–224. doi:10.1111/j.1466-7657.2005.00429.x

Tuckett, A. G. (2007). The meaning of nursing home: 'Waiting to go up to St. Peter, OK! Waiting house, sad but true'—An Australian perspective. *Journal of Aging Studies*, 21(2), 119–133. doi:10.1016/j.jaging.2006.08.001

Uhlenberg, P. (Ed.). (2009). *International handbook of population aging*. Dordrecht, The Netherlands: Springer Science + Media.

Ullrich, S., McCutcheon, H. & Parker, B. (2011). Reclaiming time for nursing practice in nutritional care: Outcomes of implementing protected mealtimes in a residential aged care setting. *Journal of Clinical Nursing*, 20(9–10), 1339–1348. doi:10.1111/j.1365-2702.2010.03598.x

UN Department of Economic and Social Affairs, Population Division. (2012a). *Population ageing and development 2012* [Wall chart]. New York, NY: Author. Retrieved from [http://www.un.org/esa/population/publications/2012PopAgeingDev\\_Chart/2012PopAgeingandDev\\_WallChart.pdf](http://www.un.org/esa/population/publications/2012PopAgeingDev_Chart/2012PopAgeingandDev_WallChart.pdf)

UN Department of Economic and Social Affairs, Population Division. (2012b). *Population facts* (No. 2012/1). New York, NY: Author. Retrieved from [http://www.un.org/esa/population/publications/popfacts/popfacts\\_2012-4.pdf](http://www.un.org/esa/population/publications/popfacts/popfacts_2012-4.pdf)

UN General Assembly. (1991). *Implementation of the International Plan of Action on Ageing and related activities* (A/RES/46/91). Retrieved from <http://www.un.org/documents/ga/res/46/a46r091.htm>

van Campen, C. & Kerkstra, A. (1998). Perceived quality of life of elderly somatic nursing home patients: Construction of a measuring instrument. *Tijdschrift voor Gerontologie en Geriatrie*, 29(1), 11–18.

van Manen, M. (1984). Practicing phenomenological writing. *Phenomenology + Pedagogy*, 2(1), 36–68.

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.

van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Canada: Althouse Press.

van Manen, M. (2006). Writing qualitatively, or the demands of writing. *Qualitative Health Research*, 16(5), 713–722. doi:10.1177/1049732306286911

van Manen, M. (n.d.). *Phenomenology online*. Retrieved from <http://www.phenomenologyonline.com/inquiry/2.html>

Vasunilashorn, S., Steinman, B. A., Liebig, P. S. & Pynoos, J. (2012). Aging in place: Evolution of a research topic whose time has come. *Journal of Aging Research*, 2012. doi:10.1155/2012/120952

Vickland, V., Chilko, N., Draper, B., Low, L-F., O'Connor, D. & Brodaty, H. (2012). Individualized guidelines for the management of aggression in dementia—Part 2: Appraisal of current guidelines. *International Psychogeriatrics*, 24(7), 1125–1132. doi:10.1017/S104161021200004X

Vines, R. (2011). Equity in health and wellbeing: Why does regional, rural and remote Australia matter? *InPsych*, 2011, 8–21. Retrieved from <http://www.psychology.org.au/Content.aspx?ID=3960>

Wacker, R. R. & Roberto, K. A. (2010). *Ageing social policies: An international perspective*. Thousand Oaks, CA: SAGE.

Wadensten, B. & Carlsson, M. (2003). Theory-driven guidelines for practical care of older people, based on the theory of gerotranscendence. *Journal of Advanced Nursing*, 41(5), 462–470. doi:10.1046/j.1365-2648.2003.02554.x

Valle, R. S., & King, M. (Eds.) (1978). *Existential phenomenological alternatives for psychology* (pp. 48-71). New York, NY: Oxford University Press.

Walliman, N. (2006). *Social research methods*. London, England: SAGE.

Wan, T. T. H., Breen, G.-M., Zhang, N. J. & Unruh, L. (2010). *Improving the quality of care in nursing homes: An evidence-based approach*. Baltimore, MD: John Hopkins University Press.

Wang, J. J. (2011). A structural model of the bio-psycho-socio-spiritual factors influencing the development towards gerotranscendence in a sample of institutionalized elders. *Journal of Advanced Nursing*, 67(12), 2628–2636. doi:10.1111/j.1365-2648.2011.05705.x

Wanless, D., Forder, J., Fernández, J.-L., Poole, T., Beesley, L., Henwood, M. & Moscone, F. (2006). *Securing good care for older people: Taking a long-term view*. London, England: King's Fund. Retrieved from [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/securing-good-care-for-older-people-wanless-2006.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/securing-good-care-for-older-people-wanless-2006.pdf)

Ward, L., Barnes, M. & Gahagan, B. (2012). *Well-being in old age: Findings from participatory research*. Brighton, England: University of Brighton and Age Concern Brighton, Hove and Portslade. Retrieved from <http://www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/Full-report.pdf>

Warnock, M. (1970). Imagination in Sartre. *British Journal of Aesthetics*, 10(4), 323–336.

Weiner, A. S. & Ronch, J. L. (Eds) (2003). *Culture change in long-term care*. Binghamton, NY: Haworth Social Work Practice Press.

Weiner, J. M. (2009). *Long-term care: Options in an era of health reform* [PowerPoint slides]. Washington DC: SCAN Foundation. Retrieved from [http://www.pascenter.org/documents/Wiener\\_2009.ppt](http://www.pascenter.org/documents/Wiener_2009.ppt)

Wells, Y., Foreman, P. & Ryburn, B. (2009). Community care for older Australians: Issues and future directions. In R. Nay & S. Garrett (Eds) (2009). *Older people: Issues and innovations in care* (3rd ed., pp. 78–104). Sydney, Australia: Churchill Livingstone Elsevier.

Wesley Mission Melbourne. (2009). *Submission to the review of the accreditation process for residential aged care homes 2009*. Melbourne, Australia: Author. Retrieved from [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0016/101770/sub311.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0016/101770/sub311.pdf)

Whitehead, L. (2004). Enhancing the quality of hermeneutic research: Decision trail. *Journal of Advanced Nursing*, 45(5), 512–518. doi:10.1046/j.1365-2648.2003.02934.x

Whitman, M. E. & Woszczynski, A. B. (2004). *The handbook of information systems research*. Hershey, PA: Idea Group.

WHO. (2002). *Active ageing: A policy framework*. Geneva, Switzerland: Author. Retrieved from [http://whqlibdoc.who.int/hq/2002/WHO\\_NMH\\_NPH\\_02.8.pdf](http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_02.8.pdf)

WHO. (2007). *Knowledge Translation Framework for Ageing and Health*. Retrieved from [http://www.who.int/ageing/publications/knowledge\\_translation.pdf](http://www.who.int/ageing/publications/knowledge_translation.pdf)

WHO. (2009). World Health Organization 2009 and World Health Organization, on behalf of the European Observatory on Health Systems and Policies. *How can health*

*systems respond to population ageing?* Retrieved from [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0004/64966/E92560.pdf](http://www.euro.who.int/__data/assets/pdf_file/0004/64966/E92560.pdf)

WHO. (2011). *What are the public health implications of global ageing?* Retrieved from <http://www.who.int/features/qa/42/en/index.html>

WHO. (2012a). *Good health adds life to years: Global brief for World Health Day 2012*. Geneva, Switzerland: Author. Retrieved from [http://whqlibdoc.who.int/hq/2012/WHO\\_DCO\\_WHD\\_2012.2\\_eng.pdf](http://whqlibdoc.who.int/hq/2012/WHO_DCO_WHD_2012.2_eng.pdf)

WHO. (2012b). *Interesting facts about ageing*. Retrieved from <http://www.who.int/ageing/about/facts/en/>

WHO (2012c.). *Are you ready? What you need to know about ageing*. Retrieved from <http://www.who.int/world-health-day/2012/toolkit/background/en/index2.html>

Wilkinson, C, Meyer, J & Cotter, A. (2009). Developing person-centred care in an NHS continuing care setting. In K. Froggatt, S. Davies & J. Meyer (Eds), *Understanding care homes: A research and development perspective* (pp. 25–46). London, England: Jessica Kingsley.

Willemsse, B., Smit, D., de Lange, J. & Pot, A. (2011). Nursing home care for people with dementia and residents' quality of life, quality of care and staff well-being: Design of the living arrangements for people with dementia (LAD)—study. *BMC Geriatrics*, 11(11). doi:10.1186/1471-2318-11-11

Willis, E., Reynolds, L. & Keleher, H. (Eds) (2009). *Understanding the Australia health care system*. Sydney, Australia: Churchill Livingstone Elsevier.

Wittenberg, R. & Malley, J. (2007). Financing long term care for older people in England. *Ageing Horizons*, 6, 28–32.

Wylie, K. & Nebauer, M. (2011). World Health Organisation (WHO). (2012d) 'The food here is tasteless!' Food taste or tasteless food? Chemosensory loss and the politics of under-nutrition. *Collegian*, 18(1), 27–35. doi:10.1016/j.colegn.2010.03.002

Yeandle, S., Kröger, T. & Cass, B. (2012). Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland. *Journal of European Social Policy*, 22(4), 432–445. doi:10.1177/0958928712449775

Yegdich, T. (2000). In the name of Husserl: Nursing in pursuit of the things-in-themselves. *Nursing Inquiry*, 7(1), 29–40. doi:10.1046/j.1440-1800.2000.00050.x

Young, J. & McGrath, R. (2011). Exploring discourses of equity, social justice and social determinants in Australian health care policy and planning documents. *Australian Journal of Primary Health*, 17(4), 369–377. doi:10.1071/PY11038

Yu, P., Qui, Y. & Crooks, P. (2006). Computer-based nursing documentation in nursing homes: A feasibility study. In H.-A. Park, P. Murray & C. Delaney (Eds), *Consumer-centered computer-supported care for healthy people: Proceedings of NI 2006* (pp. 570–574). Amsterdam, The Netherlands: IOS Press.

Zahavi, D. (2003). *Husserl's phenomenology*. Stanford, CA: Stanford University Press.

Zigante, V., Costa-Font, J., & Cooper, Z. (2012). 5 Choice in health care: Drivers and consequences. *The LSE Companion to Health Policy*, 79.

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## **Appendix A: Accreditation and residential care standards**

Standard 1: Management systems, staffing and organisational development

### ***1.1 Continuous improvement***

This expected outcome requires that “the organisation actively pursues continuous improvement”.

### ***1.2 Regulatory compliance***

This expected outcome requires that “the organisation’s management has systems in place to identify and ensure compliance with all relevant legislation, regulatory requirements, professional standards and guidelines”.

### ***1.3 Education and staff development***

This expected outcome requires that “management and staff have appropriate knowledge and skills to perform their roles effectively”.

### ***1.4 Comments and complaints***

This expected outcome requires that "each resident (or his or her representative) and other interested parties have access to internal and external complaints mechanisms".

### ***1.5 Planning and leadership***

This expected outcome requires that "the organisation has documented the residential care service’s vision, values, philosophy, objectives and commitment to quality throughout the service".

### ***1.6 Human resource management***

This expected outcome requires that "there are appropriately skilled and qualified staff sufficient to ensure that services are delivered in accordance with these standards and the residential care service’s philosophy and objectives".

### ***1.7 Inventory and equipment***

This expected outcome requires that "stocks of appropriate goods and equipment for quality service delivery are available".

### ***1.8 Information systems***

This expected outcome requires that "effective information management systems are in place".

### ***1.9 External services***

This expected outcome requires that "all externally sourced services are provided in a way that meets the residential care service’s needs and service quality goals".

Standard 2: Health and personal care

### ***2.1 Continuous improvement***

This expected outcome requires that “the organisation actively pursues continuous improvement”.

### ***2.2 Regulatory compliance***

This expected outcome requires that “the organisation’s management has systems in place to identify and ensure compliance with all relevant legislation, regulatory requirements, professional standards and guidelines about health and personal care”.

### ***2.3 Education and staff development***

This expected outcome requires that “management and staff have appropriate knowledge and skills to perform their roles effectively”.

### ***2.4 Clinical care***

This expected outcome requires that “residents receive appropriate clinical care”.

### ***2.5 Specialised nursing care needs***

This expected outcome requires that “residents’ specialised nursing care needs are identified and met by appropriately qualified nursing staff”.

#### **2.6 Other health and related services**

This expected outcome requires that “residents are referred to appropriate health specialists in accordance with the resident’s needs and preferences”.

#### **2.7 Medication management**

This expected outcome requires that “residents’ medication is managed safely and correctly”.

#### **2.8 Pain management**

This expected outcome requires that “all residents are as free as possible from pain”.

#### **2.9 Palliative care**

This expected outcome requires that “the comfort and dignity of residents is maintained”.

#### **2.10 Nutrition and hydration**

This expected outcome requires that “residents receive adequate nourishment and ”.

#### **2.11 Skin care**

This expected outcome requires that “residents’ skin integrity is consistent with their general health”.

#### **2.12 Continence management**

This expected outcome requires that “residents’ continence is managed effectively”.

#### **2.13 Behavioural management**

This expected outcome requires that “the needs of residents with challenging behaviours are managed effectively”.

#### **2.14 Mobility, dexterity and rehabilitation**

This expected outcome requires that “optimum levels of mobility and dexterity are achieved for all residents”.

#### **2.15 Oral and dental care**

This expected outcome requires that “residents’ oral and dental health is maintained”.

#### **2.16 Sensory loss**

This expected outcome requires that “residents’ sensory losses are identified and managed effectively”.

#### **2.17 Sleep**

This expected outcome requires that “residents are able to achieve natural sleep patterns”.

### **Standard 3: Resident lifestyle**

#### **3.1 Continuous improvement**

This expected outcome requires that “the organisation actively pursues continuous improvement”.

#### **3.2 Regulatory compliance**

This expected outcome requires that “the organisation’s management has systems in place to identify and ensure compliance with all relevant legislation, regulatory requirements, professional standards and guidelines, about resident lifestyle”.

#### **3.3 Education and staff development**

This expected outcome requires that “management and staff have appropriate knowledge and skills to perform their roles effectively”.

#### **3.4 Emotional support**

This expected outcome requires that "each resident receives support in adjusting to life in the new environment and on an ongoing basis".

### ***3.5 Independence***

This expected outcome requires that "residents are assisted to achieve maximum independence, maintain friendships and participate in the life of the community within and outside the residential care service".

### ***3.6 Privacy and dignity***

This expected outcome requires that "each resident's right to privacy, dignity and confidentiality is recognised and respected".

### ***3.7 Leisure interests and activities***

This expected outcome requires that "residents are encouraged and supported to participate in a wide range of interests and activities of interest to them".

### ***3.8 Cultural and spiritual life***

This expected outcome requires that "individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered".

### ***3.9 Choice and decision making***

This expected outcome requires that "each resident (or his or her representative) participates in decisions about the services the resident receives, and is enabled to exercise choice and control over his or her lifestyle while not infringing on the rights of other people".

### ***3.10 Resident security of tenure and responsibilities***

This expected outcome requires that "residents have secure tenure within the residential care service, and understand their rights and responsibilities".

## **Standard 4: Physical environment and safe systems**

### ***4.1 Continuous improvement***

This expected outcome requires that "the organisation actively pursues continuous improvement".

### ***4.2 Regulatory compliance***

This expected outcome requires that "the organisation's management has systems in place to identify and ensure compliance with all relevant legislation, regulatory requirements, professional standards and guidelines, about physical environment and safe systems".

### ***4.3 Education and staff development***

This expected outcome requires that "management and staff have appropriate knowledge and skills to perform their roles effectively".

### ***4.4 Living environment***

This expected outcome requires that "management of the residential care service is actively working to provide a safe and comfortable environment consistent with residents' care needs".

### ***4.5 Occupational health and safety***

This expected outcome requires that "management is actively working to provide a safe working environment that meets regulatory requirements".

### ***4.6 Fire, security and other emergencies***

This expected outcome requires that "management and staff are actively working to provide an environment and safe systems of work that minimise fire, security and emergency risks".

### ***4.7 Infection control***

This expected outcome requires that there is "an effective infection ".

***4.8 Catering, cleaning and laundry services***

This expected outcome requires that "hospitality services are provided in a way that enhances residents' quality of life and the staff's working environment".

(ACSAA, 2013)

## Appendix B: Information statement for participants



School of Health

Faculty of The Professions  
Armidale NSW 2351  
Professor Steven Campbell  
Head of School  
Phone 61 2 6773 3656.  
Fax 61 2 6773 3666

### INFORMATION STATEMENT for PARTICIPANTS

**Research Project:** A hermeneutic phenomenological exploration of the lived experiences of residents in high care facilities.

I wish to invite you to participate in my research on above topic. The details of the study follow and I hope you will consider being involved. I am conducting this research project for my Doctorate at the University of New England. My supervisors are Dr Penny Paliadelis and Dr Glenda Parmenter of the University of New England, Armidale, NSW. Dr Penny Paliadelis can be contacted by email at [ppaliade@une.edu.au](mailto:ppaliade@une.edu.au) or by phone on 02 6773 3653. Dr Glenda Parmenter can be contacted by email at [gparment@une.edu.au](mailto:gparment@une.edu.au) or by phone on 02 6773 3683.

#### **Aim of the Study:**

The aim of this study is to explore nursing home residents' perceptions of the lived experiences of high care nursing homes, and to explore the issues of dependency, dignity, and structural and situational relations, in order to identify the potential for enhancing their quality of life.

Background and significance of the study:

- Recent research has found that people demand more from the health system in response to people's needs and expectations, and want a say in what affects their health and communities.
- Increased understanding of their daily life is essential to assess residents' everyday experience and establish their perception of adequacy of care, and ultimately their quality of life.
- The research is important as the findings may enhance policy makers' and health care providers' understanding of the lived experience of older nursing home residents, thus guiding the evaluation and development of nursing home services to assess resident's needs and improve residents' care.



## School of Health

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- The study intends to acknowledge that management and care can be personally orientated, and ultimately influence quality of life for residents.

### **Time Requirements:**

It is proposed that a face to face interview will take place with you in the nursing home. The interview is expected to last approximately 90 minutes and can be conducted over 2-3 stages should that be necessary. Interviews will be audiotaped with your consent.

### **Methodology:**

The study will consist of a series of open-ended questions (semi-structured) that allow you to describe your experiences in the nursing home. Initially, the nursing home manager suggested that you may be interested in participating. The questions will relate to your personal experiences and feelings, however they are completely voluntary and you can stop the interview at any time. No names or identifiable material will be included in any written documents. A pseudonym will be used in the research report.

Following the interview, a transcript will be provided to you if you wish to see one. You will be free to withdraw at any time as your participation is completely voluntary. The audiotapes will be kept in a locked filing cabinet at the researcher's office until they are transcribed and then they will be destroyed. The transcriptions will be kept in the same manner for five years following thesis submission and then destroyed.

A consent form is provided should you agree to participate. If you are unable to sign the consent form but still wish to participate in the interview, I can record your consent via a witness on audiotape. If you are unable to physically read the information sheet, but still wish to participate in the interview, it will be read to you.

It is unlikely that this research will raise any personal or upsetting issues but if it does you may wish to contact your local Community Health Centre.



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**Research Process:**

It is anticipated that this research will be completed by the end of 2011. The results will form the basis of a thesis and may be presented at conferences and written up in journals without any identifying information.

This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. ...., Valid to../....)

Should you have any complaints concerning the manner in which this research is conducted, please contact the Research Ethics Officer at the following address:

Research Services  
University of New England  
Armidale, NSW 2351.  
Telephone: (02) 6773 3449 Facsimile (02) 6773 3543  
Email: [ethics@une.edu.au](mailto:ethics@une.edu.au)

Thank you for considering this request and I look forward to further contact with you.

Yours Faithfully,

Helen Walker

Candidate – Doctor of Health Services Management, Faculty of the Professions, University of New England, Armidale, NSW

## Appendix C: Consent form for participants



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Professor Steven Campbell  
Head of School  
Phone 61 2 6773 3656.  
Fax 61 2 6773 3666

### Consent Form for Participants

I, ....., have read the information contained in the Information Sheet for Participants and any questions I have asked have been answered to my satisfaction.

Yes/No

I agree to participate in this activity, realising that I may withdraw at any time.

Yes/No

I agree that research data gathered for the study may be published using a pseudonym

Yes/No

I agree to the interview being audiotape recorded and transcribed.

Yes/No

.....  
Participant Date

.....  
Researcher Date

## Appendix D: Human research ethics committee



Ethics Office  
Research Development & Integrity  
Research Division  
Armidale NSW 2351  
Australia  
Phone 02 6773 3449  
Fax 02 6773 3543  
jo-ann.sozou@une.edu.au  
www.une.edu.au/research-services

### HUMAN RESEARCH ETHICS COMMITTEE

MEMORANDUM TO: Dr P Paliadelis, Dr G Parmenter & Miss H Walker  
School of Health

This is to advise you that the Human Research Ethics Committee has approved the following:

PROJECT TITLE: A hermeneutic phenomenological exploration of lived experiences of residents in high care facilities

APPROVAL No.: HE09/194

COMMENCEMENT DATE: 21/12/2009

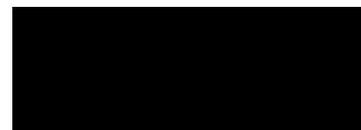
APPROVAL VALID TO: 21/12/2010

COMMENTS: Nil. Conditions met in full.

The Human Research Ethics Committee may grant approval for up to a maximum of three years. For approval periods greater than 12 months, researchers are required to submit an application for renewal at each twelve-month period. All researchers are required to submit a Final Report at the completion of their project. The Progress/Final Report Form is available at the following web address: <http://www.une.edu.au/research-services/researchdevelopmentintegrity/ethics/human-ethics/hrecforms.php>

The *NHMRC National Statement on Ethical Conduct in Research Involving Humans* requires that researchers must report immediately to the Human Research Ethics Committee anything that might affect ethical acceptance of the protocol. This includes adverse reactions of participants, proposed changes in the protocol, and any other unforeseen events that might affect the continued ethical acceptability of the project.

In issuing this approval number, it is required that all data and consent forms are stored in a secure location for a minimum period of five years. These documents may be required for compliance audit processes during that time. If the location at which data and documentation are retained is changed within that five year period, the Research Ethics Officer should be advised of the new location.



21/12/2009

Jo-Ann Sozou  
Secretary

## Appendix E: Demographic data sheet



### DEMOGRAPHIC DATA FOR NURSING HOME RESIDENTS

Resident's Name: \_\_\_\_\_

1. Age \_\_\_\_\_

2. Gender M\_\_\_\_ F\_\_\_\_

3. Nationality if not Australian \_\_\_\_\_  
If moved to Australia during life, place of origin and years in Australia  
\_\_\_\_\_

4. Marital Status

Single, never married	
Widowed	
Divorced	
Separated	
Married	
Partner (M or F)	
Other	

5. How long married or with partner? \_\_\_\_\_

6. How long divorced or widowed? \_\_\_\_\_

7. Number of children? \_\_\_\_\_

8. Highest level of education? \_\_\_\_\_

9. Income status for nursing home –

Private	
Public	
Returned Veteran	
Other	

If Other, details: \_\_\_\_\_

10. Place of Residence Immediately Prior to Nursing Home

Place		Years
Private home		
Assisted living/hostel		
Nursing home (low care)		
Nursing home (high care)		
Acute care hospital		
Psychiatric care		
Rehabilitation facility		
Other		

If other, please state \_\_\_\_\_

11. Place of Residence Prior to 6. Above

Place		Years
Private home		
Assisted living/hostel		
Nursing home (low care)		
Nursing home (high care)		
Acute care hospital		
Psychiatric care		
Rehabilitation facility		
Other		

If other, please state \_\_\_\_\_

12. Who were you living with prior to coming in to the nursing home?

\_\_\_\_\_

## Appendix F: Decision trail data organisation—Theme 1

Participant's stories/phrases	Connecting Key words	Emerging concepts	Sub-theme	Theme
<i>And we <b>had to get one fairly quickly</b>, so ... we have a son (who lives near here) so we came up here. Well, it wasn't too bad, so to say, because we got in the next day. So it was a short period of time that we got in. And, ah, <b>the good ones were booked out</b> so far ahead. (Beryl - one of a couple)</i>	Urgency	No choice	1. Relocation	Issues of self and control
<i>Well, no, it wasn't, <b>no, wasn't my choice</b>. And then my time was up (in rehabilitation) and I moved up to here, which I'm glad of, but it's too far from home. (Odie)</i>	No choice			
<i><b>They (family) said I had to go</b> straight to the nursing home, and they arranged it. I wasn't too keen to come here, to be honest. <b>I had no choice</b>. (John)</i>	No involvement			
<i>I really <b>didn't want to come in here</b>. I don't like these sorts of places. But we had to make a very quick decision because this unit, as you can see, that we've got here, is ours. We bought, we sold our house, or our son did, and we had to make up our minds very quickly because we <b>didn't have anywhere else to go</b>. (Pricilla – one of a couple)</i>	No options, urgency			
<i>My daughter looked after me for over 10 years or more on her own. Anyway, it was getting her down, you know. And she wanted a break, so her husband said, “Would <b>you mind coming in here</b> (referring to the nursing home)?” No, I knew, I knew it would be (for) a while. I think it is <b>gonna be forever</b>. (Kitty)</i>	Family stress, no choice	Family unable to cope		
<i>I had in mind that I would (go to a nursing home), that <b>he (husband) would put me in here</b>, because I realised that he couldn't look after me. And he couldn't go to work or he couldn't leave home, and he'd have to be with me all the time. So I realised I'd have to go somewhere. So I came here all of a sudden. I fell over and I couldn't walk, I, I didn't think I was going to get better and <b>we just made up my mind</b>. (Nellie)</i>	Family stress, urgency, no choice			

Participant's stories/phrases	Connecting Key words	Emerging concepts	Sub-theme	Theme
<i>Well, you have to get away <b>without a lot of your personal belongings</b>, sort of thing. She (wife in nursing home as well) used to be a dressmaker, and make dresses and skirts and everything, well, we decided, well, it was no good having that out here, so a lot of the stuff had to go. Suits of mine and other personal belongings that we couldn't take. As far as furniture was concerned so, some of the things that I made over the years, ah, but there was a lot of things that <b>we had to leave behind</b> there 'cos we couldn't take in here, we are <b>confined</b> to a certain area down here. And other things we had there sort of thing, pictures and clocks and other things, more or less, something to make it homely. It is sort of, quite a <b>change in life</b> rather and it <b>takes a bit of adjusting</b>. (Leo - one of a couple)</i>	Crisis of identity, restricted	Missing home life and things of importance	2. Loss of identity and independence	Issues of self and control
<i>Oh, well, chatting to everyone I know and <b>home life</b> and everything, years ago we used to do fishing trips ... and that's something <b>I miss</b>, doing that, really. But, (sighs) <b>life goes on</b>. That was really the best of it. (gets upset) But don't worry about me, <b>I get broken up</b> (pause) when I talk about things. (Quentin)</i>	Feelings of despair			
<i>Oh well, <b>it's different</b> anyway, it's just different. Well, <b>I'd like to (have) freedom</b> to get around, and get around the back yard and little things like that but can't bear it when you're locked, <b>you're locked in</b>, you're just in all day in the room. So it all goes back to living at home, like I, I don't, don't go, my daughter, my son visits and, but (to) <b>take me home</b> for a day, or two, half a day or something, it would <b>make a hell of a difference</b>. (Odie)</i>	Loss of freedom, despair, no choice			
<i>But I like it here, it's quite nice, it took me <b>a while to settle in</b>. I had everything at my fingertips (at home), friends ... and it was hard. Oh yes, <b>it was hard, really hard</b>. (Alice)</i>	New life not easy			
<i><b>It's not the same as home</b>. Oh, (missing) everything, the kids, I think. The family, oh, they're, they're not home now, they're at work, but they used to call in and see me a lot. It's just that, I just don't like being away from home, that's all. But it all comes to somebody sometimes. Oh, <b>it's a terrible thing</b> really. (Nellie)</i>	Crisis of identity, anguish			
<i>Oh, <b>I miss a lot of that</b>. I was a great one going out shopping. But, um, I do miss that. Yes. Not walking is a bugbear. (Ruby)</i>	Sadness, crisis of identity			
<i>And sometimes I used to go out and sit out in the sun with the dogs. <b>Do I ever (miss it)</b>. That little (name of dog) sees me and she goes for the life and I go and sit in the lounge ... and she flies and sits on top of me and licks me. (Kitty)</i>	Sadness	Grieving loss of relationship with pet from home life		

Participant's stories/phrases	Connecting Key words	Emerging concepts	Sub-theme	Theme
<i>Yes, oh, it (<b>independence</b>) has changed, well, it does. Because <b>it's got to really, hasn't it?</b> Oh, I don't know, being independent. I think I can't, can't just say - "Right, I'll go and do something today", I can't do that now. <b>I've just got to stay here.</b> Oh, well, I used to go and come as I pleased, I could go, I couldn't go up the street now, now I couldn't walk. I used to walk up the street nearly every day for an outing. Oh, <b>you lose your independence.</b> Oh, I never notice it now, I think <b>I've got used to it.</b> (Nellie)</i>	Assume evolving dependence, accepting status	Being rendered submissive and dependent		Issues of self and control
<i>Oh yes, it did (feel like independence was lost), this place is not like home. But, anyway, <b>I've got over that and here I am.</b> (Odie)</i>	Accepting status			
<i>It's a <b>different life</b> altogether, I get very <b>frustrated.</b> We all do. Even though we have a lack of independence, I don't think you could, ah, <b>get much better.</b> (Beryl - one of a couple)</i>	Frustration, accepting			
<i>Yes, it was a bit of a change, oh, as far as that was concerned, and the shock in so far as losing your independence and, it takes a heck of a time to, ah, get adjusted to it. <b>It was a matter of having to and that was it.</b> Yes, absolutely (you lose) all of your independence really. (Leo - one of a couple)</i>	Accepting status, no choice			
<i>I see (the cleaner) doing some dusting, and you think "I have already done that" or "<b>I can do that myself</b>", "I can fix it". And that's what I say to them "I'll do that, I am going to do that in five minutes". And in five minutes (the cleaner) <b>got it all done.</b> My daughter will come in and she'll do something for me and she'll take washing home and do it, and I'll say "<b>Look, don't do that, I'll just do a few things for myself for today</b>", and she'll say "<b>No</b>", she says. (Alice)</i>	Made to feel useless			
<i>He's the one (refers to husband in bed) who <b>hasn't settled down.</b> He wanted his home, home-cooked meals and everything that went with it. Well, I mean, <b>you don't get that here.</b> The main thing I miss is my cooking. Well, you see, I've always been a cook, I've always loved cooking. Pottering around, yes. Now you can't, they <b>won't let us have a little microwave</b> here. Well, my independence is being able to do cooking or sewing or whatever I wanted to do ... Well, the worst part I think is that <b>you can't do exactly what you want to do.</b> (Pricilla – one of a couple)</i>	Being made compliant			
<i>Yes, I have lost a bit (independence)...I don't ring the buzzer, very, very seldom I ring it, and <b>I hate ringing it.</b> And, I am so used to doing everything, sort of thing, for myself. And I have <b>had that taken away from me.</b> (Alice)</i>	Sense of loss, hating reliance			
<i>I loathe, and I mean <b>loathe, having to ring that bell.</b> (Maude)</i>	Hatred, hating reliance			
<i>I've taken bad, and it's before I could get to the toilet it's all come away and <b>I'd better not ring them</b> and tell them, I'll clean it up, and I've cleaned it up myself. Because I, <b>I was too embarrassed</b> to ring it (the nurse's call bell). Yeah, I know, I know, and they (the nurses) tell me (not to worry), they tell me that but I still, still do that.... (Maude)</i>	Humiliated			

Participant's stories/phrases	Connecting Key words	Emerging concepts	Sub-theme	Theme
<i>Sometimes she gets into me bed. I just take her out. (Fred)</i>	Putting up with behaviours	Loss of privacy and dignity	3. The paradox of care	Issues of self and control
<i>Oh, most of them go out when you tell 'em. Yes. I had a man come in here once, he came in here in the 'nuddy' one night. He got into bed with me, and I, I rung the bell and I tried to get him out.. (Hyacinth)</i>	Dealing with behaviours			
<i>No, they (other residents) just come in. They took all the chains off (from across the door), I don't know why they (management) took all the chains off (the door). Oh, he was always coming around here. No harm in him, but I didn't like the men coming in my room. Yeah, I'd say "You stay there", or "Get back into your room". They (the chains) haven't been put back on, I don't know why they took 'em off. (Kitty)</i>	Annoyed with behaviours			
<i>Yes, sometimes, there was a couple of them (other residents) walking and they were coming in and taking things, you know? Taking everything, and they were annoying me and getting to the stage where I, I thought, oh God, I couldn't stand it and I shut the door but they keep..(they) learn to open the door. And then they come in, and one, one lady took, took me, took the walker and she, she pinched the, we had the walking stick in there (points to walker). They don't mean to take anything, but they do. (Nellie)</i>	Furious at behaviours			
<i>That's the only trouble I have with me is my toilet. Yes, that's why I've got that there (refers to the commode). I have to go on there because there's someone in there (refers to the man using shared bathroom adjacent for a shower). (Kitty)</i>	No choice	No respect		
<i>No, they just had the one, this is the only room that (they) had, that had the toilet and bathroom all out there, out that door and, ah, I have to share it with a man, there's a man, in there, in that next ward. None of the others have to share anything, but I have to apparently and because he can't get out of bed. But I have to share a toilet and that with him. Sometimes I open the door and he's in there, I shut it again. (Nellie)</i>	Unfair treatment			
<i>I said "I don't snore", and she (daughter) said "You bloody snore all right". And when the girls (nurses) come in, they come in to bring something into me or something and that, and they said to me and they say "You snore like a pig". (Kitty)</i>				
<i>No, they've just changed managers (of the home). And I haven't even seen her, she didn't even come and introduce herself to us. No, no, "you'd think she would (introduce herself), wouldn't she", I said to the nurse. But it wouldn't have hurt her to come in and say hello. Oh well, I suppose I'll be disowned. (Ruby)</i>	Being ignored, retribution			
<i>Yeah, ah, no, they (the staff) don't even ask, they come to your drawer, my drawers and all that and they don't even ask what they're looking for. And they just come and have a look. And one of the girls just helps herself to me lollies, she doesn't even ask. She just helps herself. (Kitty)</i>	Disrespectful			
<i>Oh, I've only got to press a button and someone will come. Oh, sometimes you've got to wait a while. Doesn't matter. The other night I had a bad night with me leg. The right leg, the pain was something shocking. They, they come around and give me a couple of panadols and then I said to the girls "If I had one of me, me knives ... still got, had one of me knives, I'd take my leg off at the knee. They said "Gerry, don't start talking like that". I said "Well, I mean it". (Gerry)</i>	Suffering, in pain, needing attention	Suffering due to lack of care		
<i>I have to wait ... in particular ... when I had the spasms ... and me leg was doing sort of that. I had to wait an hour and three quarters. They've got to wait until someone comes down there ... I rung the bell again, but it was one and three quarter hours. (Hyacinth)</i>	Suffering, needing attention			
<i>Well, the only handicap, that is the weekends, here they are always short staffed, and particularly last night, they weren't, not any girls in particular, there wasn't enough staff on the floor. (Leo – one of a couple)</i>	Needs not met	Deprived of right to adequate care		
<i>I think I'm quite lucky, but there are times, and things don't go right, such as last night. I take, (Ruby shows me a Webster pack). No one ever comes to see whether you've taken them or not. Oh, everyone here says they (the visiting doctors) only come in every now and again too. I said I don't want to end up around in the</i>	Lack of accountability			

Participant's stories/phrases	Connecting Key words	Emerging concepts	Sub-theme	Theme
<i>coroner's court.</i> (Ruby)				
<i>Oh, I'm starting to walk around a bit now, I don't use me whansaname (walker). I just walk around. Yeah, and they go crook, because I'm not supposed to.</i> (Kitty)	Go against the rules			
<i>I'm not supposed to, but I do, I get up and have a shower. There's supposed to be somebody around but they've got other people to attend so I shower myself, but I get, have to get them to make the bed and that. Staff everywhere is very hard to get.</i> (Maude)	Forced to go against the rules			
<i>It was 11 o'clock when they came to shower me, and I'd had it, I was wild, I mean they could have put another girl on and be a bit better organised. I said to the girl "I wasn't happy with that, I didn't have anybody." And the bed wasn't made until nearly 12. You know, I was fed up. And I thought I wasn't very popular, I'd said too much. I thought 'Oh well, blow it.'. I said "I've been easy, I've been easy." She said "Yes, you're one of the easiest patients we've got." "Well," I said "I'm not now." I said, "I'm cross." Because I was left to that hour, nobody came near me, no one came in that door. No, that's about all. I'm getting over it. But I think they are a bit inclined to do that, that, they'll cut down on all the staff, and the patients suffer. And that's not right. They shouldn't do it.</i> (Nellie)	Suffering, upset, needs not met			
<i>Well, they haven't got a regular chef here, you know a girl might do the cleaning one day and the next she's in the kitchen cooking the meals. This is the ordinary floor staff cooking the meals. I can imagine what's it's like, they gotta cook for 50-60 people, they just whack it on a plate. To look at it sometimes just puts you off it already.</i> (Leo - one of a couple)	Poor service			
<i>It's not marvellous ... It's a good thing I'm not hungry, but they've got so many to feed, it can't be ... and all the cooking, and the lack of funding ... I wouldn't mind having a hot meal at night instead of the middle of the day, but I believe most nursing homes are like that, hospitals too, so you have to accept that that is the way it is.</i> (Beryl - one of a couple)	No choice			
<i>Oh don't, I wouldn't wish it on anyone, no, I don't like 'em, I don't like 'em. Don't like the flavour. Each meal you don't get a choice.</i> (Charles)	No choice			
<i>Oh, ... some of it's all right, some of it's shocking. I've been having vegemite sandwiches ever since. Well, I wasn't putting any weight on and I wanted to get some nourishment.</i> (Gerry)	Poor service			
<i>Oh, all right, they shower you every morning. That's what I don't like, you don't really need a shower, when you're in bed, in, in a home, you don't really need one every day. Really. I don't have one every day (at home). Now and again, I get jack of it. No, I don't need it. They do that early, I wake up early because I go to bed early, but they get me up and shower me. And dress me.</i> (Nellie)	No choice over care, preferences ignored	No control over the dominance of routine tasks which affect care and comfort		
<i>There are little things that upset you at times, but you've got to expect that. Well, not having a shower until it's getting onto to 10 o'clock, and sometimes it's six o'clock. But that's to be expected 'cos they've got a lot of people to look after.</i> (Odie)	No options, compliant, acknowledging routine			
<i>Yes, they encourage them (visitors) later in the evening, after tea, and they don't mind that at all. No, I don't (go to the dining room), they don't really encourage you, so I ... just stay. I could go down, but they bring my meals so ... I just stay.</i> (Beryl - one of a couple)	Submissive status, no real choice			
<i>Oh yes, I can sit here and read me book anytime, all day if I wanted to. I go for a walk all about. I've got to keep walking or otherwise they'll put me to bed. Because I don't want to go to bed. It's terrible to see the people in bed. It's shocking. I don't like that.</i> (Fred)	Lack of freedom, no real choice			
<i>Look, I could sit here for a day, not see anybody, only at meal times, when they bring a meal in would see them. They don't have time to sit and talk. None of them. Mind you, it's a hard job to them.</i> (Nellie)	Acknowledging routine, loss of			

Participant's stories/phrases	Connecting Key words	Emerging concepts	Sub-theme	Theme
	contact time			
<i>She (daughter) promised that when I wasn't able to drive myself to church, she would take me. And now she won't, she's got bad shoulders and she won't take me down the street. No, no, <b>they're (staff) not allowed to. No, I would like to be able to walk down to that shop. I'm not allowed to.</b> (Hyacinth)</i>	Lack of freedom			
<i>Generally my wife is there, you know, the nurses would take you out but they can't, they, they <b>can't stop with you all the time, they've got too much to do.</b> (Quentin)</i>	Acknowledging routine, loss of contact time			
<i>Of course I will take that one (Parkinson's medication). Anything else I don't want. No, <b>I don't like going to the manager, I loathe having to complain, I loathe it when anything is wrong. There's no use complaining.</b> (Maude)</i>	No use complaining, acknowledging situation	No one listens		
<i>You might have to wait some of the time (for the nurses), but that doesn't matter. I don't know about that (reporting problems to management). <b>I'm not one to complain</b> really. You can get annoyed but you keep it to yourself. I don't know (why I don't report it). Just me. (Ruby)</i>	No use complaining			

## Appendix G: Decision trail data organisation—Theme 2

Participant's stories/sentences	Connecting Key words	Emerging concepts	Sub-theme	Theme
<i>The last 10 days I reckon we were, we were 60-70% agency staff. Yes, a few months, a few months ago one or two agency girls, and I should have reported it, and she came in, and she was looking for (lady X), the lady next door. Ah, "Hello (lady X), how are you?" (said the agency nurse), I said "That's not (lady X)". "Oh, yes, that's (lady X), here are your tablets." I said "No, you're not on your life, you're not going to give those tablets to her." "No, no, that's (lady X)." She said "That's Room 19". I said "Have a look at the flaming door then". "Oh", she said "I'm awfully sorry." I should have reported that. But that <b>sort of thing can happen</b>, you know. ... ah, you see, <b>the regular girls know the quantity</b> what they have. <b>I should have reported that one.</b>" (Leo – one of a couple)</i>	Disgruntled at incompetence	Reliance on regular staff	1. Continuity of carers	Important relationships
<i>We've a lot of agency here, that's one thing about ... see when you have to take tablets or take medicine, you <b>get used to the same nurse</b> coming in. ... because you get used to the (regular) nurse coming up and <b>she gets used to you</b>, and you, and she knows what you take, otherwise they get all confused especially with the tablets and things like that. You like to have your own medic-nurse like that. No, I'm quite satisfied because I know I'm right up here (points to her forehead), and I can tell if I don't take this or I don't. <b>This has happened before</b>. Now, look, in this end (of the drawer), I've put them (spare tablets) in here, <b>if anything happened</b>, the tablets didn't come, I've got some, <b>I'm right</b>. (Maude)</i>	Wanting continuity of care			
<i>Because it is a nursing home, but they're pretty good, they're, you know, some, at the moment we've got agency ones, but <b>they're not so hot</b>. Oh, I don't know, they just have to learn. They were, they are no good, they're, they're the youth of today. Oh, they're no good, <b>hopeless</b>, they're <b>not trained</b> properly, they can't shower you, all they do is just put water all over you, and of course, put no soap on you. Oh, <b>I complained</b> about that one day. (Nellie)</i>	Despair at lack of training	Care suffers with temporary relationships		
<i>They are very good, but at the moment we are having a lot of extras (agency staff). And it's getting quite a habit. I mean I'm not being selfish I don't think, I mean <b>these sort of people think they know it all</b>, well, I'll give you an instance the other day. We were in the big room and they gave me a tablet, she got a glass out of the kitchen, and there was something in it, I got a very... this dreadful thing in my throat and I couldn't talk and I was choking and she said "<b>Sort yourself out</b>". As I said, I had that person, it didn't work and I said to them "Don't ever give me that girl again." Yes, there's a lot of that and <b>you've just got to accept it</b>. (Pricilla - one of a couple)</i>	Dissatisfied with lack of care			

Participant's stories/phrases	Connecting Key words	Emerging concepts	Sub-theme	Theme
<i>The positions altered now, mother and daughter are the opposite. <b>She helps me</b> ... for all the years I mothered her. She does all my washing and ironing, she takes it home. She brings them all back and ... colour ... I lose colour, and she says "Oh Mum, you can't wear that with that", and she puts them all on different hangers with what to wear. What goes with what. (Alice)</i>	Appreciation	Family and friends make a difference	2. Relationships with family	Important relationships
<i>My wife comes in once every day to <b>make sure I'm all right</b>. Not to say much, right, but to get me out of bed, get me fixed up, in there, oh, hour, two hours a day.(Quentin)</i>	Acknowledge help			
<i><b>You want your friends and family</b> not too far away. (Beryl - one of a couple)</i>	Appreciation			
<i>You see now, there's quite a few now, their partners, are, you know, coming in every day, and sort of coming, and <b>they've got someone else</b> to talk to. <b>It makes a difference</b>. (Derek)</i>	Company			
<i>The kids come in, the three boys come in different days, and <b>that takes over</b>. 'cos they're working too, they can't come in all the time, but they come in when they can. I like to see them. (Nellie)</i>	Company			
<i>(Husband) <b>misses his security</b>, that to me is what he misses. In every way. I think he <b>feels very unsafe</b>. I don't really know, I haven't been able to pinpoint it yet, I can just sense it, I can see it, but ah, oh, I mean (son) comes into see us every other day, I mean we are very lucky. Oh yes, if I say to him "<b>Now son's coming</b>", well, <b>he'll get up</b> and get dressed and <b>do everything</b>. But then on the other hand (if son doesn't visit), he just doesn't want to. Yes, no, as I say, I'm quite happy, I mean, as I said (son) comes and sees us which is a great asset, and then you see I've my other son that I got in (different state) and they come over here. And they write, and they ring me, always ringing me. (Pricilla – one of a couple)</i>	Security with family			
<i>But I think what makes the <b>difference is that we're together</b> sort of thing and we talked things over there, <b>once you're on your own</b> there in a small room eh, <b>you've got no one</b> to visit you, no one to converse with ... you start to fall back into... and <b>you get smaller, smaller and smaller</b>, and in the end you couldn't care less about whether you're alive or dead...Quite happy together, both of us. As long as we can be together, that's the main thing." (Leo - one of a couple)</i>	Loss of self, difference			
<i>My daughter, the ex-wife and granddaughter, grandson I should say, and his wife, but no, they don't come down much, but a little bit, but <b>you don't expect them</b> much either, they <b>got to live their life</b> themselves. That's the point. (Quentin)</i>	No expectations	Didn't want to burden family		
<i>All my family's gone now, bar my own children, ...they've got to come from town down here, but he's marvellous, my eldest son. He comes down to make sure I'm all right. But no, <b>I think it's wrong</b>. I feel, ah, they have got their lives to finish. And not to be having to rush out here, not rush, but to come out here and see that I'm all right, and take me out and all that. I feel that they <b>should be free to live the end of their lives also free</b>. (Maude)</i>	No expectation			
<i>They would be quite willing to have me there, but <b>I don't want to</b> sort of, I have always said that I wouldn't live with my son or my daughter, because I think <b>they have to be by themselves</b>, you know, cos they have family too. (Alice)</i>	No expectation			
<i>And it was time I had to go somewhere and <b>I never expected my children to take me in</b>. (Isabelle)</i>	No expectations			

Participant's stories/phrases	Key words	Emerging concepts	Sub-theme	Theme
<i>You know if I walked down the road, down the passage there, I would say hello to everybody. Or I could just go by, but I don't believe in that. I think <b>if you've having to live with them</b>, just say hello. (Pricilla - one of a couple)</i>	Being friendly	Friendship makes it easier	3. Living in a public realm	Important relationships
<i>I've got to know them (the other residents) here. Yes <b>it helps with living here</b>, you've got to get to know a few people. Even if you don't know their names, you would never remember them all anyway. But you say hello, they say hello, just get to know them all that way. (Nellie)</i>	Welcoming			
<i>Yes, you make friends, you know, I've got a lady at the same table, and she's deaf and blind and I am going blind. Yes, and I just feel that... I have got <b>something in common</b>. Where I can sort of see what has happened to her. (Alice)</i>	Common link			
<i>Yes, and in the other rooms and across the road there when she sings out 'Nurse', yeah. She's all the time doing that and no sooner than the nurse goes out, she's doing it again, she's calling again and the girls get sick of it. She's not bad now, I started to talk to her and <b>she's talkin' to me. We're getting on all right now</b>. I don't yell at her now, I just let her go. (Kitty)</i>	Communicating	Relating to others		
<i>Yes, and I go over there and lecture that one (indicates towards another resident's room). She says "You'll hit me", I says "I don't". She says she can walk. She can't. And then I tell her that nothing can make me more happier to be able see you walk and get around. She says she's in jail and in different places. (Hyacinth)</i>	Communicating			
<i>When we get a new resident down there, I always ask the girls (staff) "Is she able to talk?" sort of thing. And if they say, "Oh yes, they're quite good, they are just handicapped physically", sort of thing, I'll go up there and <b>have a natter</b> with them, you know and tell them that they've got a beautiful staff down there, the girls and it <b>makes all the difference</b>. (Leo - one of a couple)</i>	Being friendly, welcoming			
<i>Oh well ... I am used to the staff as I can't do anything on my own now. But they are always there, they don't mind. They are very caring. Often they are short on staff and they have to work harder, sometimes <b>the patients suffer</b>. Some people expect care like having a private nurse and to be completely everywhere, <b>but they can't</b> do that. But they are very kind and very caring. So I was pleased when I got a place, a friendly place and a place where the nurses cared for you, they didn't just do what you asked them to do, they cared for you. I think the care is what I like best about it. <b>I've quite accepted everything</b>. (Beryl - one of a couple)</i>	Appreciation, accepting	Compliance despite issues with staff	4. More than care	Important relationships
<i>Oh, it's (the care) very good, I get on very well, I can't complain. Oh well, there's some that'll treat you extra good, and <b>some that'll treat you just right, so I can't complain</b> about anything. (Odie)</i>	Uncomplaining			
<i>Well, I get on with most of them, there are some that I don't, ah, two or three that I am <b>not too keen on</b> at all, but it's like everything, <b>I just put up with it</b>. If they're put here to do a job, they're to do it, I mean, that's my opinion. You have to mix with other people (staff) and <b>you have to be patient</b> with people. And if you're patient with other people, you get on ok. (Pricilla - one of a couple)</i>	Tolerance			
<i>Oh yes, I get on well with them all really, which is good. There are certain ones <b>you don't get on with</b>, you know, but you know what they are, who they are, <b>but it's all right</b>. You wouldn't get on with everybody anyway. (Nellie)</i>	Acceptance			
<i>There used to be one here that <b>I didn't have too much time for</b>. But there's one here, she's brilliant. Yes, I think with the difficulties that the staff's got, they <b>give all the services that you require</b>, they do a marvellous job. They give you everything you need. (John)</i>	Make do			
<i>You'll get one who will just come and dump everything, your meal and everything in front of you and say nothing or some, <b>they'll come in and talk</b> and carry on, they're, <b>they're a lot different</b>, but, well, you've just got to put up with that. (Nellie)</i>	Grateful for extra attention	Friendships make a difference		

Participant's stories/phrases	Key words	Emerging concepts	Sub-theme	Theme
<i>One of the nurses there, she thinks I'm a Collingwood supporter, that's me gift (hand knitted scarf), she thinks I barrack, I barrack for them too. <b>Makes your day</b>, you know. Here, they're (staff) up and down the passage all the time, they're working admittedly, but <b>you know there's someone there</b>, when you need, which is good though admittedly. Oh no, I couldn't fault them. (Quentin)</i>	Grateful for extra attention, sense of safety, know someone is there			
<i>Favourite things? Oh well, <b>talking to the staff</b>, and I think that's about it. But, ah, they're very good. Some of the night staff I love, you know. They're lovely, the night staff. (Ruby)</i>	Appreciation			
<i>Oh, yes, they (the staff) <b>bring their family in</b> sometimes to meet me. (Beryl - one of a couple)</i>	Appreciation			
<i>They are <b>friends of ours</b> and they treat us like that, <b>they're company</b> and they don't just take the sheets off and clean up and take off again, they stop and stay here for 10 or 15 minutes, they have a natter with us, they tell us their troubles at home and their experiences. (Derek)</i>	Closeness, friendship			
<i>Absolutely yeah, if you haven't got that sort of contact (relationship with the staff) there, it would be difficult. Oh yes, there are some that come in and talk for about ten minutes and talk about their personal troubles or experiences, or after they have been on holiday, and when they go on holiday, they'll say "See you in a fortnight". We get all their stories about their teenage daughters and we say we've been there, done that. That <b>contact</b> the girls have, I reckon, <b>makes all the difference</b>, you know, you've got sort of <b>a family feeling</b> with them. (Leo - one of a couple)</i>	Closeness, familiarity			

## Appendix H: Decision trail data organisation—Theme 3

Participant's stories/sentences	Key words	Emerging concepts	Sub-theme	Essential Theme
<i>So I haven't got that much longer to live so ... so I'll be alright. Yes, that's what I mean, so I don't worry about that. It's as good as I'll get, and what I could ask for? (Fred)</i>	Accepting, resigned	Finality of place	1. Mortality	Resigned acceptance
<i>...move to somewhere else, but how would I find something better than this? (Charles)</i>	Resigned			
<i>Oh well ... somewhere to live I suppose. Oh, well, what can you do? (sighs) You can't do anything. You sit in your room on your own ... I knew I had to get used to it because I knew I'd be here till they cart me out. (Gerry)</i>	Reconciled with lot in life, submissive			
<i>Oh yes, but it's, ah, the place to be if you're not well and your husband can't look after you. Yes, I don't think I'll ever get out of here. I don't think I'll ever get out of here now. (Nellie)</i>	Acceptance, acquiescent			
<i>Some of the ladies that come in here after me and they say about going home, and I say "You're here to stay. You ain't going home". (Ruby)</i>	Reconciled			
<i>And then my time was up (in rehabilitation) and I moved up to here, which I'm glad of, but it's too far from home. I'm a little mobilised, I can get around, but I just want to see home, but anyhow, so anyway, we've settled on that, that I'm not coming home. I'm, I'm very, very crook on this. (Odie)</i>	Angry, suffering	Can't go home, sense of loss		
<i>It's a part of it now, isn't it, we're used to it now, sort of thing. We know we can't go back on our own, on our patch anymore. But, no, you know beforehand when you get here, that it's the last stop, innit? (Leo - one of a couple)</i>	Prepared to accept			
<i>Because you've got to be able to live somewhere, don't you? Well, I can't go to my house 'cos I sold it. (John)</i>	Prepared to accept			
<i>It (nursing home life) doesn't really worry (me), I know I won't be here that long. (Kitty)</i>	Reconciled, tolerant	Awaiting death		
<i>But that's life, 'cos I'm quite happy here. Really. I'll be carried out. (Isabelle)</i>	Reconciled, tolerant			
<i>I can't say that I get depressed about it (living in a nursing home), because, ... now, you say this won't be going to them (management), I will be saying things... euthanasia. It's a bit of a shock when you come in and see dementia and Alzheimer's and things, things like that and really, I think it's terrible really, because these people who are like that, they don't know, they get spoon fed, they don't know, and I think when you get to a certain age, like I am now in my 89<sup>th</sup> year, I really, I want to go, I'm tired. I don't want to be stuck here, and stuck in bed, for the rest of my days. I'd like to go, I'd like to go. I can go out with my pride and dignity intact. (Maude)</i>	Reconciled, frustration	Living with death OK		
<i>Last week there was, was three that died. Didn't worry me. (Kitty)</i>	Resigned			
<i>I was thinking about that the other night when I was awake in me bed, how many would have passed away? Since we were here, and how many are left here that we know? And I reckon there that there would be 30-odd that's gone. It happens quite often. Sometimes two in a week. Oh, it doesn't affect us, doesn't affect us (seeing people pass away). There's quite a few that have passed away, (X) passed away there, (Y) passed away there sort of thing and (Z) laying on the bed there, she doesn't come about the floor anymore. No, no, that doesn't bother us. We're quite settled in now. (Leo - one of a couple)</i>	Accepting, expected			
<i>I thought the way they (the staff) were carrying on yesterday, I thought she had died, she will go all of a sudden like that, but she's very good for her age. (Nellie)</i>	Expected			
<i>And, you see, yesterday, we had a little service, we lost one of the ladies and we had a little service up there for her yesterday. The funeral, I presume it's today, I don't know, we had a little service for her yesterday. Well, sometimes it affects me, it all depends if I get to know or near to people, you know what I mean? (Ruby)</i>	Prepared to accept			

Participant's stories/sentences	Key words	Emerging concepts	Sub-theme	Theme
<i>Well, I don't (relax). I go and tell her to be quiet (refers to another resident yelling) or she might want something, drops something, I'll go and do that. One day, <b>you might be like it yourself.</b> (Hyacinth)</i>	You might be like it yourself	Worried about own future	2. Dual reality	Resigned acceptance
<i>And then afterwards she might (stop incoherent talking), I talked to her last night, I heard her going on, but I think, you never know, <b>you might be like it yourself.</b> (Ethel)</i>	Sorrow			
<i>I feel that <b>I don't want to be like that.</b> Yes, and I feel that a lot of people just stay in their room. And they don't get out for breakfast at all, and they don't go, sort of thing, outside. And I think that's <b>very sad.</b> (Alice)</i>	Decline in identity			
<i>But the only thing I think that I get a bit sad about is just seeing the people being fed. And that worries me and I <b>hope it doesn't happen to me</b> and I <b>feel so sorry</b> for them. They can't do anything. (Gerry)</i>	Positive attitude	Positive attitude not-negotiable		
<i>I've seen that here with a lot of people, we've been here over the last 18 months, and we've seen it with a lot of people. They go back in <b>their own little world</b> there and they don't, they stay in their room most of the time and it comes to the point where they're still quite physically to be able to get around in among a group of people to get back into the mainstream of life. I'd imagine so. I can't, I don't know what other people feel like, but in my opinion it would be. If I was in that situation, <b>I don't think I could go that way.</b> (Leo - one of a couple)</i>	Think positive			
<i><b>You make the best of it.</b> Well, our attitude is that we've got our whole lives in front of us, innit? (Leo - one of a couple)</i>	Think positive			
<i>Well, I hope I have (a positive attitude). I look at it from all angles, that's what I say. <b>You have to.</b> Otherwise you couldn't live in it. You couldn't live in this environment if you didn't have patience. <b>Give and take,</b> that's what it calls for. Oh heavens, no, <b>it's not an easy world but,</b> then again, <b>you get there.</b> (Ruby)</i>	Be positive			
<i>Yes. You've <b>got to think positive.</b> (Isabelle)</i>	Positive, accept			
<i>I am a <b>positive</b> person. I say I realise what the situation is ... there are a lot of trained staff here who know what they're doing and they are very good to me. (Beryl - one of a couple)</i>				
<i>Yes, you've <b>got to have a positive attitude,</b> a happy attitude. It does (help). Well, there's a lot of other people <b>worse off</b> in here. When I came in here I was the only one who could get around and walk and talk to people. The others couldn't talk. No (it wasn't a shock), <b>I just accept it.</b> (Hyacinth)</i>				

Participant's stories/sentences	Key words	Emerging concepts	Sub-theme	Theme
<i>It is <b>upsetting</b> to see people decline. I don't allow myself to get close. And I <b>don't allow myself to get close</b> to anyone. Very few walk out. (Isabelle)</i>	Upset, avoiding closeness	Avoidance	3. Ageing	Resigned acceptance
<i>Before, in my lifetime, I was always very sociable. But I've grown more like <b>I'd like to be on my own</b>. I like my visitors, my friends to come in, because a lot of them, most of them (other residents) I think, are a lot younger than me here, and I don't know, maybe because <b>I have seen too much</b> of the dementia and that around (in the home). (Maude)</i>	Changed behaviour, avoiding others, confronting			
<i>I sort of, sort of, don't get out into the big room a lot. They said to me would I have my lunch out there when I come here. And I said, I said yes, I'll go out there if they all have their lunch out there in the big room, not all of them. And I went out there a couple of times, but I was sitting with all of those who weren't saying anything, they don't talk, I mean they can't help it. But they've got to be fed. So they feed them out there. Well, I <b>knocked off going out there</b>, I said "No, I didn't like sitting there. I'd rather have it here on my own." Yes. It <b>doesn't make me happy</b> seeing all them out there, I feel <b>sorry</b> for them, but I, but I don't like the look of it. No, no, I'm, I'm happy here, apart from that. (Nellie)</i>	Sorrow, changed behaviour, confronting			
<i>No. It's (living with dementia/palliative residents) a <b>very difficult position</b> to be in. Sometimes I take it, sometimes I don't. You understand me? I mean if I think they're being pushy, <b>I just tell them</b>. I say that's enough. (Pricilla - one of a couple)</i>	Invidious position	Upsetting emotions		
<i>As one of the nurses said to me the other day, and I think it was her son, he had to have his dog put down, he was, he was saying "They put a dog down when he gets too old or too ill, but these people are left here." And it's <b>terrible</b> when you've got to have a commode chair here of a night-time here, and you can't get out to the toilet, and they've got to have their bums wiped and everything, oh, and they <b>can't even tell you</b> that they want to go...and no, I reckon it's terrible. (Maude)</i>	Distress, upsetting, anguish			
<i>But this is it, I'm sure <b>nobody wants</b>, I'm sure you don't, want to <b>finish up in a nursing home</b>. It's just seeing people like that and a lot of them are younger than me, oh yes, which I didn't realise that. (Odie)</i>	Confronting, sad			
<i>Yeah, it <b>does get me down</b>, lying here, thinking things through. I don't know what, there's only me and another two who are normal. All the others are old, have got something the matter with them. Yeah. A lot of them, a lot of them just sleep, sleep all the time. No, no, no. (Kitty)</i>	Depressing, upsetting			
<i>I didn't think I'd end up in a nursing home, but ... I did, so. Oh, it's quite good. Been pretty good. Oh, occasionally, I <b>get a bit depressed</b>. I don't know (how to get over it), <b>I just have to</b>. Yes, <b>you're here to stay</b>. (Ruby)</i>	Depressed, resigned			

## Appendix I: Study questions

### Study Questions

#### *Opening questions*

- What is it like living here?
- What do you like most?
- What do you like least?

#### *Semi-structured questions*

- How were you welcomed when you first arrived here?
- Did you talk to other residents about living here before you decided to move in?
- Tell me about the staff?
- Did you feel that you are cared for?
- Tell me about your needs for assistance with getting in and out of bed, dressing and going to the bathroom; eating/food service?
- Is help readily available for these activities?
- Do you feel that your special needs are taken into consideration?
- Tell me about your health care and personal care services which are available for your specific needs?
- What types of activities and social events are available to you?
- Are you encouraged to participate?
- What are your favourite times?
- What are your least favourite times?
- Tell me about your room and the facility; daily life?
- Do you feel safe here?
- Tell me about privacy, independence levels, quality of life?

#### *Concluding questions*

- Is there anything you would like to change about your living environment and/or daily life?
- What are your overall impressions of nursing home life?