FORMAL CAREGIVING RELATIONSHIPS WITH YOUNGER RESIDENTS IN
VICTORIAN AGED CARE FACILITIES: A SITUATIONAL ANALYSIS

In partial fulfilment of the requirement for the

Doctor of Psychology (Clinical)

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Abstract

The occurrence of younger people living in residential aged care facilities has become a poignant topic of Australian political and social discussion. Though considered inappropriate, more than 6000 people under the age of 65 currently live in an aged care facility. This is due to limited alternative accommodation that can provide them with the level of care required. Once entering residential aged care, previous government funding for accommodation and/or disability support intended to maintain and enhance health, life, relational and care needs, ceases. Further, the aged care sector is neither created nor adequately funded to meet the unique needs of younger residents, resulting in poorer life quality for this group than their peers and other residents. Much of the fulfilment of a younger person’s life and relational needs that impact mental health and wellbeing, are often indirectly met through relationships formed with formal caregivers. Until now, formal caregiving relationships with younger residents have remained largely unexplored. This dissertation aimed to understand these relationships and to examine the barriers and influences that shape formal caregiving relationships with younger residents. Twenty-six formal caregivers and two managers from ten residential aged care facilities and two purpose-built facilities in Victoria were recruited and interviewed about their experiences working with younger residents. Employing a constructionist Grounded Theory Method (GTM), the transcribed data were inductively coded word-by-word and line-by-line along focused, axial and theoretical principles. Analytical categories were identified through the constant comparative method underpinning GTM. Situational Analysis using social worlds/arena maps and situational and positional maps, was employed to further broaden data analysis beyond descriptive categories and the concepts identified from coding alone. Exploration and analysis of the relationships between all human and non-human actors, the discursive and other elements, the groups of collectives, and the spoken and unspoken dialogues and debates within the Victorian residential aged care
sector, was undertaken. The findings from this process revealed that formal caregivers identify with younger residents because of similarities in ages, experiences, and the unique situational environment of a residential aged care facility. This identification both positively and negatively affects the quality of relationships formed. Though better able to identify and understand younger residents’ unique needs, formal caregivers are faced with systemic issues within the aged care sector that negatively impact their ability to meet those needs, and leaves them feeling powerless and helpless. Attempts to deal with these emotions often results in formal caregivers using strategies to minimize emotional connection, and diminish the relationship formed with younger residents. By understanding the obstacles and challenges of formal caregiving relationships, interventions that enhance these relationships can be created. In turn, this may improve the life quality of younger residents and their caregivers. This begins with firmly embedding the concept of the ‘therapeutic use of self’ within the formal caregiving role, both in policy and procedure, to better elevate and prioritize these relationships.
I would like to thank my supervisor, Dr Tess Knight for her review, feedback and suggestions for this thesis. You have provided me with much support throughout the duration of the Doctorate, and allowed me the freedom to pace the process, as I needed to. I am so thankful for your guidance and accessibility especially when difficulties arose. To Craig Olsson, who also assisted with the thesis, thankyou for your timely advice. To my mum, I am profoundly grateful for your encouragement and prayers that have saturated my life, especially over the past twelve years of study. I know the completion of the Doctorate in Psychology has long been your dream for me, and this achievement was made possible because of your faith, love and steadfastness. To my wonderful husband, Ian Cowan, who entered my life in a time of chaos and brought me the stability and security I needed to finish. You have been my rock and an endless source of love, comfort, support and encouragement. You were able to ‘dream my dream’ when I could no longer. We have not known a life together that has been “thesis-free”, and I am truly grateful for the sacrifices you made so that I could complete this course. Doxa Theos, the calling to be a counsellor when I was seventeen has finally been realised twenty-seven years later. I am humbled to have been chosen for this path, and though the journey has been horrendous, it has brought me healing to my innermost parts, and an unwavering hope for the future.

“all we have accomplished, you have done for us” (Isa 26:12)
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Chapter One: Dissertation Overview

In Australia, more than six thousand people under the age of 65 years of age currently live in residential aged care (RAC) accommodation, and around six-hundred of these residents are less than 50 years of age (AIHW, 2014b). Their placement into a RAC facility is due to disabilities and resulting complex care needs that cannot be properly met within a younger person’s own home (Winkler, Farnworth & Sloan, 2006). These disabilities are the result of a catastrophic brain injury such as an acquired brain injury (ABI) and traumatic brain injury (TBI), or a progressive and degenerative neurological disease including, neuromuscular disorders (such as muscular dystrophy), motor neurone disease, multiple sclerosis, Parkinson's disease and Huntington's disease (Parliament of Australia, 2015). Young people with intellectual disabilities such as Down Syndrome or severe autism can also enter RAC due to the advanced ageing or death of parent carers (Parliament of Australia, 2015).

Systemic government resource and funding issues within the disability and health sector has resulted in the care and accommodation needs of people under the age of 65 largely fulfilled by the RAC sector (SCARC, 2007). Unfortunately, the RAC sector was not intended to accommodate and provide care to this minority group of people. The unique needs and presentations of younger residents differ qualitatively to other aged care residents, requiring the development of a different set of formal caregiving skills, beliefs and knowledge (Parliament of Australia, 2007). Currently, Commonwealth legislation and policy fails to acknowledge the presence of younger residents in aged care facilities. This omission is against a back drop of systemic issues within the RAC sector. Collectively, this produces an environment in which many of the life and care needs of younger residents remain unacknowledged and unmet (Parliament of Australia, 2007; SCARC, 2007; 2015).

Much of the responsibility of meeting younger residents’ needs falls to formal caregivers to fulfil. Inevitably, some form of relationship often develops within this context of caregiving.
Research continues to affirm the value of positive relationships for enhancing quality of life, and in aiding in the coping of negative life events (Seligman, 2011; Song et al., 2015). For many younger residents though, entry to a RAC facility causes a loss in peer relationships and a diminished quality of life. The formal caregiving role is then uniquely placed to promote the quality of life of younger residents through the formal caregiving relationship. What those relationships look like, and what influences their development and continuation, is currently unknown. This knowledge may help shape the RAC sector to better support formal caregiving relationships with younger residents. In doing so, these relationships can become an effective conduit in the enhancement of younger residents’ quality of life, and better fulfil their unique life and care needs.

**Younger People in Australian Residential Aged Care: Causes, Consequences and Cures**

In Victoria, there exists two separate funding sources for the aged care and disability sectors. The Commonwealth provides funding for the aged care sector, while the Victorian government bears the costs of disability services. The existence of two funding sources has created a lack of integration between these two sectors, making it problematic for providing younger people with high care needs with more age appropriate supportive accommodation (Bigby 2008a; Bigby et al., 2008). The lack of alternative accommodation and a de-prioritisation in relocating younger residents already in an aged care facility hinders the movement of younger residents out of aged care (Fyffe, McCubbery & Honey, 2003).

Younger residents with high care needs are not identified in Commonwealth and state legislation, such as the Aged Care Act (1997), nor within governances directing the RAC sector. Subsequently, the complex presentation and care needs associated with younger residents remains poorly identified, under-represented and largely ignored within the RAC sector (SCARC, 2007; 2015; YPINH, 2015).
Any individual government funding allocated to meet the care needs of a younger person is unfortunately rescinded upon entrance into an aged care facility, with the aged care service provider being deemed wholly responsible for the provision of all aspects of care and support, including the meeting of life needs (YPINH, 2015). However, these facilities, which are designed to provide support and accommodation to older people who are typically frail and require ongoing nursing care (AIHW, 2012), are neither funded nor designed to meet both the care needs and the unique social and emotional needs of younger residents (Cameron, Pirozzo & Tooth, 2001; Stringer, 1999; Winkler et al., 2010).

Formal caregiving to younger residents is also qualitatively different than caregiving to older residents, and deficits in resources and skills further hinders attempts to meet younger residents’ life and care needs. The Australian Nursing Federation submission to the senate review on younger people in RAC acknowledged caregiving to younger residents requires specialised knowledge, and that aged care staff (nurses and formal caregivers) struggle to deliver quality care to both younger and older residents within a funding budget designed only for one group (Parliament of Australia, 2007).

Additionally, the senate inquiry also noted a lack of funding, chronic staff shortages, high turnover of staff and the use of agency or temporary staff typically negatively impacts younger residents, resulting in their care needs being overlooked. The lack of staff training to better aid formal caregivers’ capacity to meet complex care needs, and assess and address mental health and behavioural issues, further hinders the meeting of younger resident’s needs (Parliament of Australia, 2007).

The lack of clear distinction in both the Aged Care and Disability Service sectors regarding service provider responsibility to younger residents stymies policy reforms that may spawn interventions and programs that better provide for their life and care needs (Bigby et al., 2008). One such program that was initiated by the Australian government to address the issue of
younger people being placed into aged care facilities was the ‘Young People in Residential Aged Care’ (YPIRAC) initiative (DSS, 2014). Commencing in 2006 for a five-year duration, the initiative aimed to relocate younger people from aged care facilities, divert those at high risk of entering a RAC facility, and enhance delivery of disability services for younger residents who chose to remain in a RAC facility (DSS, 2014).

In a senate review, a joint study between the Summer Foundation and Monash University of the outcomes of the YPIRAC initiative, found around one quarter of young people utilised the initiative. This included 250 relocations from a residential aged facility, 244 diversions from entering the aged care, and 456 younger residents accessing enhanced services such as counselling or community participation (DSS, 2009; Winkler, Farnsworth, Sloan & Brown, 2011b). It was hoped ongoing funding would be allocated to continue the YPIRAC initiative; however, this has not occurred. According to the Australian Government’s Department of Social Services website, to date, there has been no other funding allocation for programs or initiatives designed for younger residents in an aged care facilities (DSS, 2014). However, it is hoped the National Disability Insurance Scheme (NDIS) may provide increased support to this minority group of aged care residents.

In July, 2013, the NDIS was launched (in stages) across Victoria (DOH, 2016). The NDIS is an initiative that provides targeted support, financial assistance and better access to services including information networks and referral pathways to individuals with a disability (such as those in aged care), their family or caregivers. It aims to better equip people with disabilities with the skills and capabilities needed to participate in employment and the wider community (DOH, 2016).

This is to be achieved through improved access to mainstream services such as health care, education, public housing, justice department and aged care systems, as well as community supports, including sports groups, libraries, charities and community groups (DOH, 2016). The
NDIS also seeks to enhance the continued involvement of informal support arrangement by providing families and caregivers with information, resources and referral networks (DOH, 2016).

The NDIS has been trialed around the country in various locations and regions and will be available to all people in Victoria with a disability by the end of 2019 including younger residents. Personal emails from the National Disability Insurance Agency (NDIA), an independent statutory agency responsible for implementing and overseeing the NDIS, confirmed their eligibility.

However, the email reflected an ambiguity regarding how the transition from one funding source to another will be undertaken. It noted “the specific transition arrangements for participants accessing HACC and ACFI funding are yet to be determined” (personal email received 23 December, 2015, ref # 28036). In follow-up phone calls, a representative from the NDIA spoke of the uncertainty of how the NDIS will impact younger residents in an aged care facility. The NDIA representative noted the transition between funding sources will be an ad-hoc process for this sub group of people, and that younger people with disabilities who currently live in a RAC facility have not been considered in the designing and application of the NDIS. Thus, the mechanics of the interface between the aged care system and the NDIS is yet to be determined, and as such, the impact on the lives of younger residents remains unknown.

While it is hoped the NDIS will have a positive impact on improving the lives of younger residents, political debate and social pressure continue to advocate for the development of more accommodation options. Until this occurs, it is beneficial to focus on utilising and maximising existing resources within the RAC sector, to better meet the care and life needs of younger residents. Once such resource would be the formal caregivers who provide younger residents with day-to-day care, and from which some sort of relationship inevitably develops.
Studies demonstrate that younger people who live or must enter a residential facility experience a deterioration to their quality of life compared to their pre-admission status. Social isolation (Winkler, Farnworth & Sloan, 2006), limited peer engagement (Winkler, Farnworth & Sloan, 2006; Winkler, Sloan & Callaway, 2007; 2010), a loss of existing independent living skills (Kelly & Winkler, 2007) and a lack of community involvement are a few of the challenges facing younger residents (Cameron, Pirozzo & Tooth, 2001; Winkler, Farnworth & Sloan, 2006). Other difficulties younger residents experience include a lack of privacy and personal space, lower levels of physical, cognitive and emotional stimulation, lack of sexual activity, and difficulty living with older residents (Cameron et al., 2001).

Some of these issues and difficulties negatively impact on the quality of a younger resident’s life, but these could be mitigated through the relationships developed with formal caregivers. The contribution personal relationships play in enhancing the health and wellbeing of people is well established (Song et al., 2015). Relationships can provide a stress-buffering effect to negative life events (Song et al., 2015), and promote positive emotional states such as a sense of purpose, identity and self-worth (Wills & Cleary, 1996). They can also provide a sense of belonging, and enhancement of social acceptance and inclusion. This in turn fosters self-esteem and positive affect (Myers, 1999). Therefore, the justification for the effective utilisation of a formal caregiving relationship with younger residents can be made.

Formal caregiving relationships are not developed in a vacuum, rather they are likely shaped by government and organisational policies. The formal caregiving role often directly facilitates any government initiatives or legislation introduced, such as providing direct assistance to a younger person when they engage in community activities. Formal caregiving relationships are also potentially shaped by individual formal caregiver characteristics, the environment in which they work and the individual needs and characteristics of residents.
As reflected in the Australian Nursing Association senate submission on younger people in RAC, a younger person’s presence in an aged care facility creates a differing care context which the formal caregiver must understand, adapt to and work within. Divergent life needs, less predictable individual decline of younger residents, and complex and differing care needs likely pose unique challenges to the formal caregiving role and ultimately formal caregiving relationships. This is not unlike other population groups commonly found in RAC. For example, formal caregiving to residents with dementia is associated with higher levels of stress and occupational strain (Brodaty, Draper & Low, 2003; Zwijsen et al., 2014) because of disruptive behaviours and displays of aggression (Schmidt et al., 2012; Zwijsen et al., 2014) and limited communicative ability (Edberg et al., 2008).

It is suggested the unique needs and presentations of those with dementia are qualitatively different to those of other aged care residents and that formal caregiving skills and knowledge may not be adequate to meet the increased demands associated with dementia care (Edvardsson et al., 2009). Similarly, the unique needs and presentations of younger residents are also likely to differ from other aged care residents and therefore the formal caregiving role and formal caregiving relationships, along with formal caregiving skills and knowledge base, e.g. with dementia care, may be inadequate.

**Thesis Overview and Chapter Outline**

**Thesis aims.** The intention of this dissertation is to understand formal caregiving relationships with younger residents in Victorian residential aged care (RAC) facilities. This will include identifying the similarities and differences in the provision of care between younger and older residents, as well as understanding the challenges and barriers formal caregivers face in developing a relationship with a younger resident. Gaining this understanding will be achieved in several ways. Firstly, an examination of Commonwealth and state legislation governing the
Victorian RAC sector, along with a synthesis of the characteristics of the Australian RAC worker will be undertaken. Understanding the laws which shape Victorian RAC, and the population characteristics of its workers will situate the formal caregiver within the socio-political arena and the individual world of the RAC sector. Secondly, a systematic review of the literature will be undertaken. This will highlight what is currently known about formal caregiving relationships, as well as identify any areas of paucity. Lastly, interviews with twenty-six formal caregivers and two managers caring for younger residents across ten RAC units, and two purpose-built facilities in Victoria will be undertaken. These interviews will be analysed using a Grounded Theory Method (GTM). The emerging themes from this data will be detailed, and Clarke’s (2005) Situational Analysis will then be applied to further extrapolate the interconnected world of formal caregiver, younger resident, and the aged care sector.

**Chapter outline.** This chapter detailed the current situation of younger people in Australian RAC facilities. It highlighted some of the socio-political issues affecting formal caregivers’ capacity to care for, and meet the needs of, younger residents. This chapter also overviewed both past and current Government initiatives designed to improve the quality of life, and the quality of care of younger residents. In the following chapter, Chapter Two, an overview of the Australian RAC sector will be detailed including examination of the current policies underpinning it. This will show that all current policies pertaining to the Victorian RAC sector omit key aspects relevant to caregiving within this context. This includes guidelines around the care of younger residents, acknowledgment of formal caregiving relationships within the aged care sector, definition of the formal caregiving role and inclusions regarding a ‘quality of life’ framework, which could aid and direct formal caregiving. These omissions create ambiguities and differences in the delivery of caregiving.

The remainder of Chapter Two will examine the characteristics of the Australian aged care worker. This exploration generates understanding of how the Australian socio-political arena
intersects with the individual formal caregiver and the world of RAC, to shape formal caregiving relationships. This is important as formal caregiving relationships are, at present, one of the few resources available that can be utilised to enhance the quality of life of younger residents.

In Chapter Three, exploration of the ‘quality of life’ of younger residents in aged care facilities will be undertaken. Beginning with ‘quality of life’ in general, and then more specifically ‘quality of life’ in a RAC setting, the current body of research will reveal that younger people, upon entering RAC, experience a significant decline in their life quality compared to their peers and other aged care residents, such as older residents. This research will also demonstrate how relationships are integral to quality of life, reinforcing the role formal caregivers may play in enhancing a younger resident’s life quality.

Though research emphasises the importance of formal caregiving relationships in the enhancement of life quality, these relationships remain constrained by organisational and governmental influences. To better understand formal caregiving relationships with younger residents, it is necessary to examine the current empirical literature. In Chapter Four of this dissertation, a systematic literature review will be detailed. This review will seek to answer the following questions; ‘What is the nature of formal caregiving relationships, and how are they defined?’, ‘What benefits to residents do formal caregiving relationships provide?’, ‘What are the barriers to the formation of these relationships?’, and ‘Which populations of residents have formal caregiving relationships been examined?’.

The systematic review of the literature will demonstrate that formal caregiving relationships with younger residents remains an area of research paucity. Chapter Five will then provide the justification and rationale for the examination of formal caregiving relationships with younger residents within a Victorian RAC setting. This chapter will detail the recruitment process of the twenty-eight participants, and the handling of the data, vis-a-vis, the resultant transcripts. This qualitative empirical research will employ Grounded Theory Method (GTM) to
 analyse the themes emerging from the data. GTM is a systematic theory generating methodology used in the examination of qualitative research, such as case studies and interviews (Glaser & Strauss, 1967).

Clarke’s (2005) use of Situational maps, Social World/Social Arena maps and Positional maps in Situational Analysis expounds GTM to provide a way of analysing deeper the complexities embedded within any given situation. The experiences of twenty-six formal caregivers and two managers will be examined through this analytic framework to detail the “major human, nonhuman, discursive, and other elements” (Clarke, 2005, p.56), along with their interactions and positions within the broad context of RAC in Victoria. The use of a Situational Analysis allows for unspoken dialogues influencing the RAC situation to be heard, along with providing a way to unpack and understand those situations, such as the care of younger residents, which are both complex and dynamic (Clarke, 2005).

Chapter Six is the first of three chapters that will provide the results from the Situational Analysis, examining of formal caregiving relationships with younger residents in Victorian RAC. This chapter will identify similarities in caring for younger and older residents. It will also reveal the struggles facing formal caregivers when caring for younger residents. Chapter Six will also explore interviewees’ beliefs regarding their role and what constitutes good caregiving. However, it will be shown the expression of these formal caregiving beliefs remains constrained by the situational context of RAC, which has embedded within it significant conflicts and issues, such as ‘managerial and workforce instability’, ‘caregiver neutrality’, the ‘burden bureaucracy’ and an ‘invisibility of the caregiving relationship’. For formal caregivers, the issues inherent in the Australian RAC sector stymie the expression of caregiving in a manner congruent with one’s caregiving beliefs, and in accordance with formal caregivers’ perceived role. Attempts to resolve this incongruence typically results in the de-prioritisation of relationship building and enhancing caregiving activities.
Chapter Seven will reveal that the incongruence between caregiving beliefs and perceived role, and caregiving action and the actual role formal caregivers undertake, is amplified when caring for younger residents. Chapter Seven will examine the caregiving differences of younger and older residents. It will highlight two significant caregiving differences. These include, ‘the ethical issue of younger residents in aged care’ and the impact of ‘identification’ with them. For most interviewees, the placement of younger people into such aged care facilities is deemed as inappropriate and ‘not good’ because of its impact on the younger residents, their family and friends, older residents within the aged care facility, and formal caregivers themselves. The presence of a younger residents in an aged care facility also elicits formal caregivers’ ‘identification’ with them. This identification is a motivator in facilitating formal caregivers to better meet the identified and preempted needs of a younger resident. But it also further facilitates incongruence and conflict between caregiving beliefs and actions.

Chapter Seven will reveal that for formal caregivers, this conflict produces intense negative emotional reactions within formal caregivers, including grief, anger, numbness, emotional disconnection, hopelessness, helplessness and despair. Their attempts to manage such emotions is often detrimental to job satisfaction, and the quality of care given. Negative emotions and the attempts to manage such feelings also affects upon the formal caregiving relationship formed with younger residents. Many formal caregivers note withdrawing from these relationships in order to manage distressing emotions. This relationship withdrawal reduces younger residents’ peer interaction, and inhibits the meeting of social and relational needs typically afforded through the formal caregiving role (Wilson, Seymour & Aubeeluck, 2011).

In Chapter Eight, the concept of identification detailed in the previous chapter, which highlighted its capacity to pre-empt and identify younger residents’ unique life needs, will be revealed as the catalyst for interviewees drawing parallels between their own life and the lives of younger people in aged care facilities. This form of identification is conceptualised within this
dissertation as the ‘shared world of paradoxes’ where both formal caregiver and younger resident identify as being the ‘same yet different’, and ‘visible yet invisible’.

Chapter Eight shows that both formal caregiver and younger resident remain thwarted in their capacity to obtain what is necessary for working or living in a manner congruent with existing beliefs and fundamental needs. This ‘same yet different’ paradox highlights that formal caregiver and younger resident both exist in an environment hostile to meeting their needs. In addition to the ‘same yet different’ paradox, formal caregivers and younger residents exist together in a shared world whereby both are ‘visible yet invisible’. Formal caregivers and younger residents are both highly visible within a RAC facility, yet both remain invisible and voiceless within government legislation and organisational policy.

In the final chapter, Chapter Nine, a synthesis of the findings emerging from the Situational Analysis examining formal caregiving relationships with younger residents in Victorian RAC facilities will be reviewed. This chapter will propose a caregiving model, in the form of suggestions, to enhance formal caregiving relationships with younger residents. These include the application of the ‘therapeutic use of self’ to the formal caregiving role, the adoption of a broad palliative care model to the RAC sector, and the prioritisation of formal caregiving relationships within legislation and organisational policy. The chapter will discuss the limitations of the Situational Analysis undertaken herein, and will conclude with suggestions for future research.
Chapter Two: Formal Caregiving in Australian Residential Aged Care Facilities

Though the focus of this dissertation is on formal caregiving relationships with younger residents, this does not occur in exclusion to caring for the older, nor does it occur within a vacuum. Therefore, to properly understand formal caregiving relationships with younger residents in Victorian residential aged care (RAC) facilities, it is necessary to identify the spheres of influence within the aged care world which shape these relationships.

In the first part of this chapter, an overview of aged care service provision in Australia will be detailed. This will be followed with an examination into the characteristics of the Australian formal caregivers who are pivotal to the delivery of aged caregiving. These characteristics include: the gender distribution of the workforce, the cultural background of formal caregivers, the degree of job satisfaction derived from the caregiving role, and the level of educational and skilling achieved\(^1\). Exploring these characteristics enables extrapolation of factors which may impede or enhance formal caregiving relationships with younger residents. Formal caregiving relationships are also likely shaped by the aged care environment itself. This environment is governed by Commonwealth and Victorian state legislation.

In the latter part of this chapter, a review of Commonwealth and Victorian RAC policies will be undertaken. Collectively, this will allow for an appreciation of how the socio-political world of the Victorian RAC arena interfaces with the formal caregiver to influence formal caregiving relationships with younger residents.

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\(^{1}\) Educational attainment, age, gender characteristics and income is taken from the Australian Bureau of Statistics derived from the Australian Census undertaken every five years. The last Australian Census took place in 2016. The information from the Census is analyzed over the following several years and broken into ‘Data Collections’, ‘Analytical articles’, ‘QuickStats’, ‘Community profiles’, ‘DataPacks’, and other interactive datasets covering a broad array of topics. Not all topic analysis reoccurs each Census period. This dissertation has endeavored to use the most recent Census details, however, not all information could be ascertained solely from the 2011 & 2016 Australian Census.
The Provision of Aged Care in Australia

In Australia, the needs of older people requiring assistance with activities of daily living (ADL) is met through several government care programs (DOH, 2013). These include community-based home care, RAC services, and a small number of flexible care programs which cater specifically for special groups or circumstances (i.e. Transition Care Program, the Multi-Purpose Services Program and the Veteran's Home Care Program) (DOH, 2013).

Residential aged care services. For many older Australians, the provision of community-based care is inadequate to meet all their care needs. In the 2013-2014 period, 137,948 people entered into a RAC facility to access ongoing 24-hour care. This was either as a temporary/respite stay (46.1%) or on a permanent basis (53.9%) (AIHW, 2014a).

These facilities provide basic accommodation related items and services, including beds, mattresses, linen, bedside lockers and chairs, general laundry and cleaning services, personal hygiene items, meals and fluids, maintenance of buildings and grounds, staff, and assistance with ADLs, such as eating, bathing, toileting, mobility and communication. In addition, RAC facilities also provide residents access to specialist support services (e.g. physiotherapy, occupational therapy, podiatry) and offer social engagement activities, both within the facility and in the local community (AIHW, 2012).

Currently, within the RAC sector, there are 2718 aged care service operators providing 186,278 beds (DOH, 2016). The Not-for-Profit sector, consisting of community-based, religious and charitable organisations, provides 60% of RAC services, followed by privately owned (30%) and then government owned (10%) services. This varies across states. Victoria currently has the largest proportion of privately-owned (40%) and government owned (24%) RAC facilities than all other states (DOH, 2016)

Aged care funding. Funding for Australian RAC facilities is primarily derived through Commonwealth monies (71%) paid to individual RAC service providers. 80% of
Commonwealth funding is derived through the Aged Care Funding Instrument (ACFI). This will be discussed in the following subsection. The remaining 20% of funding is delivered in the form of government aged care supplements. Care fees paid by the resident, as well as accommodation bonds upon entry into a facility, constitute the remainder of monies funding the Australian RAC sector (DOH, 2013).

**Assessment of aged care funding.** Australian government funding for residential aged care is allocated on an individual basis to the aged care service provider, based on a resident’s care needs. While in the past, residential facilities were deemed either low care (called hostels) or high care (labelled as nursing homes), introduction of the ‘Ageing in Place’ policy removed such labels. This allows an individual to remain in the same residential facility even when their care needs increase (AIHW, 2015). For the facility, a change in a resident’s care needs (from low to high care) attracts a higher government funding subsidy, paid to the service provider, to enable the facility to better meet these needs (DHS,

Determination of the subsidy an aged care service provider can receive from the government is derived through the ACFI. It is a resource allocation instrument, assessing the primary areas of need to distinguish the care requirements of each resident. The ACFI examines three care domains, namely, ADL (nutrition, mobility, personal hygiene, toileting and continence), behaviour (cognitive skills, presence of wandering, aggression and depression) and complex health care (comorbid diagnoses and use of medication), from which a score for each of the three domains is derived. (DHS, 2016). Each resident assessed is appraised as having nil, low, medium, or high needs along each of the three domains, with funding allocated accordingly (DHS, 2016)

**Evaluation of the Aged Care Funding Instrument.** The ACFI is not without its criticisms. Despite its attempts to match adequate funding to unique and often complex care issues which arise in a RAC facility, issues inherent in the ACFI impact upon aged care service providers,
staff and ultimately, residents alike. These issues are highlighted in a report on the ACFI system undertaken by Anglicare Australia (2010) and Alzheimer’s Australia (2010) on behalf of the Department of Health and Ageing. This report identified several key issues\(^2\). Firstly, documentation requirements, including duplication of information needed to complete the ACFI is regarded as detrimental to administrative efficiency, while the complexity of the assessment form generates disagreement between aged care providers’ appraisals of a resident’s care needs and the findings of departmental validators (Alzheimer’s Australia, 2010; Anglicare, 2010). The ambiguity with the ACFI User Guide, coupled with a lack of aged care service provider feedback into the rationale behind ACFI decisions regarding appraisals, particularly where they have been contested, further increases disagreement between aged care service providers and ACFI administrators. This produces longer delays in accessing needed funding (Alzheimer’s Australia, 2010; Anglicare, 2010).

Secondly, the complex needs of many residents, especially younger residents, and those with alcohol or other drug problems, mental health and other behavioural issues, or residents in the early stages of dementia, are not adequately represented in the instrument (Alzheimer’s Australia, 2010; Anglicare, 2010). The use of the ACFI has therefore become a disincentive for aged care service providers in accepting and providing care to individuals with care needs that do not attract the necessary funding. Anglicare (2010) notes that aged care service providers that do accept those individuals whose care needs are not adequately funded, face compromising their service viability and, in doing so, place additional burden on those primarily responsible for their caregiving, namely formal caregivers.

\(^2\) The submissions by Anglicare Australia and Alzheimer’s Australia did not contain a research methodology depicting how information was obtained. As such, this dissertation is unable to reflect upon the quality of these findings and recommendations.
Additionally, the rapid decline in functioning seen in residents with degenerative disorders necessitates a quick reassessment and adjustment of funding level to better meet the changing needs of the resident. However, the laborious nature of ACFI reassessment, coupled with the time delay in the allocation of funding, places more burden on formal caregivers and management in the interim period (Alzheimer’s Australia, 2010; Anglicare, 2010). In these instances, the funding level is often inadequate. This places additional strain on formal caregivers, management and other allied health professionals as they struggle to provide adequate care (Alzheimer’s, 2010; Anglicare, 2010).

Beyond issues with the funding level assigned, the ACFI fails to recognise and remunerate the use of enrolled nurses and allied health professionals often utilised in pain management and post-operative rehabilitation services. These services are commonly needed within the RAC sector (Alzheimer’s, 2010; Anglicare, 2010). The ACFI also fails to renumerate every form of caregiving which occurs in a RAC facility. The provision of emotional support, and consultation and counselling to residents and their family members, especially during transition periods (entry into aged care or end-of-life stage) or periods of resident’s decline, is not recognised or funded by the ACFI. Alzheimer’s Australia (2010) notes that for younger people entering RAC, the initial transition period along with the changing nature of their neurodegenerative decline, produces a complexity, diversity and variability of needs that often necessitates the type of care not currently recognised or remunerated by the ACFI.

Alzheimer’s Australia (2010) notes issues embedded within the ACFI frequently result in formal caregivers assuming surrogate roles, such as counsellors and advisers, in an attempt to alleviate the suffering of a resident and/or their family. This has a flow-on effect throughout the entire aged care facility with less staff availability and an increasing work load to be undertaken (Anglicare, 2010). Both Alzheimer’s Australia and Anglicare acknowledge ultimately, those who are employed in the caregiving role make decisions about which care needs can be met, and
which must be neglected. The impact of these decisions is widespread, affecting residents, their family, the formal caregiver, and the facility itself (Anglicare Australia, 2010; Alzheimer’s Australia, 2010).

**Summary.** In Australia, care of older residents and those with high care needs which cannot be met within an individual’s own home, is provided for by a range of aged care services, including RAC. The majority of funding for these services is derived from the Commonwealth government and distributed to aged care providers through the Aged Care Funding Instrument. The ACFI is not without its limitations. Disagreements in the assessment of resident’s needs, its onerous bureaucracy, and the lack of funding for the range of caregiving and services required in a RAC facility, all impact service provision. Inadvertently, residents and formal caregivers bear the consequences of ACFI’s limitations. Residents are less likely to receive the types of care they require, and formal caregivers have an increased workload as they attempt to meet these needs by assuming ancillary roles to the formal caregiving one. However, the flaws within ACFI are not the only influences shaping formal caregiving and the relationships formed between caregiver and resident. Within the RAC sector, both the workforce and the policies governing aged care provision also impact upon formal caregiving relationships. In the following section, an overview of the Australian aged care workforce will be detailed. This will be followed by an examination of Commonwealth and Victorian state aged care legislation.

**The Australian Residential Aged Care Workforce**

**The formal caregiving role.** There is currently no unified definition of a formal caregiver. Titles given for the formal caregiving role in Australia include; Residential support worker, disability support worker, personal care assistant, personal care worker, aged care worker, nursing aide, care service worker, and community service worker (FairWork Ombudsman,
Remuneration for the formal caregiving role falls under several Australian state government awards including:

- Social, Community, Home Care and Disability Service Industry Award (2010) [MA000100] and Charitable Sector, Aged and Disability Care Services (State) Award (2003) [AN120117].
- Social, Community, Home Care and Disability Service Industry Award (2010) [MA000100] and Social and Community Services Award [AN150140].
- Social, Community, Home Care and Disability Service Industry Award (2010) [MA000100] and Social and Community Services Employees (State) Award [AN120505].
- Social, Community, Home Care and Disability Service Industry Award (2010) [MA000100] and Community Services Award [AN 170020].
- Social, Community, Home Care and Disability Service Industry Award (2010) [MA000100] and Disability Support Workers Award (State) [AN140093].

Despite the differences in state government awards, and in the titles ascribed to the formal caregiving role, formal caregivers are employed to assist those people who are chronically ill, frail or those have a disability with ADL’s, physical mobility, therapeutic care needs and personal needs (Family Caregiving Alliance, 2014). This assistance typically occurs in either a home setting or within a residential service such as a residential aged care facility.

**Overview of the Australian aged care worker.** The Aged Care Workforce (ACW) (King *et al.*, 2012) report provides analysis into the characteristics of the current aged care workforce. The ACW report was conducted by the National Institute of Labour Studies, and based on data...
from the National Aged Care Workforce and Census Survey, administered to both residential facilities and community outlets, and individual aged care employees. In addition to the National Aged Care Workforce and Census Survey, individual interviews with aged care workers were also undertaken. Information from the census about residential facilities was supplemented with administrative data (postcodes, locations, facility ownerships and number of beds) provided by the Commonwealth.

A total of 8,568 employees from 2,481 facilities completed the survey. Additionally, 101 aged care workers, randomly sampled, were interviewed via telephone in a semi-structured format to gather qualitative data pertaining to the experiences of culturally and linguistically diverse workers, as well as emerging issues within the aged care sector. The ACW report estimates around 165,482 people are employed in a caregiving and/or health role within the RAC sector in Australia (King et al., 2012). Of these 165,482 employees, 16.5% are registered nurses (27,274) and 44% are either disability/aged care workers (35,105) or nursing support/personal care workers (37,930). The remaining employees (39.5%) are involved in counselling services, social work, teaching, managerial positions, welfare support, or specialised care3 (King et al., 2012).

**Income & working hours.** The ACW report (King et al., 2012) finds that formal caregivers on average have the lowest weekly earnings compared to employees across all other occupations. Formal caregivers typically earn around $27 per hour (including overtime and penalty rates) and work no more than 26 hours per week (King et al., 2012). This correlates to yearly incomes less than $37,000 (or $53,976 annual income for fulltime formal caregivers). This is lower than the average yearly income of $77,116 across all other industries (King et al., 2012).

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3 For the purpose of this dissertation, disability/aged care workers and nursing support/personal care workers have been grouped together as each of these roles involve predominantly instrumental caregiving (assistance with ADLs), with differences between the roles minimal. The collective group will be referred to as formal caregivers and any figures given will be the combined average of both of these groups.
The majority of formal caregiving work is part-time (68% of aged/disabled care workers, and 63% of nursing support/personal care attendants), which is a higher percentage than all other occupations in Australia, outside of the aged care sector (34%) (King et al., 2012). Just under half of all formal caregivers cite a preference to change their current working hours (King et al., 2012). These figures potentially explain why twice as many employees (10%) in the RAC (and the larger community service sector) undertake a second job compared to the national average (5%) (King et al., 2012). Consequently, formal caregivers typically cite poor financial remuneration for their role as their biggest job dissatisfaction, along with noting difficulties in coordinating two jobs because of shift inflexibility in their primary place of employment (King et al., 2012).

**Gender, age & ethnicity.** The ACW report (King et al., 2012) also notes that the aged care sector contains a disproportionate number of female formal caregivers (89%) to males (11%). This is significantly higher than the proportion of women in all other occupations (44%). Nearly one in four formal caregivers employed is aged either under 35 years of age (25%) or over 55 years (24%) with the average age of the formal caregiver being 48 years (King et al., 2012).

The ACW report (King et al., 2012) finds that one third of formal caregivers in the residential aged care sector identifies as culturally and linguistically diverse (CALD), with less than 2% from Aboriginal or Torres Strait Islander decent. Most CALD formal caregivers have been in Australia less than five years, and because of the language barrier many RAC facilities (40%) cite communication difficulties with other workers, management, residents and their families, as the number one issue impacting formal caregiving within their facility (King et al., 2012). Poor English language skills, as well as a lack of cultural knowledge about Australia, is seen by many CALD formal caregivers as a significant disadvantage to working within the aged care sector. Poor English language skills makes communication with residents difficult, and creates barriers to understanding training courses (King et al., 2012)
**Work/life balance & job satisfaction.** The ACW report (King *et al.*, 2012) notes achieving a satisfactory work/life balance is difficult for formal caregivers (DSS, 2012). A work/life balance is defined as the extent to which one’s working life negatively impacts upon one’s capacity to undertake tasks in one’s home life. Formal caregivers with children under the age of 18 report higher work-life interferences than their single counterparts or employees in other areas, as do formal caregivers in a part-time role. Additionally, formal caregivers who undertake education and/or training whilst also being employed, report higher than the national averages in difficulty engaging in activities and responsibilities outside of work (King *et al.*, 2012).

Despite difficulty obtaining a good work/life balance, the ACW report notes 85% of formal caregivers find their work satisfying, viewing their role as essential and a “reflection of their professional identity or their perception of themselves as being caring person” (King *et al.*, 2012, p.59). However, more than half of formal caregivers are dissatisfied with the amount of time they spend with residents, rating their level of dissatisfaction at 3.8/10. Formal caregivers also reflect the amount of respect and acknowledgement deserved for their role is inadequate, rating it a score of 4.8/10 (King *et al.*, 2012).

Formal caregivers also cite dissatisfaction (4.4/10) with the level of autonomy within the formal caregiving role (King *et al.*, 2012). This is problematic since research into nursing staff turnover has found role autonomy to be positively correlated with a sense of control, motivation level and job enjoyment (Hayes *et al.*, 2015; Squire *et al.*, 2015). When combined with the dissatisfaction in wages, a lack of perceived respect and acknowledgment of their role, as well as difficulty in achieving a satisfactory work/life balance, the formal caregiver faces many obstacles in the delivering of quality care.

**Education, qualifications and previous work experience.** According to the ACW report (King *et al.*, 2012), formal caregivers (66%) hold either a Certificate III in Aged Care, or Certificate III in Home and Community Care (7.7%). These are considered the minimum level of
certification. A further 20% have obtained a Certificate IV in Aged Care Work, Service Coordination (1.3%), Aged Care Nursing (0.6%) or other aged care certificates (13.1%). Around 16% of formal caregivers have completed only a secondary school education, and are yet to gain post-secondary qualification relevant to the aged care sector (King et al., 2012, p. 34). However, 76% engage in mandatory training with nearly half of the formal caregivers undertaking some form of continuing and professional development whilst employed in the RAC sector.

Unlike other occupational roles found in the RAC sector, formal caregivers are the largest proportion (15%) of workers with no prior paid employment experience. Around 33% of formal caregivers enter into residential aged care after leaving sales, hospitality, cleaning, clerical work, or other industries that required little-to-no post-secondary education. Only 15% acquire previous employment experience in either a health or social care setting (King et al., 2012).

While one in two formal caregivers stay in their role for more than ten years, only one in five will stay ten or more years within the same facility. Thirty-five percent of formal caregivers remain in their current facility for no more than four years (King et al., 2012). Research examining staff turnover in the RAC sector notes this has a deleterious impact on remaining staff and residents alike (Castle & Endberg, 2005). In Castle and Endberg’s (2005) study, 128 respondents completed a Likert-type survey of their job satisfaction, intention to leave and the impact on their role when new staff commence. The results showed more than half (63%) of the participants experienced significant adjustment issues and were negatively impacted by a facility’s loss of more than 25% of its staff. This turnover created an unequal distribution of care work for existing staff (when new staff began) and a loss in knowledge of residents’ needs, likes, dislikes and routines. This was considered detrimental to the standard of care residents received.

Summary. Central to the provision of aged care services are the formal caregivers, paid to meet many of the needs of residents in aged care facilities. In Australia, these workers typically earn less than other employees working in different fields (King et al., 2012). Poor remuneration
is one of the causes of formal caregivers’ biggest job dissatisfaction, along with their limited capacity to spend time with residents (King et al., 2012). Formal caregivers note that the burden of bureaucratic demands results in them having to prioritise non-care demands over one-to-one interactions with residents. Australian formal caregivers also perceive a lack of autonomy within their role and they report feeling devalued as a worker. Many formal caregivers believe the level of respect and acknowledgement shown to them is inadequate. Despite these dissatisfactions with aspects of formal caregiving, most workers find their role satisfying, and they regard their work as essential and meaningful (King et al., 2012).

However, the dissatisfaction formal caregivers cite about aspects of formal caregiving may be contributing to the high turnover in staff observed within the sector. This sees more than a third of formal caregivers change aged care facilities within a four year period (King et al., 2012). This has deleterious effects on the quality of care shown to residents, and hinders the formation of formal caregiving relationships (Castle & Endberg, 2005).

Formal caregiving in Australia is also a predominantly female based occupation in which many of its workers have a CALD background (King et al., 2012). Subsequently, language barriers are often cited by aged care facilities as the number one difficulty impacting care provision, with CALD formal caregivers regarding their communication difficulties as a serious impediment to formal caregiving work (King et al., 2012). The impact of staff turnover within the RAC sector, and the language barriers and communication difficulties experienced by many CALD workers, is likely to stymie the formation of formal caregiving relationships with younger residents.

Besides those influences stemming from various features of the aged care workforce, formal caregiving relationships are also likely to be shaped by the aged care environment itself. In the Victorian RAC sector, the aged care environment is governed by several key pieces of legislation. These include the Commonwealths Aged Care Act (1997), the Quality of Care
Principles (2014), and Carers Recognition Act (2012), as well as Victorian state legislation, the Supported Residential Service Act (2010). These important pieces of legislation will be reviewed in the following section.

**Policies Underpinning the Australian Aged Care Sector**

The Australian aged care sector, for which Victorian RAC services are subsumed under, are governed by extensive aged care legislation and policies. The examination of this legislation helps to situate Victorian formal caregiving within the broader socio-political context. This provides an insight into how caregiving work in Victorian RAC facilities, and formal caregiving relationships with younger residents, might be shaped.

There are several key pieces of legislation and numerous other subordinate policies that currently underpin the aged care sector. Over the years these policies have been superseded, amended or abolished to better streamline and facilitate the provision of quality aged care services (Federal Register of Legislation, 2017). As of the 28th June 2013, five Bills and sixteen pieces of subordinate legislation had been created to direct the aged care sector in Australia. See Appendix D for an overview of these key legislatives, and Appendix E for the core principles/objectives underpinning the entire Aged Care Act (1997).

While it is beyond the scope of this chapter to review all five aged care Bills and the sixteen subordinate pieces of legislation, the following Bills and subordinate policies are considered fundamental to the RAC sector and will be discussed in detail in the following sections; The Aged Care Act (1997), Quality of Care Principles (2014); and the (Victorian) Supported Residential Services (Private Proprietors) Act (2010). See Appendix F for an overview of the Supported Residential Services Act (2010). Also relevant, and will be examined, is the Carers Recognition Act (2012), which upholds the sanctity and importance of the care relationship between a resident and caregiver.
The Aged Care Act (1997). The Aged Care Act (1997) outlines the guidelines, rights, responsibilities and financial obligations of consumers, government, and aged care service providers within the Australian aged care sector (Federal Register of Legislation, 2017). At 444 pages in length, it has now undergone fifty-two amendments and revisions since its conception. The act is broken into eight chapters, including an introduction, preliminary matters in relation to subsidies, structure of fees and payments which can be charged, the responsibility of approved providers, access and use of funding from grants, administrative matters, and miscellaneous items.

Of particular relevance for this dissertation is Chapter Five of the Aged Care Act (1997), the ‘Responsibility of Approved Providers’ (Federal Register of Legislation, 2017). This chapter of the Aged Care Act details what approved aged care service providers must deliver. It also enforces the application of the Quality of Care Principles (2014) as a vehicle for the delivery of quality service provision (Federal Register of Legislation, 2016). The Aged Care Act (1997) (Federal Register of Legislation, 2017) states approved aged care providers are mandated to;

1. Ensure adequate numbers of appropriately skilled staff are available in order to meet the care needs of care recipients.
2. Provide care and services of a quality that is consistent with any rights and responsibilities of care recipients specified in the User Rights Principles.
3. Comply with the Accreditation Standards stipulated for each designated area of the aged care sector.
4. Provide quality of care based on the Quality of Care Principles outline in the Act

Quality of Care Principles (2014). The Quality of Care Principles (2014) set forth the standard and types of care and services (residential, community, or home care services) that can be offered and charged for by approved aged care service providers (Federal Register of Legislation, 2016). These principles are divided into six parts;
1. Residential Care Services – Responsibilities of Approved Providers,
2. Residential Care Services – Accreditation Standards
3. Residential Care Services – Care & Services
4. Home Care Services – Responsibilities of Approved Providers
5. Home Care Services – Care and Services
6. Home Care Services – Home Care Standards.

As this dissertation focuses exclusively on formal caregiving within a RAC facility, only the Residential Care Services section on Accreditation Standards and Care & Services will be explored.

Residential Care Services- Accreditation Standards. This section of the Quality of Care Principles (2014) sets forth the minimum guidelines in service provision which a service provider must achieve to remain registered (Federal Register of Legislation, 2016). The accreditation standards encompass four domains in aged care service provision, namely: management systems (including staffing and organisational development), care-recipient lifestyle, health & personal care, and physical environment & safety systems (Federal Register of Legislation, 2016). Relevant to formal caregiving relationships with younger residents are the stipulations and directives of both the management systems, and care-recipient lifestyle.

Management systems, staffing & organisational development. These guidelines seek to enhance the quality of care through improvement in service delivery. They indicate management systems and processes must be responsive to the needs of their residents, stakeholders and staff. Specifically, it charges service providers with the task of educating staff to maintain an appropriate number of skilled/qualified staff, and the utilisation of quality, externally sourced services, in the goal of achieving service quality goals (Federal Register of Legislation, 2016).

Care-recipient lifestyle. These guidelines endorse residents’ preservation of their personal, civic, legal, and consumer rights. It states residential facilities must enable residents to gain
active control of their own lives. This is to be achieved through the provision of emotional support in aiding an individual’s adjustment to residential care, ensuring the rights to privacy, dignity and confidentiality are maintained, and through encouragement of leisure activities. Residential facilities are also directed to accept, encourage, and foster residents’ individual, cultural and spiritual needs, and to facilitate their autonomy through independent decision making (Federal Register of Legislation, 2016).

Residential Care Services – Care & Services. The guidelines contained within this section of the Quality of Care Principles (2014) specifies the items a RAC facility must provide residents. These include: furnishings, bedding material, mobility aides, mechanical lifting devices, nursing services, and allied health therapy services (Federal Register of Legislation, 2016). In addition, service providers are mandated to also provide residents with the following services: assistance with ADLs, meals and refreshments, emotional support, treatment and procedures, recreational therapy, rehabilitation support, referral pathways to allied health professionals, and support for residents with cognitive impairments (Federal Register of Legislation, 2016).

Criticisms of The Quality of Care Principles (2014). The Quality of Care Principles (2014) provide service providers with only a general guideline of what constitutes good caregiving. It fails to offer specifics on what the achievement of these guidelines looks like. For example, support for residents with cognitive impairments, (Schedule 1, Part 2.9 of Quality of Care Principles) (Federal Register of Legislation, 2016) requires the provision of individual attention and the development of individual therapeutic activities and/or specific programs. This support is designed to “prevent or manage a particular condition or behaviour, and to enhance the quality of life and care” (Federal Register of Legislation, 2016, Schedule 1, Part 2.9). However, the Quality of Care Principles (2014) fails to detail which therapeutic activities or programs should be implemented, nor offer guidelines around managing and/or preventing conditions or behaviours.
The same absence of specifics is seen in the mandate upon service providers to offer ‘emotional support’ to residents the guidelines merely states facilities must provide “emotional support to, and supervision of, care recipients (Federal Register of Legislation, 2016, Schedule 1, Part 2.3). However, a description of what constitutes emotional support, or how emotional support is to be delivered (i.e., through a care program run by the facility, or from a formal caregiver, family member or management) is omitted.

The lack of clarity within the Quality of Care Principles (2014) creates problems in promoting and achieving these standards within the RAC sector. It also allows for the ‘handballing’ of responsibility from management to formal caregivers. This is especially problematic since many formal caregivers cite ‘lack of time to spend with resident’ as a major dissatisfaction within their role (Anglicare, 2010). The implementation of many of the guidelines stipulated in the Quality of Care Principles (2014) are undertaken by formal caregivers, such as ‘individual support to those with cognitive impairment’, assistance with ADLs, and recreational therapy. Subsequently, a limited availability of time for residents, makes it potentially difficult to fulfil all directives set forth in the Quality of Care Principles (2014).

Also problematic is the fact the Quality of Care Principles (2014), which are subsumed under the larger Aged Care Act (1997), are created and intended for older people only (Federal Register of Legislation, 2016). The Aged Care Act itself makes no reference to younger residents. This absence means their potential unique life and care needs cannot be addressed within the existing legislation. This makes it difficult operationalising and standardising the provision of care to younger residents in Victorian aged care facilities.

It is clear from examination of the Aged Care Act (1997), including the Quality of Care Principles (2014), that despite extensive guidelines there remains much ambiguity and omissions. While most of this ambiguity pertains to the specifics in operationalising government mandates, its glaring omission is the absence of younger residents. Perhaps also striking is the
lack of reference to, and description of, quality of life of residents. While health-related quality of life indicators can be found in initiatives employed within the sector to improve quality of care, mental-health quality of life (psychological health and wellbeing) are only superficially dealt with in the accreditation standards mandated in the Quality of Care Principles (2014) for Residential Care Services.

Despite calls for the care experiences of formal caregivers and residents to be included in the formation and operationalising of policy, this is yet to occur. Fundamentally, caregiving is a human relational process, and in RAC facilities, formal caregivers and formal caregiving relationships are central to the provision of care. Yet the formal caregiving role and formal caregiving relationships are not considered in caregiving legislation. Excluding the voices of both formal caregivers and residents, and the relational aspects of caregiving, reflects a lack of ‘humanisation’ within the aged care system. Humanisation is understood as valuing those aspects that make us human, with the recognition that humanising care emerges when these human aspects within caregiving are emphasised (Todres, Galvin & Holloway, 2009).

Todres et al. (2009) depict eight dimensions of care, which value those aspects that make us human. The eight dimensions “express a spectrum of possibilities that constitute ideal types” (p. 69) of humanised care. They include; “Insiderness/objectification”, “Agency/passivity”, “Uniqueness/homogenization”, “Togetherness/isolation”, “Sense-making/loss of meaning”, “Personal journey/ loss of personal journey”, “Sense of place/dislocation”, “Embodiment/reductionist body” (Todres et al., 2009, pp. 70-74). These eight dimensions of care will be described using references to RAC.

Todres et al. (2009) suggest that to be human is to possess an understanding of our own inner world, and how we make sense of our life. This is called “insiderness” (p. 70). In the legislation governing the Victorian residential aged care sector, the tendency towards diagnostic labelling (‘objectification’) of residents and their care needs can, at times, discount residents’ perceptions
and prioritisation of their own needs (p. 70). In the same way, argue Todres et al. (2009), both residents’ and formal caregivers’ sense of “uniqueness”, as key aspects of one’s sense of identity, are often minimised in the quest for “homogenization” of care and caregiving within the aged care sector. (p. 71). Homogenisation of care and caregiving encourage adherence to systematic and codified caregiving standards, as depicted in legislation, but which often ignore residents’ individual preferences, and hinder formal caregivers’ capacity to shape caregiving to meet residents’ unique needs.

The Victorian residential aged care sector also reduces residents’ “agency”, rendering them “passive” and unable to make choices concerning their own life and healthcare needs (p. 71). In much the same sense, Australian formal caregivers may be considered as having less personal agency within the caregiving context. The Aged Care Workforce report (DSS, 2012) identified formal caregivers’ dissatisfaction with the degree of autonomy within the formal caregiving role. Formal caregivers speak of having very limited freedom and flexibility, and therefore less “agency” to perform or schedule their duties and responsibilities during the work shift (DSS, 2012).

Though caregiving is deeply embedded in the human relational context, Todres et al. (2009) note health care systems can reduce an individual’s sense of ‘togetherness’ through community. This can generate feeling of ‘isolation’. Younger residents often experience a decline in peer friendships and have a diminished social network when entering a RAC facility (Winkler, Farnworth & Sloan, 2006; Winkler, Sloan & Callaway, 2007; 2010). The loss of these friendships and relationships is also likely a loss of the sense of “togetherness” and belonging. For younger residents, the limited capacity for developing new friendships within a residential aged care facility creates an environment in which they experience “isolation” (Todres et al., 2009, p. 71).
Younger residents also experience a “loss of meaning” (p. 72) to their lives through residential aged care compartmentalisation of their life into discreet categories of social and care needs, “private and public” lives, “concerns of the body and concerns of the mind”, rather than viewing younger residents needs holistically (Todres et al., 2009, p. 71). Todres et al. (2009) would argue that when a younger resident is provided caregiving in the same way care is provided to all older residents, this type of caregiving can fail to make sense to the younger resident. Todres et al. (2009) adds, “what is important statistically [or that which has been determined as best form of caregiving because it suits the majority] does not necessarily connect with the individuals [younger residents] human experience” (p. 72). In effect, the failure of Australian aged care legislation to acknowledge the presence of younger residents within RAC renders them as being part of the larger aged care population, rather than distinct from it.

The Victorian residential aged care sector can also hinder younger resident’s connection to their individual ‘personal journey’ and sense of self-continuation. Todres et al. (2009) conceptualise an individual’s “personal journey” as how we “move through time meaningfully…connected to the familiarity of the past”, while also being connected to the “unfamiliarity of the future” which offers the “possibility of novelty and something different” (p. 72). The routines of RAC limit a younger resident’s “possibility of novelty and something different” for the future (p. 72). The failure to recognise and value both the “history and future possibility” of the younger resident’s life diminishes their personal journey, while the focus on meeting the here-and-now needs of younger residents, can unwittingly emphasise “how the person is, [rather than]…who the person is” (p. 73).

The relocation of younger residents into RAC creates a sense of “dislocation” from the places and environments they considered meaningful, prior to living in an aged care facility, and which provided “security, comfort, familiarity, continuity and unreflective ease” (p. 73). Todres et al. (2009) add that connection to a sense of place can promote or hinder an individual’s sense of
wellbeing. Therefore, the spaces provided by RAC facilities can aid the humanising of care through the provision of “privacy, dignity, homeliness and hopefulness”, (p. 73).

The eighth dimension of humanised care, conceptualised by Todres et al. (2009), is the “embodiment/reductionist view of the body” (p. 74). A reductionist view of the body focuses on the fragility and diseased physical body, and ignores those aspects that make life worthwhile (p. 74). Embodiment, on the other hand, facilitates attention towards “[other] people, places and tasks in life” (p. 74), which brings meaning to life and fosters wellbeing. For residents of aged care facilities, the loss of capabilities and independence responsible for entering aged care are constant reminders of the frailty and the limitations of the human body.

The aged care sector’s use of health-related measures of care quality, and emphasis on ADLs, facilitates the prioritisation of the physical body’s role in residents’ wellbeing over those aspects that make life meaningful, such as relationships with others. The lack of humanisation within the RAC sector is evident in the failure of the Australian aged care legislation to include the voices of formal caregivers and residents’ experiences. The lack of humanised care is also seen in the failure of the legislation to capture the human aspects of care, especially formal caregiving relationships. Fundamentally, “human dimensions of care” upon which good caregiving is based have been eclipsed in the pursuit of improving health and wellbeing through “specialization” and “technological advances and research” (Todres et al., 2009, p. 68).

**Carers Recognition Act (2012).** Despite the absence of formal caregiving relationships within state and Commonwealth legislation, the importance of care-relationships within residential facilities remains recognised and extolled. In 2012, the Australian government inaugurated the Carers Recognition Act (2012) to recognise, promote, and value the role of people in care relationships (Federal Register of Legislation, 2010). This Act promotes a greater understanding of the significance of care relationships and seeks to identify the different needs of persons in care relationships. Its goal is to provide support to those relationships. The Act is
founded on the premise that care relationships benefit, not only the carer and recipient, but also the wider community (Federal Register of Legislation, 2010).

The Carer Recognition Act (2012) applies to public service care agencies, funded care agencies and any person or body that enters into a contract or funding arrangement with a relevant service care agency (Federal Register of Legislation, 2010). This includes the RAC sector. It stipulates a carer should be respected and recognised as having their own health and wellbeing needs, possessing specialist knowledge of the person receiving care, and be supported when the care-recipient care needs change. The Act also acknowledges carers should be recognised for their efforts and contribution, and have their own views taken into consideration in the delivery and management of care services to the care recipient (Federal Register of Legislation, 2010).

The Carers Recognition Act (2012) also acknowledges the fundamental importance of relationships between resident and informal caregiving systems in care services and agencies. However, the Act is only for those who are not “under a contract of services or the provision of services; or under an employment contract; or in the course of doing voluntary work for a community organization; or as part of the requirements of an education course or training” (Federal Register of Legislation, 2010, Part 1.4).

The importance of the relationship between a care-recipient, and their informal care network of friends, children, spouses and siblings is to be acknowledged and promoted, yet the lack of recognition in government policy about formal caregiving relationships with residents is disconcerting. In the subsequent chapters, it will be argued that formal caregiving relationships should be acknowledged and enhanced as these relationships are fundamental to promoting care quality and in enhancing the quality of life of residents and formal caregivers. This dissertation will also contend this is especially true and necessary in the context of formal caregiving of younger residents in an aged care facility.
Residential Aged Care in Victoria

For this dissertation, examination of formal caregiving relationships with younger residents is limited to aged care facilities in the state of Victoria. It is important then to understand the socio-political arena of the Victorian aged care sector, which, unlike most Australia states (except Western Australia), is funded jointly by both state and Commonwealth monies. Funding for RAC services continues to be assessed and distributed through ACFI.

Currently, there are 770 Victorian RAC facilities in operation (AIHW, 2017). Four hundred and twenty-five facilities are owned and run by various not-for-profit, community and/or charitable organisations (AIHW, 2017). These facilities receive 70% of funding through the Commonwealth government, with the remainder made up from residents’ fees, grants, and accommodation bonds (AIHW, 2017). Not-for-profit, community and/or charitable organisation-run residential facilities are registered with the Victorian state government and are governed by both state and Commonwealth legislation. These facilities must comply with the standard of care operationalised in the Aged Care Act 1997 as well as legislation by the Victorian government.

The remaining residential aged care facilities are owned and managed by either the Victorian government (known as Public Sector Residential Aged Care Service - PSRACS) or private-operators. In total, 200 facilities are operated by the Victorian state government and the remaining 145 facilities are privately owned and managed (AIHW, 2017). These facilities are known as Supported Residential Services (SRS) (AIHW, 2017). Both PSRACS and SRS will be reviewed in the following sections.

Public Sector Residential Aged Care Services (PSRACS). Unlike most other State Governments throughout Australia, the Victorian government remains a major provider of RAC services. Public Sector Residential Aged Care Services provide facilities which cater to small rural communities and to population groups with specialist care needs that are not being met by
other residential care providers (AIHW, 2017). All PSRACS are operated under the public health service, which also manages and directs acute health services and programs. As part of their governing responsibilities, the Board and executive management of Victorian health services also oversees RAC services. Therefore, operational governances, including quality outcomes for aged care residents within a PSRACS facility, are a combination of policies and legislation, including the Victorian Residential Aged Care policy (2009), Victorian Health Services Act (1988) and ACFI (DHS, 2016).

While all Australian aged care facilities continue to be funded, regulated and must meet accreditation standards as determined by the Commonwealths Aged Care Act (1997), in Victoria the interplay between the State and the commonwealth adds a layer of complexity in governances and legislation not witnessed in other states. The Victorian Department of Health states, “the importance of the operational context of PSRACS across Commonwealth and State jurisdictions cannot be overstated, as it impacts on the approaches adopted by health services operating PSRACS in driving safety and quality” (Australian Government, 2013, page not specified).

For PSRACS which are managed and directed under the banner of Victorian health services, aged care quality systems have developed differently and not to the same extent as those within the wider health sector. While quality improvement in Australian RAC services are typically adapted from the acute health sector, their implementation is driven by aged care accreditation, which requires a different approach. At the state level, the Victorian Government Department of Health ‘Beyond Compliance’ initiative aims to improve quality and safety in PSRACS.

‘Beyond Compliance’. The Victorian governments ‘Beyond Compliance’ initiative is designed to improve mandates and regulations contained within the ‘Quality of Life Principles (2014)’, a subsection of the Aged Care Act (1997). The ‘Quality of Life Principles’ are considered the minimum standard for residential services, and the ‘Beyond Compliance’
initiative provides the framework for improving quality and safety within PSRACS. This is achieved through initiatives targeting four areas: ‘governance, risk management & performance improvement’, the development of tools and resources designed to enhance quality and safety of aged care facilities, the provision of specialist advice and support for staff and management, and education and training. These initiatives include: targeted educational activities, development of quality of care indicators, the inception of the Residential Aged Care Coronial Communiqué and ‘SCORE’, standardised clinical processes to meet residents common care needs.

**Education and training initiatives.** Improvements to education and training within PSRACS have seen the implementation of educative and/or training programs. These include a comprehensive health assessment of the older person; Dementia forums; Use of quality indicators for improved resident outcomes; Plan to act emergency management; Accreditation forums; Infection control; and Crisis prevention. Due to the newness of these training programs, there is no information available detailing their effectiveness in improving the quality of care within Victorian residential aged care facilities.

**Tools, resource & performance improvement initiatives.** Due to declining health and increasing frailty, older residents are often prone to falls, fractures, and pressure ulcers. The frequency of these occurrences is used as an indicator into the quality of care being provided within a facility. The Campbell Research & Consulting group was appointed by the Victorian Department of Health to develop realistic and achievable limits around the occurrences of key health related issues. These include the incidences of: pressure ulcers, falls and fall-related fractures, use of physical restraints, use of nine or more different medicines, and incidences of unplanned weight loss. Four other health related issues are yet to have a reference range determined. These include incidences of depression, dental issues, behaviours of concern, and use of pain management strategies (DHHS, 2015).
The ‘Residential Aged Care Communiqué’. The ‘Beyond Compliance’ initiative also funded the Victorian Institute of Forensic Medicine to publish a quarterly Residential Aged Care Coronial Communique. This free electronic publication (e-newsletter) contains narrative case reports detailing findings and recommendations from the Coroners’ investigations into preventable deaths in Victorian RAC facilities. Each edition focuses on a single theme and provides commentaries from a recognised expert, about optimal clinical practice (Victorian Institute of Forensic Medicine, 2017). All editions can be accessed through free subscription.

Strengthening Care Outcomes for Residents (SCORE). The final initiative of ‘Beyond Compliance’ was the development of standardised care processes to improve quality outcomes for residents (DHHS, 2012). The SCORE initiative helps residential facilities address health risks to residents in a consistent manner. These risks include: abuse, infections, constipation, medication management, delirium, dental needs, diabetes management, pain, depression, palliative care, falls, skin integrity, functional decline, sleep problems, hydration and nutrition, swallowing difficulties, incontinence, unmet needs behaviour (DHHS, 2012).

Currently, standardised care processes have been developed for constipation, polypharmacy, physical restraint alternatives, response to hypoglycaemic episodes, weight loss (unplanned), depression, choking, delirium, dental and oral hygiene and dehydration. However, the SCORE initiative does not indicate how standardisation of these care processes arose, nor provides evidence justifying what is considered ‘best practice’. This is noted in the Department of Health and Ageing (2008) report, evaluating the impact of accreditation in the delivery of quality of care, and Victoria’s Department of Health (2009) review of the use of SCORE and clinical care indicators in improving care quality.

Criticisms of the ‘Beyond Compliance’ initiative. Absent from the ‘Beyond Compliance’ initiative is recognition and incorporation of residents’ experiences of care. Also missing is the role of formal caregivers in achieving better resident outcomes. This is despite such aspects of
care being assessed in performance reviews of PSRACS facilities. In 2015, the Australian Government (2015) devised ten clinical care indicators to measure the quality of PSRACS facilities, of which both resident and formal caregiving experiences were deemed important measures in the assessment of care quality. The other clinical care indicators included: incidence of pressure ulcers, incidence of new fractures as a proportion of falls, incidence of daily physical restraints, incidence of residents using nine or more different medications, incidence of weight change (i.e., a significant increase or decrease from the norm), prevalence of symptoms of depression, incidence of behavioural symptoms, and health-related QOL of residents (Australian Government, 2015).

The first five clinical care indicators (incidence of pressure ulcers, new fractures, daily physical restraints, use of nine or more different medications and weight changes) are utilised as measures in the assessments of care quality throughout all of Victorian RAC services (DHHS, 2012). The other indicators are yet to be formally operationalised. However, behavioural symptoms, which are reflected in ACFI subsidy levels, and the use of health-related QOL instruments to inform care practice are also utilised, though unofficially (Department of Health, 2009).

**Privately-owned residential aged care services.** In addition to the PSRACS and not-for-profit and/or charity owned residential facilities, Victoria has around 145 privately-operated aged care facilities. These are known as Supported Residential Services (SRS) and provide accommodation and support to the aged or those with care needs unable to be met through home-based care. Being privately-operated, SRS differ to facilities run by the Victorian government or not-for-profit organisations. Their primary difference is evident in the range and quality of services provided, the fees charged, and the diversity of people being accommodated.

Though SRS are privately-operated services, they must be registered with the Victorian government and are required to achieve the same mandated standards in personal support and
accommodation as provided in PSRACS facilities. They must also abide by the dictates set forth

Supported Residential Services (Private Proprietors) Act (2010). The Supported Residential
Services Act (2010) comprises of twelve parts, the details of which can be found in Appendix F.
The purpose of the Supported Residential Act (2010) is to provide a registration regime for
privately-operated aged care facilities and to indicate the minimum standards in service provision
and personal support to be offered to residents (Victorian Government, 2010).

This legislation sets out the obligations of operators, and seeks to ensure the safety and
wellbeing of residents living in these facilities (Victorian Government, 2010). The Act advocates
that residents should enjoy the same rights and freedoms as other members of the community,
including: privacy, freedom of expression, fair and equal treatment, dignity and respect, right to
participate in activities involving a degree of risk, and freedom from abuse, neglect or
exploitation (Victorian Government, 2010). It also mandates that private operators support
residents to live as independently as possible, recognising their right to make decisions, and their
need to have information provided that assists such decision making (Victorian Government,
2010).

Unlike the Aged Care Act (1997), the Supported Residential Services Act (2010) does
specify staffing minimums and personal support standards. It states there must be at least one
personal support worker on duty, who is trained in the administration of first aid, for every thirty
residents (Victorian Government, 2010). Each facility must also have a personal support
coordinator who is responsible for the coordination and continuity of the personal support
provided to residents (Supported Residential Services Act, 2010, p. 35).

The Supported Residential Service Act (2010) also mandates personal support workers and
personal support coordinators must hold one of the following qualifications: Certificate III in
Aged Care; Certificate III in Home and Community Care; Certificate III in Disability; Certificate
Conclusion

This aim of this chapter was to locate the formal caregiver within the context of the Victorian residential aged care sector, to understand how influences within aged care may shape formal caregiving relationships with younger residents. In an overview of the Australian aged care workforce, it was revealed that formal caregivers are poorly renumerated compared to other occupations, and they have difficulties achieving a good work/life balance. Formal caregivers also cited their two biggest dissatisfactions within the formal caregiving role are: the limited amount of time spent with residents, and the perceived lack of respect from management and nursing staff. However, many formal caregivers view their work as personally meaningful, but the difficulties and dissatisfactions within the role is likely a contributory factor in the high turnover of staff seen in the aged care sector. Staff turnover within RAC is potentially detrimental to the development of formal caregiving relationships with younger residents.

In the examination of Australian aged care legislation, several oversights were identified which are potentially influential on formal caregiving relationships with younger residents. The review of the Aged Care Act (1997), Quality of Care Principles (2014) the Victorian Supported Residential Act (2010) and ‘Beyond Compliance’ initiative exposed ambiguities and omissions that impact service provision, care delivery, and ultimately those within the aged care system.

Specifically, Australian aged care legislation fails to recognise and utilise quality of life attributes as a benchmark guiding care provision. It also lacks a definition for the formal caregiver role, and fails to formally conceptualise and acknowledge formal caregiving
relationships. Consequently, the formal caregiving role and formal caregiving relationships remain deprioritised within policy and in aged care operation. This minimises the capacity of these relationships, and the formal caregiving role to promote resident wellbeing, and enhance their quality of life. In the following chapter, quality of life within the context of RAC is explored, and the link is made between formal caregiving relationships, residents’ quality of life, and the provision of quality care.
Chapter Three: Life Quality in Residential Aged Care Facilities

As was discussed in Chapter Two on the review of Australian aged care legislation, quality of life is only superficially used and acknowledged, with mandated standards in care based primarily on health-related quality of life indicators. However, quality of life is much broader than just health-related issues, and is incorporated into policy considerations, directing governances in fields of sociology, philosophy, politics, education, psychology and healthcare (Schalock, 2004).

Gaining momentum in the 1980s, in response to an ageing American population and concerns over treatment outcomes in care, quality of life has spawned much research (Guyatt, Feeny & Patrick, 1993). Once defined through objective measures (education, employment, housing and income level), quality of life has now developed into an extremely broad, multifaceted notion encompassing more subjective concepts, including psychological wellbeing, life meaning, physical and spiritual functioning, connectedness to others, and life satisfaction (Mandzuk & McMillian, 2005; Rajovic & Bulatovic, 2016; Seligman, 2011; Slavuj, 2012). However, there is little consensus on what constitutes ‘quality of life’ within the academic world, with researchers and authors alike adopting various definitions (Ilić, Milić, & Arandelović, 2010; Milivojević et al., 2011; Rajovic & Bulatovic, 2015; Vallerand & Payne, 2003). This lack of consensus impacts the formation of a comprehensive ‘Quality of Life’ theory, which in turn, creates difficulty in both its operationalising, measurement and future research applications (Roop, Payne & Vallerand, 2011).

In this current chapter, quality of life in residential aged care (RAC) will be explored and a definition of quality of life proposed. Following from this, the quality of life of residents, including older and younger residents will be examined. This will identify those factors which research shows to enhance and diminish residents’ quality of life.
Defining ‘Quality of Life’.

The concept of ‘quality of life’ encompasses multiple life and social domains with emphasis on certain elements often contingent on the academic disciplines utilising the concept (Oort, Visser, & Sprangers, 2005). For example, quality of life within the field of economics was previously determined solely through objective measures of wealth, which typically excluded subjective ratings of individual happiness and satisfaction in life (Foregeard et al., 2011; Stiglitz et al., 2009). Within the medical sciences, the focus of quality of life research is often on the absence of physical disease symptomology, usually determined through self-report assessment measures including subjective ratings of pain or distress (Karimi & Brazier, 2016;). In the social sciences, quality of life is a broader concept, encompassing notions of subjective wellbeing and overall life functioning as well as objective measures of wealth, educational status and health (Cummins et al., 2003; Deiner et al., 2003; Foregeard et al., 2011).

For the purpose of this dissertation, quality of life as conceptualised within the social sciences field of clinical psychology will be utilised. While there is no current universal definition for quality of life adopted within clinical psychology, several researchers have contributed to a broader understanding. These include: Diener et al. (2000a; 2000b; 2003), Frisch (1994; 1998; 2006), Headey et al., (1993) and Seligman (2011). In Diener and Suh’s (2000a, 2000b) view ‘quality of life’ as a combination of subjective wellbeing (an individual’s beliefs and emotional responses to their life quality) and objective social indicators including health, wealth, ecology, human rights, and education. Collectively, Diener and Suh (2000a; 2000b) posit subjective wellbeing and social indicators may better conceptualise what constitutes ‘quality of life’ (Diener & Suh, 1997).

Headey et al. (1993) also utilise a notion of subjective wellbeing which they define as a combination of “life satisfaction, positive affect, [and the absence of] anxiety and depression” (p. 63). However, Headey et al., (1993) contends personality traits and the impact of major life
events (such as, marriage, childbirth, divorce, and retirement) also contribute to an individual’s experience of quality of life.

Frisch (2006), developer of ‘Quality of Life Therapy’, an intervention designed to enhance life satisfaction, holds that quality of life is the level of life satisfaction one has gained through the achievement of valued goals and the fulfilment of one’s wishes and needs in life. Similarly, Seligman (2011, p. 58) also notes the importance of achieving goals in attaining quality of life. He conceives ‘quality of life’ as a combination of subjective wellbeing (presence of positive emotions like joy, pride, and excitement), engagement in activities of interest, connection to others like family, friends and colleagues, meaning and purpose in life, coupled with accomplishments that generate a sense of success and mastery.

From these contributors, several themes emerge providing us with a number of factors associated with ‘quality of life’. These themes include subjective wellbeing, which incorporates notions of life satisfaction and affective evaluation (individual appraisal of one’s emotions and mood), meaning in life, and connection to others. Both subjective wellbeing, meaning in life and connection to others will be examined individually and a tentative definition of ‘quality of life’ will be given at the conclusion of this section.

**Subjective wellbeing.** Subjective wellbeing, like ‘quality of life’, cannot be easily defined within a singular concept, but instead is understood as the level of overall life satisfaction derived from one’s experiences of work, relationships, leisure activities, goals, and hobbies (Diener et al., 2000a; 2000b; 2003; Headey, et al., 1993; Seligman, 2011). The concept of subjective wellbeing also includes the cognitive appraisal and emotional responses to these various aspects of life. Therefore, the combination of life satisfaction and the relative frequency of positive and negative affect from experiences derived from life (work, relationships, hobbies etc.) perhaps best explains the concept and an individual experience of subjective wellbeing (Clark, 2015; Diener et al., 2003; Steptoe et al., 2015).
Because of its emphasis on the subjective nature of experiences in life, formal academic measures of subjective wellbeing often omit factors such as health status (Diener et al., 2003; 2000). However, health issues, along with other factors, impact upon a person’s experience of subjective wellbeing. These factors include innate personality traits (Steel et al., 2008) and the quality of leisure activities engaged in (Hribernik & Mussap, 2010). In the following section, the impact of health status, personality traits and the experience of leisure quality upon subjective wellbeing will be explored in more depth.

**Health & subjective wellbeing.** Despite the fact that health items are often omitted from formal academic measures of subjective wellbeing, the relative health of a person is correlated with their perception of subjective wellbeing. In Steptoe, Deaton and Stone’s (2015) meta-analysis, 35 studies examining subjective wellbeing, health and ageing published between January 2000 and March 2012, and data from the Gallup’s World Poll from 2006-2010 were analysed together.

The Gallup’s World Poll commenced in 2006, and since its inception has been annually surveying people from 160 countries. This represents 98% of the world’s population. The Gallup World Poll data is derived from telephone interviews among high income world regions, and through face-to face interviews elsewhere. In total, 1000 people from each country are randomly selected to participate. Steptoe et al. (2015) suggests the Gallup Poll is a valid source of data from which to derive correlations such as health, age and subjective wellbeing since it uses pretested questions to restrict method bias, undertakes consistent yearly interviews, and ensures a random selection of participants.

The results from the meta-analysis undertaken by Steptoe et al. (2015) found a wide range of health related issues to be correlated with the increased prevalence of depression and decreased reports of subjective wellbeing (p. 6). Steptoe et al. (2015) found the presence of chronic pain,
cardiovascular disease, diabetes, coronary heart and/or lung disease, cancer, rheumatoid arthritis and chronic kidney disease decreased an individual’s life satisfaction and their emotional/mood state. In individuals afflicted with more than one of these conditions, subjective wellbeing progressively declined as comorbidity increased.

However, the correlation between health and subjective wellbeing may be bi-directional with increased subjective wellbeing being a protective factor for health. In Chida and Steptoe (2008), meta-analysis of 35 epidemiological studies, positive psychological wellbeing, including increased life satisfaction and reports of positive emotions, was correlated to reduced mortality in both healthy and disease populations. The experience of joy, happiness, energy, emotional well-being, positive mood and “positive trait-like dispositions (e.g., life satisfaction, hopefulness, optimism, sense of humor)” (p. 750) was associated with reduced mortality in healthy populations especially death from cardiovascular issues. Positive psychological wellbeing was also positively correlated with reduced rates of mortality among people with human immunodeficiency virus-infection or kidney disease.

Both Chida and Steptoe (2008) and Steptoe et al. (2015) meta-analyses suggest health status is correlated to subjective wellbeing, with this relationship being bi-directional (Chida & Steptoe, 2008). But research also indicates several other factors impact upon a person’s assessment of their subjective wellbeing. These factors include personality traits and leisure activities (Hampson & Goldberg, 2006; Hribernik & Mussap, 2010; Steels et al., 2008).

**Personality traits.** Personality traits are stable qualities or characteristics which, together, form an individual’s personality (Costa & McCrae, 1992; Eysenck & Eysenck, 1985; Eysenck, 1997). These traits are considered innate and often genetically or biologically determined (Eysenck & Eysenck, 1985) and include many characteristics, such as openness to experience, extraversion, agreeableness, conscientiousness, neuroticism, self-esteem, harm avoidance, perfectionism, novelty seeking, alexithymia, rigidity, disinhibition, impulsivity, psychoticism
While differing between individuals, personality traits are relatively stable over time, unlike ‘states’ which are more temporary dispositions, and have the capacity to impact behaviour (Lynam et al., 2005; Costa & McCrae, 1990).

Theories of personality typically define traits in terms of characteristics an individual either has or does not have, or else regards traits as falling somewhere along a spectrum of traits (extraversion verses introversion) (Costa & McCrae, 1990). The idea that traits are dimensional has spawned the Big-Five model of personality (Five Factor Model) which identifies Openness To experience, Extraversion, Agreeableness, Neuroticism And Conscientiousness as the traits forming the basis for personality (Digman, 1990). These five personality traits have been examined and researched extensively, including their correlation to quality of life and subjective wellbeing (Richard & Diener, 2009; Specht et al., 2011; Steel et al., 2008).

In the Steels et al. (2008) meta-analysis, the authors sought to determine the correlation between subjective wellbeing and the ‘Big-Five’ personality traits; Extraversion, Agreeableness, Conscientiousness, Neuroticism and Openness to experience. Steel et al. (2008) surveyed 1,177 published articles, book chapters, and masters and doctoral dissertations which had examined personality and subjective wellbeing. In total, 249 published articles, book chapters, and masters and doctoral dissertations were deemed usable because of their inclusion of an effect size (t score, d score, or F score), and use of either the ‘Neuroticism, Extraversion and Openness to Experience Personality Inventory’ (NEO-PI-3) (McCrae & Costa, 2010), Eysenck Personality Questionnaire (EPQ) (Eysenck & Eysenck, 1975), or the Eysenck Personality Inventory (EPI) (Eysenck & Eysenck, 1964).

The Steel et al. (2008) meta-analysis found that 39% of the variance or 63% disattenuated in subjective wellbeing could be accounted for by the personality traits measured through the NEO-PI-3. Specifically, Neuroticism was identified as the strongest predictor of subjective wellbeing,
especially for negative affect ($\rho = .64, k = 73, p < .0001$), happiness ($\rho = -.51, k = 6, p < .0429$), overall affect ($\rho = -.59, k = 15, p < .0001$), and quality of life ($\rho = -.72, k = 5, p < .0133$). Individuals who identified as being more neurotic, defined as a greater tendency towards moodiness, anxiety, guilt, envy, anger or lowered mood, reported higher levels of negative emotions and lower quality of life than individuals who were not identified as neurotic. Similar correlations were also seen with the EPQ (negative affect ($\rho = .69, k = 33, p < .0001$), overall affect ($\rho = -.63, k = 12, p < .0432$), quality of life ($\rho = -.64, k = 10, p < .0001$), and happiness ($\rho = -.52, k = 32, p < .0001$), and the EPI (negative affect ($\rho = .54, k = 23, p < .0001$), life satisfaction ($\rho = -.42, k = 12, p < .005$), overall affect ($\rho = -.51, k = 7, p < .0001$), and happiness ($\rho = -.40, k = 5, p < .0111$).

On the NEO-PI-3 measure, the personality trait of Extraversion was positively correlated with positive affect ($\rho = .54, k = 53, p < .0001$), happiness ($\rho = .57, k = 6, p < .0048$), overall affect ($\rho = .44, k = 11, p < .0001$), and quality of life ($\rho = .39, k = 5, p < .05$). Likewise, correlations from the EPQ (happiness ($\rho = .48, k = 37, p < .0001$), positive affect ($\rho = .43, k = 40, p < .0001$), overall affect ($\rho = .45, k = 7, p < .0173$), and quality of life ($\rho = .39, k = 5, p < .05$), and the EPI (positive affect ($\rho = .31, k = 24, p < .0001$) and life satisfaction ($\rho = .29, k = 7, p = .4602$) also echoed the correlations derived from the NEO-PI-3. Individuals who were more extroverted, defined as having more “warmth, gregariousness, assertiveness, activity and excitement seeking” were more likely to experience greater levels of positive emotions and happiness, than their introverted counterparts (Steel et al., 2008, p. 150).

Steel et al. (2008) also found that the NEO-PI-3 trait of Conscientiousness (NEO-PI-3) was a strong predictor of quality of life ($\rho = .51, k = 4, p < 0468$). Openness to experience was found to be positively and significantly correlated with happiness ($\rho = .14, k = 5, p < .0258$), positive affect ($\rho = .26, k = 27, p < .0001$), and quality of life ($\rho = .23, k = 6, p < .0178$). However, there
were no significant correlations found between Openness to experience and life satisfaction, negative affect, or overall affect.

While the innate personality trait of extroversion has been found to be a relatively fixed and stable disposition between childhood and adulthood, neuroticism is not so strongly fixed across the life span, and may be amenable to interventions that could decrease the level of neuroticism and therefore enhance subjective wellbeing and overall quality of life (Roberts & DelVecchio, 2000; Caspi et al., 2005; Hampson & Goldberg, 2006). In a study by Hampson and Goldberg (2006), 2404 primary school children divided into six subsets were evaluated by a single teacher (for each subset of children) for the Big-Five personality traits (Openness to experience, Extroversion, Neuroticism, Agreeableness and Conscientiousness). This consisted of a survey listing 49 personality attributes, each of a single word or short phrase, followed by a more extensive definition. Four decades later, around 2000 of these grown children were recruited and completed a demographic survey of health-related behaviour (e.g. drinking, diet, smoking, and exercise) and undertook another assessment of the Big-Five personality traits in the 44-item Big-Five Inventory (BFI) (John & Srivastava, 1999).

The 44-item BFI was administered twice to adult participants, with a 2-4 year period of time elapsing between each assessment. In the first administration of the 44-item BFI, participants also answered two items measuring self-perceived physical attractiveness. In the second administration of the 44-item BRI, conducted 2-4 years later, participants completed an 84-item questionnaire including an adult version of the 49 personality attributes given during their childhood, as well as two items regarding self-perceived attractiveness, and one additional item containing personality-trait adjectives.

Analysis of the stability correlations between childhood and the two time frames in adulthood, revealed Extroversion ($r = .27$, $p < .01$) and Conscientiousness ($r = .25$, $p < .01$) to be most stable across time. Openness to experience ($r = .17$, $p < .01$) was only moderately stable
between childhood and adulthood. Though Openness to experience achieved statistical significance, it was not to the same extent as Extroversion and Conscientiousness. The least stable of traits was Neuroticism \( (r = .00) \) which failed to gain statistical significance, and Agreeableness \( (r = .08, p < .05) \). The findings suggest the trait of Neuroticism, which Steel et al. (2008) found was negatively correlated with subjective wellbeing, may be amenable to changes in environment, such as improvements to one’s meaning in life (Diener & Suh, 2000a), quality of connection with others (Seligman, 2011), and engagement in leisure activities which are pleasurable (Diener & Suh, 1997).

**Leisure.** Aside from personality traits, research into subjective wellbeing has shown several variables which can enhance an individual’s subjective wellbeing (Hribernik & Mussap, 2010). One such variable is the degree of satisfaction and pleasure derived from engagement in leisure activities. Leisure is time free from essential life maintenance tasks (sleeping, eating) and obligations (paid and unpaid work) that enables an individual to engage in those activities which generate either pleasure, relaxation, personal growth or personal meaning, depending on individual preference (Hurd & Anderson, 2011). For satisfaction to be derived from leisure activities, these activities must be undertaken freely and voluntarily by an individual who has an intrinsic motivation to participate, and the belief they have the competence to do so (Hurd & Anderson, 2011, p. 78). Activities that lack these elements fail to produce feelings of satisfaction, or provide enhancement of subjective wellbeing.

The role of leisure upon subjective wellbeing has been examined by Hribernik and Mussap (2010). This study was aimed at determining if leisure’s contribution to subjective wellbeing was independent of other elements such as age, gender, marital status or mood. Subjective wellbeing was considered to “reflect an individual’s satisfaction with various domains of life” (p. 702). Four hundred and eighty-seven adults completed the Personal Wellbeing Index (International Wellbeing Group, 2006), which had an additional item, included measuring leisure satisfaction;
“How satisfied are you with your leisure?” (Hribernik and Mussap, 2010, p. 702). The Personal Wellbeing Index contains seven domains related to how satisfied an individual is with their health, achievement in life, safety, relationships, standard of living, community-connectedness, and future security (Hribernik and Mussap, 2010, p. 702). Collectively, these domains answer the question of “How satisfied are you with your life as a whole?”, providing a measure of an individual’s subjective wellbeing.

The results from Hribernik and Mussap’s (2010) study found a positive correlation between leisure satisfaction and subjective wellbeing. Leisure satisfaction explained 37% of the variance in life satisfaction (b = .11, p < .001). Analysis of the role “core affect” has on an individual’s leisure satisfaction and subjective wellbeing found that in the absence of positive core affect both leisure satisfaction and subjective wellbeing decreased. Hribernik and Mussap (2010) conceptualised “core affect” as the degree with which an individual feels happy, excited and contented (p. 703). Hribernik & Mussap (2010) explained the degree of satisfaction an individual derives from leisure appears to be contingent on how happy, excited and contented they feel (p. 705). This core affect influences an individual’s perception of how satisfying their life and leisure activities are.

With respect to the focus of research for this dissertation and the contents of this current chapter, understanding traits and any other variables, such as leisure satisfaction, which may improve subjective wellbeing and quality of life of residents, is important. The bi-directionality of subjective wellbeing and health status add further impetus to the need for resources and interventions specifically designed to improve the lives of residents. This is especially relevant for younger residents of aged care facilities. Their admission because of high care needs and disability, hinders the capacity to engage in meaningful leisure activities, or derive life satisfaction from those aspects of life shown to enhance it.
Summary. Subjective wellbeing, a component of ‘quality of life’, is the evaluation a person has about the extent in which they are satisfied with their life, and how well they enjoy their life (affective evaluation) (Diener & Lucas, 1999). Yet these evaluations are contingent on how healthy a person is, the level of pain experienced, personality traits, underlying core affect, and the extent to which their leisure activities bring pleasure and a sense of satisfaction. However, in the broader concept of ‘quality of life’, subjective wellbeing is only one element. The other is ‘meaning in life’ and ‘connection to others’. Having now examined subjective wellbeing, the remainder the chapter shall examine ‘meaning in life’ and ‘connection to others’.

Meaning in life. Meaning in life is a concept, like subjective wellbeing and quality of life, which lacks a consensus regarding opinion of its true nature and definition (Mascaro & Rosen, 2006; McKnight & Kashdan, 2009). The concept of ‘meaning in life’ was coined by researcher Victor Frankl (1959; 2004), who suggested all humans have the innate drive to find meaning in life, and to achieve a sense of accomplishment through the fulfilment of life goals. Meaning in life is a cognitive phenomenon encompassing beliefs, values and a framework in which one understands life. This understanding, in turn, generates motivational and affective responses including feelings of satisfaction and fulfilment, and the setting of goals (Halama & Bokosova, 2009).

Meaning in life also serves as a mediator in facilitating an individual to cope with negative life events (Halama & Bokosova, 2009; Mascaro & Rosen, 2006). This was examined in Halama and Bokosova’s (2009) study. Two hundred and four university students (44 males, 160 females) were recruited to examine if a higher level of meaning in life was associated with an individual’s capacity to cope more effectively in the advent of a negative life event. Participants completed the ‘Perceived Stress Scale’ (Cohen et al., 1983), ‘Life Meaningfulness Scale’ (Halama, 2002) and the ‘COPE’ questionnaire (Carver et al., 1989).
The Perceived Stress Scale (PSS) contains 10 questions rated on a 5-point Likert-type scale examining a global perception of stress from the previous month. It achieves a coefficient alpha reliability of .86 (Cohen \textit{et al.}, 1983, p. 390). The Life Meaningfulness Scale (LMS), an 18-item instrument, measures an individual’s overall level of meaningfulness in their life. The LMS has a reliability of .77 (Halama, 2002).

The COPE questionnaire contains 60-items examining 15 different types of coping strategies. These include: turning to religion, acceptance, social support seeking (instrumental and emotional), positive reinterpretation, active coping, planning, suppression of competing activities, restraint coping, denial, venting of emotions, disengagement (behavioural or mental), use of humour, use of alcohol or drugs. In a hierarchical cluster analysis of these 15 coping strategies, three clusters emerged; adaptive coping (social support seeking, active coping, planning, suppression of competing activities), avoidant coping (disengagement, use of alcohol, drugs or humour, and denial) and emotion-based coping (turning to religion, and venting). The COPE questionnaire subscales have acceptable internal consistency values ranging from .66 to .91 (Carver \textit{et al.}, 1989).

Findings from Halama and Bakosova’s (2009) study revealed higher levels of stress were positively correlated to increased use of avoidant coping ($r = .309, p < .01$) and emotion-based coping ($r = .311, p < .01$). However, individuals with high levels of stress but who also reported high levels of life meaningfulness, were less likely to use avoidant based coping strategies than those individuals with lower life meaningfulness and high stress levels. Halama and Bakosova (2009) suggest meaning in life provides the basis upon which to reinterpret and transform the stressful situation into a potential beneficial challenge. This, in turn, could enhance a person’s capacity to master the situation through careful planning and deliberate rational decision making, rather than through merely avoiding the stress.
The generalising of these findings to differing ages and populations is problematic, because of the recruiting pool used. The participants were all drawn from a university setting with ages ranging from 18 to 32 years (\(M=21.81\) and \(S.D=2.26\)). It is possible the sources of stress participants had experienced in the past month may be substantially different to the types and levels of stress found among different ages and population groups. Despite these limitations, Halama and Bakosova’s (2009) study lends support to the idea that meaning in life may buffer against the stress from obstacles and challenges that arise in every-day life.

Beyond enhancing an individual’s capacity to cope in stressful situations, meaning in life can also impact upon psychological well-being and quality of life (Park et al., 2008). In the Park et al. (2008) study, meaning in life, coping and quality of life were examined in 155 patients with congestive heart failure. The construct for coping in the Park et al. study was borrowed from Aldwin’s (2007) conceptualisation of coping. Aldwin (2007) posits coping refers to the behavioural and cognitive strategies utilised by individuals to manage stressful situations and any negative emotions arising from such situation (p. 21). Positive coping strategies include the acceptance and positive reinterpretation of a negative or stressful event, seeking support from one’s social network, or turning to religion to find meaning (Aldwin, 2007). Aldwin (2007) suggests maladaptive coping strategies are those which involve avoidance or disengagement from a stressful or negative event.

Participants completed several instruments at two time intervals (6 months apart). Meaning in life was assessed through the Perceived Personal Meaning Scale (PPMS) (Wong, 1998), which consists of 5 items rated on a 4 point Likert-type scale measuring life meaning (e.g. my life as a whole has meaning) from 1 (strongly disagree) to 4 (strongly agree) (Park et al., 2008, p. 23). The PPMS has achieved good concurrent and predictive validity and the internal consistency reliability in the present sample was .92.
Participant’s capacity to cope was measured through the COPE questionnaire (Carver, et al., 1989; see section above for tools reliability) and their quality of life was examined using the 36-item Medical Outcomes Study Short Form health status questionnaire (SF-36; Ware et al., 1994). The SF-36 questionnaire yields two scores: a mental health component score, encompassing measures of social functioning, vitality, mental health, and role-emotional; and a physical health score examining pain levels, physical functioning, general health, and role-physical. The Medical Outcomes Study Short Form questionnaire has good psychometric properties with the two subscales (mental health and physical health components) achieving internal consistency reliabilities of .74 and .77.

The results of the Park et al. (2008) study revealed that higher levels of meaning in life correlated with better mental health and physical health at Time 2 (.31 & .30, p < .05). Coping, especially religious coping and acceptance/reappraisal was also associated with life meaning and increased life meaning at Time 2 (.24 and .25, p <.01). Avoidant coping strategies was correlated with poorer mental and physical health scores at Time 2 (-.25 and -.15, p <.01 and p <.001). Those individuals who engaged in positive coping strategies, such as acceptance/positive reinterpretation strategies, recorded higher levels of meaning in life.

Park et al. (2008) suggests some individuals dealing with highly stressful chronic health issues, may also derive benefits from their condition in terms of opportunities to engage in a more intentional and purposeful way of living. Park et al. (2008) attributes these benefits to focusing, reevaluating and reprioritising one’s life on what is truly important, which allows an individual to begin developing a greater appreciation for their life. Coping with chronic health issues through the use of more adaptive and positive strategies, may enable an individual to begin developing different sources of meaning for their life. This in turn may enhance an individual’s perceived sense of meaning. Individuals who employ more maladaptive coping
strategies such as denial or avoidance, may subsequently miss the potential for enhancing life
meaning, learning, insight and wisdom that could be gained from their illness.

Meaning in life has been shown to enhance psychological wellbeing, quality of life and an
individual’s capacity to cope with stressful situations (Halama & Bakosova, 2009; Park et al.,
2008). Meaning in life has also been associated with mood (Mascaro & Rosen, 2006). One
hundred and forty-three university undergraduates completed measures for depression, hope and
meaning, to determine if meaning in life was associated with the experience of depression and
the absence or presence of hope. An extensive battery of measures was given including the
Depression, Anxiety & Stress Scale (DASS; Lovibond & Lovibond, 1995a), Becks Depression
Inventory-II (BDI-II; Beck et al., 1996), Adult State Hope Scale (ASHS; Synder et al., 1996),
Hearth Hope Scale (HHS; Hearth, 1992), Spiritual Meaning Scale (SMS; Mascaro et al., 2004)
and Life Regard Index – Revised (LRI-R; Debats, 1998).

Participant’s mood was measured using the Depression, Anxiety & Stress Scale (DASS;
Lovibond & Lovibond, 1995) & Becks Depression Inventory-II (BDI-II, Beck et al., 1996).
The DASS is a 42-item Likert-type questionnaire measuring depression, generalised anxiety and
physiological symptoms of panic. Answers are given on a 4-point Likert-type scale. For
example, “I find it hard to wind down”, 0 = does not apply to me at all, 3 = this applies to me
very much. The internal consistency of the Depression, Anxiety and Stress subscales achieve
Cronbach alphas of .94, .92 and .95 respectively (Antony et al., 1998). The DASS has good
concurrent validity with the BDI with the Depression, Anxiety and Stress subscales gaining
correlations of .77, .57, and .62 respectively (Antony et al., 1998).

The other instrument used to measure Depression was the Beck’s Depression Inventory - II
(BDI-II). The BDI-II is a 21-item questionnaire measuring depressive symptomology. Each item
has four possible responses. For example, “I do not feel like a failure; I feel I have failed more
than the average person; As I look back on my life, all I can see is lots of failures; I feel I am a
complete failure as a person” (Beck et al., 1996, p. 28). Scoring is between 0-3, and higher scores indicate greater severity of depressive symptoms. The BDI-II has a good internal consistency achieving coefficient alpha of .86 and .81 for psychiatric and non-psychiatric populations (Beck et al., 1988). Convergent validity with the BDI-II among psychiatric outpatients achieved a correlation of .93 (p< .001) (Beck et al., 1996).

The level of agency and awareness participants perceived they had in attaining their goals, along with feelings of hopelessness, were assessed using the Adult State Hope Scale (ASHS; Synder et al., 1991) and the Herth Hope Scale (HHS; Herth, 1992). The ASHS is a 12-item measure answered on an 8-point Likert-type scale examining two constructs: individual’s perceived will to attain goals (agency) and awareness of the means to achieve those goals (pathways). The ASHS achieves an average coefficient alpha of .91 (Synder et al., 1991). It has convergent validity with Adult State Self-Esteem with correlations of $r(166) = .75$ (Synder et al., 1991). The HHS measures the presence of hopelessness in participants through a 30 item instrument rated on a 4-point Likert-type scale. The HHS has achieved good reliability with a coefficient alpha of .87 (Herth, 1992).

Participants’ meaning in life was assessed using the Spiritual Meaning Scale (SMS; Mascaro et al., 2004) and the Life-Regard Index - Revised (LRI-R; Debats, 1998). For the purpose of Mascaro and Rosen’s (2006) study, spiritual meaning was defined as the “belief in a higher power which has a purpose, will or way for an individual’s life resulting in the perception of a ‘calling’ upon one’s life to pursue a specific purpose” (p. 170). The SMS is a 15-item, Likert-type, self-report inventory assessing a person’s sense of spiritual meaning in life. The SMS obtains a coefficient alpha of .91 (Mascaro et al., 2004). The Life Regard Index - Revised (Debats, 1998) is a 14-item, Likert-type, self-report scale measuring the degree to which an individual identifies with having a framework or philosophy for living. The LRI-R has a coefficient alpha of .81 (Debats, 1998).
Mascaro and Rosen’s (2006) study revealed a significant negative correlation between meaning in life and depressive symptoms (LRI-R \( r = -0.45, p<.001 \); SMS \(-.32, p<.001\)), and a positive correlation between meaning in life and presence of hope (ASHS \( r = 0.59, p<.001 \); HHS \( r = 0.54, p<.001\)). Individuals who reported higher levels of personal and spiritual meaning were less likely to experience depression. These individuals noted having a greater sense of hope for the future and stronger beliefs in their capacity to overcome adversity to achieve their goals. Mascaro and Rosen (2006) suggest having a sense of purpose or calling about one’s life can provide an individual with a sense of hope about the future. This in turn buffers against everyday stresses and reduces the likelihood of depressive symptoms.

**Summary.** Collectively, Halama and Bakosova (2008), Mascaro and Rosen (2006) and the Park *et al.* (2008) studies suggest meaning in life is beneficial in aiding to cope with negative life events and promotes greater physical and psychological health. Meaning in life provides an individual with an organising framework of fundamental beliefs and values upon which one can make decisions in spite of negative life events or emotions. It also facilitates adaptive coping strategies that promote more effective problem solving of issues. Greater meaning in life is correlated with less depressive symptoms and greater sense of hope for the future. As such, meaning in life, along with subjective wellbeing, contributes to an individual’s perceived quality of life.

**Connection with others.** In addition to subjective wellbeing and meaning in life, connection to others is considered another component of quality of life (Frisch, 2006; Seligman, 2011). Social bonds between people meet an innate human need for connection with others. It is suggested the formation of social bonds has a biological evolutionary basis, aiding survival and propagation of both the individual and the larger group (Baumeister & Leary, 1995). Beyond enhancing survival and reproduction, the need for connection to others enables humans to gain a sense of belonging, which enhances social acceptance and inclusion (Myers, 1999). Social bonds
in infancy, known as attachment strategies, ensure an infant’s or child’s caregiver remains physically close, thus aiding the meeting of emotional and physical needs (Bowlby, 1988). The meeting of such needs maximises the chance of survival. Social bonds in adulthood ensure continuation of the species through reproduction, and mutual cooperation in raising offspring (Baumeister & Leary, 1995). However, social bonds also enhance survival and quality of life of vulnerable adults who are ill or have a disability (Cohen, Gottlieb & Underwood, 2000).

It is beyond the scope of this section, and indeed the larger chapter, to fully capture all the literature, definitions, debates and proposed theories regarding the underlying evolutionary and neurobiological pathways mediating social relationships. Instead, this section will focus on the benefits of social bonds as they pertain to mental health and wellbeing. For simplification, the term social bonds will be used as a broad umbrella term denoting social support, social integration, and enduring social relationships, which also may include the enactment of attachment strategies (Bowlby, 1969).

Social support relates to provision of psychological and material resources from within a social network which may facilitate an individual’s capacity to cope with stress. This support includes instrumental (provision of material aid), informational (provision of information to aid coping – guidance or advice), and emotional support (expression of reassurance, empathy, and caring that provides emotional expression) (Cohen & Syme, 1985).

Social integration is the participation and engagement in a variety of social relationships that aids a sense of community and enhances a sense of self within that community (Brissette et al., 2000). Collectively, social bonds, which include romantic relationships, friendships, caregiving relationships, familial and peer relationships, as well as integration into social networks, meet innate human needs for belonging that aids survival and coping of life, through the provision of material and emotional resources. As such, social bonds are consistently implicated in the role of health and wellbeing (Song et al., 2015).
Social bonds are seen to promote health through their stress-buffering effects and capacity to promote positive emotional states (self-worth, identity, purpose, positive affect). It is likely they aid reduction in the level of stress from a negative event or situation by diminishing emotional and physiological responses and altering potentially maladaptive behaviours (Wills & Cleary, 1996). As such, the lack of such social bonds is likely to have significant deleterious effects upon a person’s mental health and wellbeing.

Examining the impact of poor social bonds, including negative and unsupportive relationships upon bio-inflammatory responses to stress, was undertaken by Song et al. (2015). Fifty-six participants (36 women, 20 men) were assessed for depression using the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The CES-D achieves a Cronbach alpha of .90. Participants were also administered the Negative Social Relationships questionnaire (NSR; Schuster et al., 1990). The NSR questionnaire is a 25-item instrument measuring the frequency of disagreements and negative social experiences such as criticism (Schuster, et al., 1990). Answers are given on a six-point Likert-type scale with 0 = never, to 5 = often. The Cronbach alpha of the NSR is .84 (Schuster et al., 1990).

Participants were given a social stress test in which blood serum was collected across three time points (prior to stress test [baseline], 15 minutes after stressor, 75 minutes after stressor) to determine cortisol levels and inflammatory marker interleukin-6 bio-inflammatory marker. Participants were told they had ten minutes to prepare a 3.5-minute speech about a personal failure that had a negative impact upon their life. Participants were informed this speech was to be videorecorded and later observed by psychologists. Upon completion of the speech, participants were administered a series of subtraction tasks followed by several maths questions and then another series of subtraction tasks. Blood serum was taken prior to commencement of the tasks, fifteen minutes after completing the social stress test and again 75-minutes post testing.
Participants were grouped according to ‘low conflict’ (reporting low levels of negative social exchanges across all relationships: romantic partner, family and closest friend) or ‘multiple conflict’ (high levels of conflict across all relationships). The findings showed that participants in the ‘multiple conflict’ group, who scored higher on the negative social relationship questionnaire also had higher levels of interleukin-6 inflammatory responses to the stress test, than did participants in the ‘low conflict group’ ($F(4, 58) = 8.53, p < .01, \eta^2 = .37$). No correlation was found between cortisol levels and negative social relationships.

Song et al. (2015) suggest ongoing constant negative social interactions produce an excessive inflammatory response stress. Specifically, the more an individual’s social bonds are characterised by conflict, resulting in feelings of isolation or lack of support, the greater the physiological inflammatory response to a stressor occurs. Chronically elevated inflammation is linked to the increased risk of chronic disease conditions, such as cardiovascular disease (Ridker et al., 2000), cancer and diabetes (Ershler & Kellor, 2000), depression and anxiety and autoimmune diseases (Kiecolt-Glaser et al., 2010)

For individuals living in an aged care facility, lack of perceived support, or social bonds characterised by conflict may generate greater inflammatory responses, thereby increasing their risk of further disease and/or disability, when confronted with life stressors commonly found in a RAC setting (changing of staff and routines, death of peers, lack of life purpose, ill-health, chronic pain). This is especially relevant to younger residents of aged care facilities, who (because of their age), will likely spend more years in a residential facility than an older person, and may therefore experience a greater number of life stressors, in addition to their chronic health conditions and placement into aged care.

While there is no current universal definition for ‘quality of life’, common themes, including subjective wellbeing, meaning in life and connection to others all contribute to an individual’s appraisal of their life’s quality. As revealed in the studies by Halama and Bakosova (2008),
Mascaro and Rosen (2006), Park et al. (2008) and Song et al. (2015), diminished subjective wellbeing, lower levels of life meaningfulness and impoverished social bonds can have a detrimental impact on an individual’s physical health, their mood, and their capacity to withstand stressful events. One such environment that may directly and indirectly impact upon all three components of quality of life is the arena of RAC.

Quality of Life in Residential Aged Care Facilities

Quality of life of older adults in residential care. Quality of life research gained momentum with the need to quantify health outcomes of older people in American residential care facilities (Guyatt, Feeny & Patrick, 1993). Since then, researchers have examined the impact of quality of life on general health with several conditions identified as causing a decrease in quality of life. These include: incontinence (Degenholtz et al., 2006), poorer vision (Degenholtz et al., 2006), level of pain experienced (Torvik et al., 2010), the presence of a chronic condition (Chang et al., 2010; Lobo et al., 2008) diminished capacity to engage in physical activity (Lobo et al., 2008; Nijs et al., 2006; Tseng and Wang, 2001), physically or mentally unable to undertake meaningful activities (Ronnberg, 1998) and high levels of dependence on others (Degenholtz et al., 2006). Additionally, the presence of a mood disorder (Chang et al., 2010; Degenholtz et al, 2006; Droes et al., 2006; Gerritson et al., 2005; Gleibs et al., 2011; Ronnberg, 1998) also significantly impacts upon residents’ perceived quality of life.

Quality of life research in RAC facilities demonstrates the capacity to help others (Guse & Masesar, 1999), being treated with respect (Robichaud et al., 2006), and upholding the uniqueness and individuality of the person (Jacelon, 1995), serves to improve the emotional world of residents, thereby enhancing their quality of life. The literature also repeatedly demonstrates mastery over one’s environment is also associated with a high quality of life in RAC facilities. Mastery over one’s environment includes: the degree of privacy and choice a
resident has (Droes et al., 2006; Chin & Quine, 2012), their capacity to engage in activities considered meaningful (MacDonald and Butler, 2007; Ronnberg, 2008), along with the sense of security in the reliability of staff (Ball et al., 2000; Kane et al., 2003).

Finally, the quality of connection with others is acknowledged as a significant contributor to quality of life in a RAC setting. A lack of social support, resulting in the experience of loneliness has been found to have a detrimental effect on life quality (Chang et al., 2010; Cohen-Mansfield et al., 2010; Guse and Masesar, 1999; 2010; MacDonald and Butler, 2007; Slettsebo, 2008; Tseng and Wang, 2001). However, high quality of life in RAC facilities is associated with social connections to supportive family and friends (Guse and Masesar, 1999;; Nijs et al., 2006; Chang et al., 2010; Degenholtz et al., 2006; Droes et al., 2006; Tseng and Wang, 2001), along with participation in social groups (Glieb et al., 2011).

Guse and Masesar (1999) examined factors associated with quality of life and successful ageing in a long-term aged care facility. Thirty-two aged care residents answered open-ended questions regarding their quality of life, degree of choice in the timing and place of activities (room and board), the importance of these activities, what they considered decreased their quality of life, and 3-4 things which they considered essential to life quality. More than 60% of participants reported spending time with family and having friends was very important for their quality of life. Participant’s also reported the importance of having privacy (75%) for their quality of life, as well as helping others (56%).

Collectively, the literature examining quality of life for people in RAC facilities identifies that connection to others and social support, the absence of mental and physical health issues, and the capacity for self-mastery and determination within and over the environment all enhance the quality of life of residents. However, much of this literature is based on studies with older residents. As such, it is important to also examine the quality of life of young people in RAC, who are the focus of this dissertation. It is likely that younger residents face issues that are not
currently captured in the aged care literature concerning the life quality of residents. Exploring the quality of life of young people in RAC is then an important ancillary research subject on quality of life in aged care.

**Quality of life of younger residents in aged care facilities.** Young and old alike, an individual’s existing network of social relationships is often negatively impacted when they enter a RAC facility (Bigby, 2008b; Winkler et al., 2006). This is the result of a combination of factors: the geographical location of the RAC facility which may impede friend, family and children visitation (Duner & Nordstrom, 2007); lack of suitable entertaining area for visitors, (Bauer & Nay, 2010); daily routines that interfere with social relationships with those outside the facility; and the level of co-operation and collaboration between staff and residents’ social and support networks (Haesler et al., 2007; Ginsberg-McEwan & Robinson, 2001).

Perhaps more acutely affected by relocation into the RAC sector are young people whose capacity to form peer relationships within the facility is significantly limited (Muenchberger et al., 2011). Research examining the quality of life of younger people in RAC facilities reveals they often lead lives “characterised by loneliness and boredom” with more than one-third unable to participate within the community (Winkler, Farnworth et al., 2006, p. 105). Winkler et al. (2006) notes younger residents are generally socially isolated and have minimal recreational opportunities because of limited financial and staffing resources that impedes social support and their access to the community. Additionally, examination of younger people in RAC finds those who do remain in contact with their existing social and support network, that the physical layout of the RAC facility is often not conducive to entertaining peers, family members or their own children. This further restricts the capacity for meaningful engagement with others with many younger residents citing the options for entertaining family and friends is limited to either their bedroom, shared living areas, or outside the facility (Winkler, et al., 2006; 2010; 2011).
These factors hinder the frequency of contact and potentially change the quality of relationship residents share with their social and support networks (Bigby, 2008b). Individually or in combination, these factors negatively impact a younger person’s quality of life, already diminished because of chronic illness or disability. In seeking new relationships to replace or supplement a dwindling social and support network, inevitably the relationship with formal caregivers may become the avenue in which relational needs are met, and enhancement of an individual’s life quality gained. This is opined in a study by Muenchberger et al. (2011) where it was shown that younger residents preferred for their carers to “sit down, have a laugh and joke, and talk to you as people, not as people they’re caring for . . . They’ll just talk to you as friends” (p. 1199).

While a relationship alone is not enough to fulfill all aspects that contribute to better life quality, formal caregivers are uniquely placed in facilitating other aspects of quality of life, including improving the quality of the emotional world of the individual. This can be achieved through aiding an individual’s capacity to help others, and through upholding the uniqueness and individuality of that person. The formal caregiving role also aids a younger person’s mastery over their environment through their provision of opportunities in decision making, and by enhancing their capacity to engage in activities considered meaningful (Droes et al., 2006; Chin & Quine, 2012).

The formal caregiving role has the capacity to influence the quality of life of residents. Thus, for younger residents, formal caregivers will often become central to their social and support network. Regular contact with formal caregivers aids development of social relationships, with the frequency of contact inadvertently meeting the companionship and intimacy needs of younger residents, and providing enhancement to other areas which improve quality of life. Even though formal caregivers have a paid role in these relationships, the nature of formal caregiving still remains firmly embedded in a social relational context.
Quality Of Life, Formal Caregiving & Person-Centered Care

While there is no current universal definition of caregiving, Fischer and Eustis (1994) suggest caregiving practices can generally be divided into instrumental and emotional caregiving activities. Instrumental caregiving involves assistance with activities-of-daily-living, provision of information or advice, care-recipient representation and advocacy within the community, and facilitation of the acquisition of tangible resources required by the care-recipient.

Emotional caregiving activities are relationally based and create, sustain or enhance the interpersonal relationship between carers and care-recipient. These activities include behaviours and actions which convey empathy and sympathy, encouragement, expressions of affection, and validation of an individual’s worth (Fischer & Eustis, 1994). Emotional caregiving behaviours also aim to promote and protect an individual’s dignity, autonomy and self-esteem, and help decrease the care-recipients distress, facilitating their capacity to cope in challenging or threatening situations (Collins, Guichard, Ford & Feeney, 2000; 2006; Fischer and Eustis, 1994).

Emotional caregiving can be regarded as the enactment of person-centred care, the care framework being predominantly adopted throughout the aged care, disability and health sector (Pol-Grevelink et al., 2012). Person-centred care emphasises the customisation of care to meet the unique and individual desires and needs of each resident. Within the RAC setting, person-centred care is espoused as the most effective type of care framework for contributing positively to the lives of residents (Edvardsson et al., 2008).

The central aims of person-centred care are to support the rights, values and beliefs of residents, provide them with unconditional positive regard, and encourage each resident to remain actively involved in the process of self-determination (Edvardsson et al., 2008). Person-centred care is ultimately predicated on the concepts of respect, autonomy, empowerment, communication, and shared decision making, which is mediated by the care relationship (PolGrevelink et al., 2012, p. 220).
In their systematic review on person-centred care, Edvardsson et al. (2008) showed this care framework contributes positively to the lives of residents in an aged care facility with improvements noted in mood and level of self-determination, increased feelings of wellbeing, and more positive relational interactions and relationships with formal caregivers. As such, person-centred care and its expression in emotional caregiving behaviours is correlated with life quality within the RAC sector (Finnema et al., 2005; Hobbs, 2009). However, like the concept of quality of life, person-centred care also lacks both a universal definition and the systematic employment with RAC. Its fluidity in concept and definition has seen it operationalised and transformed into various forms of care. These include emotion-oriented care (Pool et al., 2004), client-centred care (Schoot et al., 2005) and integrated emotion-oriented care (Van der Kooij, 2001).

Pool et al. (2004) defines emotion-oriented care as the relational experience of the care recipient with a caregiver based on equality, togetherness, appropriateness and autonomy. Client-centred care is described as the relational processes between care-recipient and carer which is dynamic, contextual, unique and complex and involves a continuous dialogue between the individuals involved (Schoot et al., 2005). Integrated emotion-oriented care emphasises the emotional connection between formal caregiver and resident, aimed at establishing positive relationships between carer and care-recipient (Van der Kooij, 2001).

The central unifying tenet among all forms of person-centred care is the relational context in which the carer and care-recipient are entwined. At its core, emotional caregiving behaviours remain the expression of this conceptual care framework. Words of encouragement, genuine affection, sympathy and empathy, and the honouring of the uniqueness of a person fulfill the directives and principles of person-centered care (Fischer & Eustis, 1994). However, the expression of all types of caregiving, including emotional caregiving behaviour, is likely
influenced by both organisational and personal variables (Edvardsson, Fetherstonhaugh & Nay, 2009).

Conclusion

Though a definition of quality of life is yet to be formally agreed upon by theorists, researchers and academics, common themes from the literature are evident and include concepts of subjective wellbeing, meaning in life, and connection to others. These aspects of quality of life are mediated by one’s environment, including other people with whom we are connected.

In a RAC setting, the connection to others and level of social support, the absence of mental and physical health issues, and the capacity for self-mastery and determination within and over the environment, all appear to enhance the quality of life of residents. For younger residents, in particular, the aged care environment creates barriers to the enhancement of their quality of life because of difficulties forming and maintaining connections with others and in creating life meaning within that context. Minimisation and resolution of some of the difficulties impacting upon younger residents’ quality of life may be found through the formal caregiving role. However, the formal caregiving role is, itself, expressed within the situational context and contingent upon formal caregivers’ individual characteristics, all of which shape the expression of caregiving behaviours. Understanding the influences upon formal caregiving within a RAC setting is therefore important in understanding the experiences of formal caregivers caring for younger residents in aged care facilities.
Chapter Four: A Review of the Literature on Formal Caregiving Relationships

An increasing aged population within developed countries has created the need for residential aged care (RAC) services. But not all residents with care needs who access these services are aged. In Australia, more than 6000 people under the age of 65 years are currently living in RAC facilities (AIHW, 2010). Central to these facilities are the formal caregivers, largely responsible for the delivery of day-to-day care to all residents (Harris-Kojetin et al., 2004; King et al., 2012). Alongside this day-to-day care some form of relationship between formal caregiver and resident inevitably develops. Despite the visibility of formal caregiving relationships with residents within the RAC sector, the definition, acknowledgement and prioritisation of these relationships remain absent from Australian aged care policy. Nevertheless, research continues to affirm formal caregiving relationships with residents, considering it important in the effective delivery of care and the promotion of a resident’s quality of life (Cooney et al., 2009; Kane et al., 2003).

As highlighted in the previous chapters, the RAC sector poses barriers to the development and maintenance of formal caregiving relationships with residents. For Australian formal caregivers, dissatisfaction with the quality and duration of time spent with residents’ results in diminished job satisfaction and a sense of inadequate care being provided (King et al., 2012). The burden of bureaucratic demands generates prioritisation of non-care demands over one-to-one resident contact, limiting the time formal caregivers and residents share. Other barriers are likely to exist impacting the formal caregiver and resident relationship.

To gain a more comprehensive understanding of the nature and quality of formal caregiving relationships, along with understanding the barriers to such relationships, it is necessary to examine what is currently known within the literature. This will provide a better understanding of formal caregiving relationships with residents as well as identify areas for further exploration where little research has been undertaken. The aim of this chapter is to present a critical appraisal of literature pertaining to the formal caregiver and their relationships with residents.
The specific questions for this review are:

- What is the nature of formal caregiving relationships, and how are they defined?
- What benefits to residents do formal caregiving relationships provide?
- What are the barriers to the formation of these relationships?
- Among what populations of residents have formal caregiving relationships been examined?

The objectives of this review are to evaluate the research examining formal caregiving relationships within a RAC facility and to determine current areas of paucity.

**Method**

The following databases were accessed individually to identify studies relevant to the questions raised: MEDLINE Complete via EBSCO, AgeLine via EBSCO, CINAHL via EBSCO, PsycINFO via EBSCO, and EBASE. Search terms were formulated through consultation with research supervisors familiar with the aged care sector, and the School of Psychology librarian with specialist expertise in the field of psychology. The five key concepts identified and the key terms within each concept were entered both individually and then in combination. A detailed search strategy can be found in Figure 4.1.
**Databases:** MEDLINE Complete via EBSCO, AgeLine via EBSCO, CINAHL via EBSCO, PsycINFO via EBSCO, and EBASE.

**Search 1:**

“barrier*” OR “issue*” OR “problem*” OR “factor*” OR “difficult*” OR “variable*” OR “psychosocial”

AND

“caregiver*” OR “nurse-patient relations” OR “nursing assistant*” OR “formal caregiver*” OR “health care staff N3” OR “personal care staff” OR “professional caregiver*” OR “direct support staff” OR “nurse*N3”

AND

“residential facilities” OR “nursing home*” OR “residential aged care” OR “assisted living” OR “residential care”

AND

“young adult*” OR “young people” OR “young person” OR “resident*” OR “aged care N3 resident*” OR “geriatric” OR “elderly”

AND

“quality of life” OR “quality of care” OR “life quality N3” OR “wellbeing” OR “well being” OR “well-being”

Limiters: English, Human, Peer-Reviewed, Year 2000-2016

*Figure 4.1 The Full Search Strategy*
Criteria for Study Inclusion and Exclusion

The search for relevant literature was limited to studies conducted in a RAC facility with no geographical limitations placed on the literature search. Both qualitative and quantitative research papers were examined but the literature search parameters were limited to peer-reviewed articles published from 2000 to 2016. The year 2000 was chosen as the starting point in the literature search as it was the catalyst for aged care reform in Australia following a government inquiry into the systemic failure of the introduced Aged Care Act (1997). This failure had resulted in the death of a number of aged care residents through inappropriate facility practices (Parliament of Australia, 1999).

Results

A total of 1136 articles were initially extracted with 593 remaining after duplicates were removed. An individual search of those 593 articles was undertaken. Papers relating to formal caregiving relationships with residents’ families were excluded, along with research pertaining to informal caregiving systems within a RAC setting. Studies detailing staff wellbeing improvement programs and in-house staff training, along with research examining formal caregiving relationships with colleagues were also omitted. Studies conducted in residential care facilities for children or adolescents, and papers associated with occupational job satisfaction were not included. Papers examining residents’ experiences and quality of life within aged care facilities were also omitted. The remaining papers were deemed suitable if they contained the following details with sufficient description; rationale for the study, description of participants and the recruitment process, explanation of the research methods used (including, descriptions of instruments employed), analysis and interpretation of the data, and limitations of the study.

In total, twenty papers were deemed relevant. Examination of the reference list for those twenty articles revealed two more studies. In total twenty-two articles were deemed appropriate.
Figure 4.2 demonstrates the PRISMA Group (Moher *et al.*, 2009) flow diagram of the studies deemed relevant for this literature review.

Figure 4.2. PRISMA Group flow diagram of included studies.
Eleven papers employed a qualitative design (Bergland & Kirkevold, 2005; Bowers et al., 2001; Brown-Wilson, Davies & Nolan, 2009; Cook & Brown-Wilson, 2010; DeForges et al., 2011; Edberg et al., 2008; Jones & Moyle, 2016; Lung & Liu, 2016; Marshall & Baffour, 2011; McGilton & Boscart, 2007; Walsh & Shutes, 2013).

Ten papers used a quantitative method (de Rooij et al., 2012; Bishop et al., 2008; Burgio et al., 2004; Edwards et al., 2003; Haugan et al., 2013; Kokkonen et al., 2014; McGilton et al., 2012; Schmidt et al., 2012; Testad et al., 2010; Zwijsen et al., 2014). Only one paper utilised a mixed model approach (Banerjee et al., 2015).

Three studies were undertaken in Australian RAC facilities (Edberg et al.; 2008; Edwards et al., 2003; Jones & Moyle, 2016). Four studies were conducted in England (Brown-Wilson, Davies & Nolan, 2009; Cook & Brown-Wilson, 2010; Kokkonen et al., 2014; Walsh & Shutes, 2013). Four studies were undertaken in America (Bishop et al., 2008; Bowers et al., 2001; Burgio et al., 2004; Marshall & Baffour, 2011), and four in Canada (Banerjee et al., 2015; DeForges et al., 2011; McGilton & Boscart, 2007; McGilton et al., 2012). Three studies were conducted in Norway (Bergland & Kirkevold, 2005; Haugan et al., 2013; Testad et al., 2010), two in Holland (De Rooij et al., 2012; Zwijsen et al., 2014), one in Germany (Schmidt et al., 2012) and one in Hong Kong (Lung & Liu, 2016). Table 4.3 in Appendix G. summarises the aims, method and results for each study.

The nature and definition of formal caregiving relationships. Seven articles examined either the nature or quality of formal caregiving relationships with residents (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010; Edward et al., 2003; Jones & Moyle, 2016; Lung & Liu, 2016; McGilton & Boscart, 2007; Walsh & Shutes, 2013). Three qualitative studies sought to define the nature of formal caregiving relationships with residents (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010; Walsh & Shutes, 2013). These studies suggested several distinctive relationship types. These included: pragmatic or functional relationships, personal & responsive
relationships, and reciprocal relationships (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010).

Pragmatic or functional relationships are those which focus on the provision of instrumental care. These relationships were also conceived of as “need orientated” by Walsh & Shutes (2013, p. 403). Personal, responsive and reciprocal relationships (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010) are defined as “friendship or familial-like” by Walsh and Shutes (2013, p. 403) and are based on relational interactions involving the reciprocal exchange of personal stories and information between formal caregiver and resident. The exchanges of such information are seen to promote trust, intimacy, companionship and reciprocity. These relationships often extended to include meeting family members’ needs as well as valuing their stories about a resident.

Formal caregiving relationships were found to be constrained by the perceptions held by formal caregivers and residents regarding the formal caregiving role (Lung & Liu, 2016). In unstructured interviews, Lung and Liu’s qualitative study revealed both formal caregivers and residents who perceived the formal caregiving role to be primarily concerned with the delivery of instrumental care, did not seek to deepen their relationship. Residents did not seek out emotional caregiving from formal caregivers and also constrained their requests for support to that which concerned instrumental caregiving activities. Formal caregivers minimised their involvement with residents, especially residents who expressed negative emotions. This ensured formal caregiving relationships remained distant. When both formal caregivers and residents viewed the formal caregiving role as the provision of both instrumental care and emotional support, reciprocal and trusting relationships were established. In turn, residents noted feeling more secure in the provision of care received when such relationships developed.

While several studies have defined formal caregiving relationships (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010; Walsh & Shutes, 2013), only one study attempted to assess
the quality of such relationships. McGilton and Boscart (2007) measured the degree of closeness between formal caregiver and resident. Interviewing staff, residents and their families, the study found perceptions of relationship closeness differed for each group. For residents, having a confidante who listens and is reliable, pre-empts their needs and acts in their best interest were hallmarks of closeness with a staff member. This was procured through staff’s technical competence in care delivery, the communication and level of interaction shared, the consistent meeting of residents’ needs and staff’s genuine care and interest in that resident. Families perceived closeness within the formal caregiver-resident relationship based on staff’s caring attitude, sense of concern and the personal attention given to the resident. Staff defined closeness within their relationship with residents by the degree of connectedness they felt. This connectedness was based on “knowing the resident” and “reciprocity” (McGilton and Boscart, 2007, p. 2152). Knowing the resident involved understanding their care needs and emotions, and knowing their individual preferences, likes and dislikes. Reciprocity was the “mutual togetherness” (p.2152) which enabled caregiving activities to be undertaken and completed.

The only two studies to examine the nature and/or quality of formal caregiving relationships with residents within an Australian setting were Edwards et al. (2003) and Jones & Moyle (2016). Both studies were undertaken in Queensland RAC facilities, with Jones and Moyle interviewing staff to explore their experiences and perceptions of formal caregiving relationships, and Edwards et al. describing interactional styles between formal caregivers and residents.

Jones and Moyle (2016) found staff preferred to not establish friendship with other staff, residents and their family. Though connection through relational interactions to residents was seen as paramount in the delivery of quality of care, the need to maintain professional boundaries impeded this. Professional boundaries were described as rules and regulations implemented to discourage the formation of friendships, such as the admonishing of hugging or kissing of residents. Jones and Moyle (2016) also revealed care demands, high familial expectations and
staff-staff conflict negatively impacted the perceived connection between formal caregivers, residents, their families, and other staff. Caregiving demands were seen to compete with engagement in relational interactions and often resulted in staff ignoring residents and their requests. The demands and expectations of residents’ families was often seen as a source of additional stress and anxiety for formal caregivers, who felt scrutinised and criticised. Unfinished caregiving demands (relegated to staff on the following shift) were noted as a common source of conflict among formal caregivers, and the perceived lack of respect from nurses was seen to hinder collaborative staff relationships.

Describing the current interactional styles within formal caregiving relationships, the Edward et al. (2003) study found formal caregiver communication with residents was “infrequent, of short duration and orientated to physical care” (pg. 35). It was revealed formal caregivers would provide praise and encourage residents’ display of dependent behaviour (accepting of assistance) 87% of the time. This was contrasted with no verbal or physical staff response 78% of the time when residents displayed independent behaviour (independent self-care). For residents who were non-engaged (e.g. staring at a wall), staff did not engage 89% of the time in any verbal or non-verbal communication with that resident.

Effective relational interactions are foundational to knowing a resident, assessing their needs, and evaluating and adapting caregiving processes to provide individualised care. Therefore, any poverty of interaction likely impedes the formation of close formal caregiving relationships, while also impacting the delivery of care.

**The impact of formal caregiving relationships with residents.** Examination of the impact formal caregiving relationships have upon residents was examined in four studies (Bergland & Kirkevold, 2005; Bowers et al., 2001; Haugan et al., 2013; McGilton et al., 2012). In two of these studies, formal caregiving relationships were associated with residents’ moods (Haugan et al., 2013; McGilton et al., 2012). Using quantitative methods, Haugan et al. (2013) and McGilton et
al. (2012) examined the relationship between formal caregivers’ relational behaviours and the mood and affect of residents with dementia (McGilton et al., 2012) and residents who were cognitively intact (Haugan et al., 2013). The two other studies examined the role of formal caregiving relationships on residents’ sense of thriving (Bergland & Kirkevold, 2005) and their perception of the quality of care being provided (Bowers et al., 2001).

Comparing three residential facilities, McGilton et al. (2012) found there were significant negative correlations between formal caregivers’ relational behaviours and residents’ mood and affect. Formal caregivers’ relational behaviours were measured using the ‘Relational Behaviour Scale’ (RBS), a three-item instrument assessing formal caregivers ‘verbal and non-verbal empathic and reliable behaviours’ (McGilton, 2004). The McGilton et al. (2012) study revealed residents’ level of anxiety and fear was negatively correlated to formal caregivers’ relational behaviours in Facility A ($r = -0.64, p < 0.01$), Facility B ($r = -0.70, p = 0.001$), and Facility C ($r = -0.86, p < 0.001$), especially during the morning care routine (bathing, toileting, dressing) (Facility A: $r = -0.49, p = 0.004$; Facility B: $r = -0.59, p = 0.006$; and Facility C: $r = -0.52, p = 0.034$).

Residents’ ‘sadness’ was also negatively correlated with formal caregiver relational behaviours in Facility A ($r = -0.57, p = 0.001$), Facility B ($r = -0.58, p = 0.007$), and Facility C ($r = -0.69, p = 0.002$). Residents who received less relational behaviours from formal caregivers experienced high levels of anxiety, fear and sadness, and displayed more anger, than those residents experiencing more relational behaviours from formal caregivers. The study also revealed that formal caregivers typically provided more consistent verbal and non-verbal empathetic behaviours during non-direct care activities rather than during the morning care routine or at meal-times.

However, residents that caregivers deemed resistive to care tended to receive less relational behaviours across all time points (morning care, meal-time and care during interpersonal contact). The McGilton et al. (2012) study also found several positive correlations between formal caregivers’ relational behaviours and residents’ positive affect. Positive correlations between
residents ‘pleasure’ and formal caregivers’ relational behaviours was seen during morning care in Facility A ($r = 0.36$, $p = 0.04$) and during interpersonal contact in Facility B ($r = 0.61$, $p = 0.004$).

Positive correlations between residents’ mood and formal caregivers’ behaviours was also seen in the Haugen et al. (2013) study involving cognitively intact residents. Using structural equation modelling, residents who had more positive interactions with formal caregivers reported less depressive symptoms than residents experiencing negative interactions with formal caregivers ($\gamma_{1,1} = -0.37$). For the purposes of the Haugen et al. (2013) study, positive interactions were described as those that made a resident feel good, enhanced a resident’s trust or confidence in the caregiver, and promoted respect and acknowledgement of the resident by the formal caregiver. Unlike the McGilton et al. (2012) study, Haugen et al. found no association between formal caregivers’ positive interactions and a reduction in residents’ anxiety levels.

In one of the two other qualitative studies examining the impact of formal caregiving relationships upon residents, Bergland and Kirkevold (2005) found these relationships were integral to some resident’s sense of thriving. Thriving, as conceived of by Berkland and Kirkevold (2005), as a “multidimensional phenomenon that includes a resident’s subjective experience of satisfaction” (p. 365); “reflecting emotional wellbeing and feelings of contentment with one’s life” (p. 365). Bower’s study revealed for some residents, a personal and close relationship with specific formal caregivers was crucial for their experience of thriving in RAC. These relationships were characterised by trust, rapport, a sense of attachment, mutuality and friendship, which developed through a common caregiving history shared by both. Formal caregiving relationships with these residents extended beyond caregiving duties to encompass support for their whole life.

Other residents noted thriving without having a close relationship with formal caregivers. However, formal caregivers’ positive relational behaviours, such as demonstrating caring, kindness, helpfulness, and friendliness, was the foundation upon which they experienced thriving. Berkland and Kirkevold (2005) also found that for some residents ‘their perception of the quality
of formal caregiving relationships was associated with their perception of the quality of care being provided (Bowers et al., 2001). This was demonstrated in the Bowers et al. (2001) study. Bowers et al. found many residents measured the quality of care they received by the quality of relationship formed with formal caregivers. This was based on the degree of closeness residents experienced, the positive impact formal caregivers had on residents’ affect, reciprocity within the formal caregiver-resident relationship, and evidence of a genuine friendship, including demonstrations of affection.

These four studies examining the impact of formal caregiving relationships on residents suggest formal caregiving relationships can play an integral role in the wellbeing of residents. These relationships facilitate aspects of psychological wellbeing, positive affect, and/or contribute to a resident’s perception of the quality of care being received. While not every resident reports gaining a benefit from formal caregiver relationships, a larger proportion of residents do. These studies also highlight the need for continuity in staff and a low staff turnover rate. Only in this context can the differing forms of relationships seen within RAC, and described in several studies, fully develop and be able to positively impact on residents’ wellbeing. Unfortunately, RAC often relies on the use of casual and agency staff to fill shift vacancies, and, as noted in earlier chapters, staff turnover within the sector is common (Quadagno & Stahl, 2003). These barriers, identified also in Brown-Wilson et al. (2009), Cook and Brown-Wilson (2010) and Walsh and Shutes’ (2013) studies, hinder the development of formal caregiving relationships with residents.

**Barriers to formal caregiving relationships with residents.** In examining the research on hindrances to formal caregiving relationships with residents, eleven papers specifically identified a number of barriers stymieing these relationships. These included: residents’ behaviors of concern (Edberg et al., 2008; Scmidt et al., 2012; Zwijsen et al., 2014), staff burnout and/or staff’s mental health issues (De Rooij et al., 2012; Testad et al., 2010), staff’s attachment style (Kokkonen et al.,
2014), staff assignment and work shifts (Burgio et al., 2004), and the organisational culture of RAC (Bishop et al., 2008; Banerjee et al., 2015; DeForge et al., 2011).

Three of the articles exploring the nature and quality of formal caregiving relationships (discussed at the start of this chapter) also identified several barriers, as well as confirming others (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010; Walsh & Shutes, 2013). These three studies revealed that discontinuity in staff, residents’ communication and visual or hearing difficulties, and formal caregivers’ unwillingness to engage in personal dialogues with residents, tended to diminish or hinder the formation of close formal caregiving relationships with residents. Walsh and Shutes (2013) also identified language barriers, stemming from a formal caregiver’s CALD background, as being an impediment to the development of formal caregiving relationships with residents.

**Residents behaviours of concern.** Frequently noted within aged care research is the impact of behaviours of concern from older people upon family caregivers (Croog, Burleson, Sudilovsky, & Baume, 2006). ‘Behaviors of concern’ pertains to any behaviors which may result in harm to the person exhibiting these behaviors, or to other people or property (The Bridging Project, 2009). Behaviors of concern typically result in emotional or psychological distress, physical injury, and/or destruction of property (Lowe et al., 2007). Behaviors of concern are considered a form of communication (Cooper et al., 2009). They may convey the message that there is something wrong within the person’s body (i.e., pain, hunger, thirst) or that they need or want something (The Bridging Project, 2009). Behaviors of concern can also communicate that a person is feeling upset, or that they may be suffering with a mental health issue such as psychosis or depression (Cooper et al., 2009). Residents’ behaviours of concern is also implicated in formal caregiving distress (Brodaty et al., 2003; Zwijsen et al., 2014). The impact of behaviours of concern on the formal caregiving relationship has been explored in three studies, all of which pertained to
residents with a diagnosis of dementia (Edberg et al., 2008; Schmidt et al., 2012; Zwijsen et al., 2014).

In a qualitative study undertaken across three countries (Australia, Sweden and England), Edberg et al. (2008) found formal caregiving relationships with residents with dementia were characterised by strain arising from “being unable to reach” residents (pg. 239). Communication difficulties and the struggle to determine residents’ needs, especially when there was minimal life history available, generated feelings of caregiver inadequacy and guilt in formal caregivers. The inability to provide comfort and alleviate a resident’s distress created strain within the formal caregiving role. This was often the result of limited opportunities and resources and caregiving constraints which hindered formal caregivers’ capacity to provide care in the manner consistent with what they believed residents needed. The Edberg et al. (2008) study also found residents’ emotional and psychological needs often overwhelmed formal caregivers, who felt their own emotional wellbeing would be negatively impacted if they attempted to engage with residents to meet these needs.

In the Schmidt et al. (2012) study, resident aggression and the presence of depression or apathy in a resident was associated with higher levels of formal caregiving distress. As these levels of distress increased, the effectiveness of formal caregiving decreased, as did formal caregivers’ work ability, general health and the degree of burnout experienced. The Schmidt et al. (2012) study also found formal caregivers who scored higher in levels of burnout demonstrated a decreased willingness to help residents. These formal caregivers reported an increased intention to quit, and increasing negative emotional reactions.

Similar to the findings of Schmidt et al. (2012), the Zwijsen et al. (2014) study also found that formal caregivers experienced the highest levels of distress when residents expressed agitation or aggression towards them. A resident’s disinhibition and irritability or lability also generated high levels of distress in formal caregivers. The Zwijsen et al. (2014) study did not find a correlation
between residents’ depression or apathy and formal caregivers’ distress, as was seen in the Schmidt et al. (2012) study.

**Burnout and mental health issues.** As implicated in both Schmidt et al. (2010) and Zwijsen et al. (2014) burnout among formal caregivers is a potential barrier to formal caregiving relationships with residents, and is associated with aged care staff turnover (Schmidt et al. 2010). Burnout is conceptualised as a combination of emotional exhaustion, depersonalisation and reduced personal accomplishment (Maslach, Jackson & Leiter, 1996). Emotional exhaustion refers to diminished emotional resources needed to effectively cope and deal with stresses and/or challenges (Maslach, Jackson & Leiter, 1996). Depersonalisation is a sense of disconnection to one’s self and environment which can generate negative and cynical feelings towards others (Maslach, Jackson & Leiter, 1996). Reduced personal accomplishment includes negative evaluation of self, and a decreased sense of achievement within the work environment (Maslach, Jackson & Leiter, 1996). Collectively, all these aspects of burnout decrease formal caregivers’ health and wellbeing and are associated with a reduction in the level of interactions formal caregivers have with residents (Schmidt et al., 2010).

Several risk factors which have been identified in the development of burnout and mental health issues among formal caregivers include; the length of time in one’s role (De Rooijs et al., 2010), one’s attachment style (Kokkonen et al., 2014), and a perceived lack of managerial and peer support (Testad et al., 2010). In the De Rooijs et al. (2012) study, emotional strain/burnout and mental health issues, such as anxiety, depression, social withdrawal and somatic symptoms, were positively correlated with the length of time in the formal caregiving role (De Rooijs et al., 2012). The De Rooijs et al. (2012) study also revealed formal caregivers who worked in small scale facilities had higher rates of emotional exhaustion, compared to those working in a traditional setting. Increased emotional exhaustion was correlated with more experiences of depersonalisation ($r = 0.58, p < .01$) and increased rates of mental health problems ($r = 0.70, p <$
Similarly, formal caregivers who experienced more depersonalisation also reported more mental health problems \( (r = 0.46, p < .01) \).

De Rooijs et al. (2010) suggest the difference in emotional exhaustion scores seen between traditional and small-scale facilities is because greater levels of teamwork and staff support are available within traditional settings. Small-scale facilities have lower numbers of staff, who, in addition to caregiving also undertake more domestic duties such as cooking, cleaning and laundry. Thus, formal caregivers have less contact and less time to interact with team members who may provide the emotional support they need.

Examination of attachment style in the role of formal caregiving burnout was examined by Kokkonen et al. (2014). Kokkonen proposed that a formal caregiver’s adult attachment style influences their capacity to manage stress (burnout), and shapes their caregiving relationship with residents, especially those with dementia. Kokkonen et al. (2014) found formal caregivers who reported more attachment-related anxiety had higher levels of emotional exhaustion \( (r = 0.26, p < 0.05) \), as did those with attachment-related avoidance \( (r = 0.27, p < 0.01) \). Thus, higher levels of burnout were found among those formal caregivers who had an insecure attachment (anxious or avoidant). Attachment-related anxiety was also correlated with lower levels of geriatric nursing self-efficacy \( (r = -0.33, p < 0.01) \), and less person-centred attitudes including recognition of personhood \( (r = -0.32, p < 0.01) \). On the other hand, formal caregivers who reported high levels of self-efficacy had less emotional exhaustion \( (r = -0.20, p < 0.05) \), a decreased sense of depersonalisation \( (r = -0.28, p < 0.01) \) and reported a greater sense of personal accomplishment \( (r = 0.37, p < 0.01) \). Both attachment-related anxiety \( (r = 0.30, p < 0.05) \) and avoidance \( (r = 0.20, p < 0.05) \) were correlated with higher levels of depersonalisation among formal caregivers.

Kokkonen et al. (2014) suggested that anxiously-attached formal caregivers were more likely to become overwhelmed by the needs and suffering of residents, whereas those who have an avoidant-attachment may be less vulnerable to burnout and stress because of their tendency to
emotionally detach from residents. Therefore, formal caregivers with either an avoidant or anxious attachment style are potentially more likely to be restrained in pursuing and maintaining a relationship with residents, than are formal caregivers who have a secure attachment.

In a study by Testad et al., (2010) organizational culture and formal caregivers’ mental health and wellbeing including their level of perceived stress, psychological distress and somatic health complaints was examined. Perceived stress was defined as the degree an individual finds their life, including working life “unpredictable, uncontrollable, and overloading” (Cohen et al., 1983, p. 387). Psychological distress was determined by the presence of symptoms of anxiety and depression, and somatic health complaints included musculoskeletal, pseudo-neurology, gastrointestinal problems and allergies.

The organisational factors surveyed in Testad et al. (2010) included ; the quality of leadership (the degree of assistance, problem solving and encouragement management provided), job demands (ability to undertake set tasks), role demands (how well the role is defined), control at work (capacity to organize one’s task and engage in decision-making), mastery of work (satisfaction with the quantity and quality of work), predictability of work, social interactions (emotional support from colleagues and managers), commitment to organisation, organisational culture (degree to which the organization is competitive, supportive, suspicious, relaxed and rule based), and work motives.

Testad et al. (2010) found that emotional support, through social interaction from other formal caregivers and managers, was associated with a reduction in a formal caregivers’ perceived stress ($r = -0.19, p < .01; r = -0.14, p < .05$ respectively). Formal caregivers who reported having less control at work were more likely to score higher in perceived stress and psychological distress ($r = -0.21, p < .01; r = -0.18, p < .05$ respectively). Similarly, formal caregivers who had less mastery over their work also scored higher in perceived stress and psychological distress ($r = -0.18, p < .05; r = -0.21, p < .01$ respectively). Leadership that showed favouritism to certain workers, failed
to encourage staff or recognize their opinions, and were reluctant to address issues raised by workers was associated with increased rates of perceived stress, psychological distress and somatic health concerns among formal caregivers ($r = -0.36, p < .01; r = -0.15, p < .05; r = -0.15, p < .05$ respectively). Lastly, organisational cultures which were encouraging, equitable, relaxed and supportive, and enabled workers to take initiative rewarding them for their efforts were correlated with less perceived stress and somatic health issues among formal caregivers ($r = -0.18, p < .01; r = -0.17, p < .05$ respectively).

**Organisational culture.** One of the findings from the Testad et al. (2010) study was that formal caregivers reported lower stress and distress levels, and had less somatic health conditions, when they worked in a facility where management was viewed as fair and supportive. Testad et al. (2010) also found that formal caregivers who had greater autonomy and congruency within their role also reported less stress and distress levels, and had fewer somatic health conditions. This suggests the organisational culture is influential upon the formal caregiving role, and as such, can negatively impact upon formal caregiving relationships with residents.

Examining organisational culture was the focus of the DeForges et al. (2011) qualitative study. Using observation methods and semi-structured interviews DeForges et al. (2011) sought to understand the culture of care within Canadian RAC facilities and examine its influence and consequence for both caregiver and care-recipient. Specifically, DeForges et al. (2010) examined formal caregivers’ perceptions of residents’ needs, both met and unmet, and how the socio-political/structural conditions impacted their relationships with residents. Two themes emerged: ‘afraid to care’ and ‘unable to care’. Participants spoke of the impact of surveillance and regulation within the RAC sector and how the need for compliance to government, state and facility mandated requirements has generated fear of ‘doing the wrong thing’. DeForge et al. (2010) found the formal caregiver’s fear of doing the wrong thing, even though it may have been the ‘right’
caregiving practice prior to the new regulation, has led to the phenomenon of being ‘afraid to
care’.

The study also found that mandated regulations have increased the time formal caregivers
spent undertaking non-care related tasks (i.e., paperwork). This has resulted in formal caregivers
having less time to engage in direct caregiving activities. The increased burden of bureaucracy
results in formal caregivers now being ‘unable to care’. DeForges et al. (2010) adds “[when]
responsibilities to care for others are displaced by measures of accountability... leaves many
frontline long-term care providers afraid and unable to care”(p. 424). Thus, time pressures,
increased burden of bureaucracy and an environment of compliance appears to facilitate feelings
of being monitored, creating an organisational culture which influences formal caregiving
relationships with residents.

The theme ‘unable to care’, identified in the DeForges et al. (2010) study was also echoed in
a feminist ethnographic qualitative study undertaken by Banerejee et al. (2015). Banerejee et al.
(2015) argued RAC is influenced by a reductionist model, whereby care is “manageable by
excluding personal and contextual properties” (p. 30) which is necessary in order to improve its
quality, effectiveness and accountability. As such, the provision of individualised relational
caregiving, often considered difficult to standardise and quantify, is difficult within a socio-
political environment which mandates time efficiency and the standardisation of all care processes.

The Banerejee et al. (2015) study revealed aged care facilities had a hierarchal structure, where
the opinions of nurses and physicians were seen as sacrosanct while the opinions of formal
caregivers held little power in the decision making about resident care. Formal caregivers were
deemed to be at the bottom of this hierarchal structure despite the fact they were often the conduit
by which nurses and physicians gained information about residents. Participants spoke of being
unable to care in a manner consistent with their beliefs about their caregiving role. Formal
caregivers noted having the least amount of autonomy within their role, felt they were voiceless,
and viewed their work as providing “assembly line care” because of high workloads and rigid timelines (p.32). Banerjee et al. (2015) found this conflicted with formal caregivers’ desire to ‘treat people as human beings’ and belief that their role should also encompass relational caregiving.

Relational caregiving was viewed as meeting residents’ spiritual, emotional, social and existential needs in addition to instrumental care duties. Banajeree et al. (2015) noted relational care provided formal caregivers with the greatest sense of achievement and satisfaction, and conversely, was the biggest source of frustration when unable to engage in relational caregiving. Participants in the Banerjee et al. (2015) study reiterated that relational care was largely undocumented work with the aged care system seeking accountability solely through documentation of instrumental care practices. As such, management prioritised instrumental care over relational care, with interviewees noting their lack of voice meant they could not influence those policies which hindered relational caregiving.

One of the limitations in the Banajeree et al. (2015) study was that it did not examine the impact of organisational culture upon residents’ wellbeing. This was considered in the Bishop et al. (2008) study, exploring formal caregivers, the organisational culture and its impact on residents’ wellbeing. Bishop et al. (2008) examined formal caregivers’ job satisfaction, their satisfaction with income, advancement opportunities, job commitment (intention to stay), quality of supervisory relationship, job autonomy, and satisfaction with supervision provided within each facility. The study also explored the quality of life and relationship satisfaction of residents.

Bishop et al. (2008) found satisfaction with pay, advancement opportunities and being respected by one’s supervisor was significantly positively correlated with formal caregivers’ intention to stay. Additionally, residents reported better quality of life and greater levels of satisfaction with the relationship formed with formal caregivers when those formal caregivers reportedly scored higher in job commitment. This suggests formal caregivers who are committed
to their role and enjoy their work are more likely to engage with residents in a positive manner (Bishop et al., 2008). This in turn enhances the formal caregiving relationship formed with a resident.

The Bishop et al. (2008) study recruited only formal caregivers who worked in a full-time capacity. This is not representative of the actual workforce within most RAC facilities, which typically employ both casual and part-time staff. Examination of the impact of staff assignment and work shifts upon the quality of care was undertaken in Burgio et al. (2004). The study found that residents rated their level of care (defined as personal appearance and hygiene) higher when cared for by formal caregivers who worked in a full-time, permanent capacity. Residents whose care was provided by formal caregivers on a rotating shift expressed less satisfaction in the level of care they received. Increased job satisfaction and lower levels of burnout were also seen among formal caregivers who were permanently employed, compared to those on rotating shifts. The Burgio et al. (2004) study highlights the importance of consistency in staff, not only for the delivery of care, but also for the emotional wellbeing of formal caregivers.

**Formal caregiving relationships with diverse populations**

RAC accommodates a myriad of residents, including older residents, the young, and residents from culturally and linguistically diverse (CALD) backgrounds. The RAC population to receive the most examination thus far has been residents with dementia. In total, the literature search yielded seven articles which examined formal caregiving relationships to residents with dementia (De Rooij et al., 2012; Edberg et al., 2008; Kokkonen et al., 2014; McGilton et al., 2012; Schmidt et al., 2012; Testad et al., 2010; Zwijsen et al., 2014).

Unfortunately, this literature search did not yield any studies examining formal caregiving relationships with residents from a CALD background. Previous studies have already established the difficulties formal caregivers experience when relating to older residents with visual and
hearing impairments (Edberg et al., 2008; Schwidt et al., 2012), while Walsh and Shutes’ (2008) study demonstrated the challenges RAC facilities face when employing formal caregivers from a CALD background. According to the King et al., (2010) examination into the use of CALD formal caregivers within Australian RAC, it was found that communication difficulties were the number one complaint among formal caregivers and managers alike. It is likely then that formal caregivers may also struggle to relate to residents who are from a CALD background, not only because of communication difficulties but also a lack of awareness around residents’ cultural requirements.

Only one article was identified of particular relevance to this dissertation and its focus on formal caregiving to younger residents in aged care facilities, examining this specific resident population group. Marshall and Baffour’s (2011) qualitative study explored the experiences of young adults aged between 30-45 years living in a long-term care (LTC) facility in Washington, USA. The LTC facility contained residents under fifty (45%) and over sixty years (65%) and provided long-term accommodation and speciality care for those with brain injuries, neurodegenerative disorders, those requiring dialysis or who had an infectious disease, such as HIV/AIDS. The length of time younger residents spent living in the LTC ranged from 2 months to 12 years.

Several themes emerged in Marshall and Bauffour’s (2011) study, including: disconnection from social supports and family, limited finances, inappropriate activities offered by the LTC facility, and poor relationships with formal caregivers. Marshall and Baffour’s (2011) study found younger residents felt unheard by formal caregivers and reported difficulties within their relationships with them. They noted formal caregiving staff often failed to listen, acknowledge and act on their requests, especially requests for privacy and autonomy. The study also found younger residents’ relationships with formal caregivers was considered to be of poor quality, since many formal caregiving staff made little attempt to engage with them.
Discussion

This review investigated the current body of literature pertaining to formal caregiving relationships with residents within a RAC setting. It sought to define the nature and quality of formal caregiving relationships, understand the benefits and barriers to these relationships, and to examine formal caregiving relationships with specific aged care populations.

Twenty-two papers were deemed relevant. Seven articles explored the nature and definition of formal caregiving relationships (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010; Edward et al., 2003; Jones & Moyle, 2016; Lung & Liu, 2016; McGilton & Boscart, 2007; Walsh & Shutes, 2013), three of which identified several distinctive relationship types (Brown-Wilson et al., 2009; Cook & Brown-Wilson, 2010; Walsh & Shutes, 2013). These included relationships which focused on the provision of instrumental care, those which were personal and responsive, and possessed qualities of friendship or familial relationships, and relationships which were considered reciprocal. The latter two of which involved mutual sharing of personal details, storytelling, and working together to achieve common goals of caregiving. ‘Personal and responsive’, and reciprocal relationships, afforded formal caregivers with a greater capacity to personalise caregiving because these relationships generated intricate knowledge of a resident, and procured their trust.

However, the formation of ‘personal and responsive’, and reciprocal relationships, appears to be contingent on the expectations and willingness of both parties. Both residents and formal caregivers who regard the formal caregiving role as providing only instrumental care may choose to not engage in conversations that might lead to a greater connection with each other (Lung & Liu, 2016). Additionally, the fear of breaking ‘professional boundaries’ as noted in Jones and Moyle’s (2016) Australian study also stymies the deepening of formal caregiving relationships with residents.
The literature search yielded only one article which explored the quality of formal caregiving relationships (McGilton & Boscart, 2007). This quality was measured by the degree of closeness shared by a formal caregiver and a resident. The construct of ‘closeness’ has yet to be formally identified and/or established by research, and as such, ‘closeness’ may mean different things to different people, making it difficult to quantify. For residents though, closeness appears to be based on the competence of the formal caregiver, and their capacity to know the resident, and their needs and preferences intricately. For formal caregivers, the hallmarks of closeness are a sense of connectedness to a resident involving knowledge of that resident, and a reciprocity that allows caregiving goals to be achieved (McGilton & Boscart, 2007).

Beyond a resident and formal caregiver’s willingness to know and become known by one another, the RAC context itself creates barriers to developing closeness. Thirteen studies, comprising of both qualitative and quantitative research, answered the question of identifying the barriers to formal caregiving relationships with residents. These barriers included resident, staff and organisational factors. Nearly a third of all the articles reviewed were devoted to the examination of dementia populations. Caring for residents with dementia is challenging work, and the behaviours of concern often accompanying it are associated with higher levels of distress, mental health issues and burnout among formal caregivers (de Rooij et al., 2012; Edberg et al., 2008; McGilton et al., 2012; Schmidt et al., 2012; Zwijsen et al., 2014). Notwithstanding, inadequate staff support, placement in smaller residential units which require more diverse formal caregiving activities (i.e., cooking and laundry), and frequent exposure to residents’ behaviours of concern, exacerbate the general distress arising from providing dementia care (de Rooij et al., 2012; Zwijsen et al., 2014).

Aside from the distress formal caregivers may experience, the formal caregiving role can often elicit caregiver guilt and inadequacy. This is often seen when communication difficulties arise which hinder the capacity to understand a resident’s need, or when a formal caregiver feels unable
to calm an agitated and distressed resident (Edberg et al., 2008). For some formal caregivers, their capacity to manage these feelings and continue on to provide care to residents is limited because of intrinsic personality dispositions (Kokkonen et al., 2014). Unfortunately, only one quantitative cross-sectional study examined personality variables in caregiving. This focus was on a formal caregivers’ attachment style, finding those with an insecure attachment were more likely to experience burnout than formal caregivers with a secure attachment style. (Kokkonen et al., 2014). A greater examination of other personality factors, such as coping styles, propensity for neuroticism, and relational beliefs systems would yield a more comprehensive understanding of formal caregiving responses when caring for residents.

Other staff barriers impeding formal caregiving relationships are language difficulties and cultural misunderstandings arising from formal caregivers from a CALD background (Walsh & Shutes, 2013). Formal caregivers from CALD backgrounds are common within the RAC sector, and the communication difficulties arising impede their relationships with other staff and residents alike. Sadly, some CALD formal caregivers experience racial discrimination from residents, which likely prevents the formation of formal caregiving relationships beyond that of solely instrumental care (Walsh & Shutes, 2013).

Also identified within the literature are organisational barriers which hinder the formation of formal caregiving relationships with residents. The use of non-permanent staff is commonplace within the RAC sector, despite research showing that full-time formal caregivers report higher job satisfaction and experience less burnout than non-permanent staff. Non-permanent formal caregivers are not the only ones impacted by variant employment. Residents also express less satisfaction with the level of care they are provided with by non-permanent staff, who will have typically had less opportunity to get to know the resident, their needs and their preferences (Burgio et al., 2004).
The nature of RAC is also one heavily regulated by compliance demands and stakeholder accountability. The extra work these generate is often relegated to the formal caregiving role. This in turn reduces the time formal caregivers can devote to residents (Banerjee et al., 2015; Jones & Moyle, 2016). A common complaint among formal caregivers is insufficient time to provide residents with an appropriate level of care, or care that is congruent with formal caregivers’ beliefs (De Forges et al., 2011).

Compliance demands create an environment of fear in which formal caregivers feel ‘unable’ and ‘afraid’ to care (De Forges et al., 2010). They fear doing the wrong thing according to organisational policy. Formal caregivers also fear getting into trouble because of procedural change, so that what was once the ‘right’ way, has now become the ‘wrong’ way of providing care. The additional non-caring duties commonly found within the formal caregiving role, coupled with feeling both ‘unable’ and ‘afraid’ to care, typically result in formal caregivers engaging in instrumental caregiving relationships only.

This is problematic, since the deeper formal caregiving relationships such as ‘personal and responsive’ and ‘reciprocal’, coined by Brown-Wilson et al. (2009), can positively impact upon residents’ mood, quality of life, and their perception of the quality of care given (Bergland & Kirkevold, 2005; Bowers et al., 2001; Haugan et al., 2013; McGilton et al., 2012). In total, four studies focused on the impact of formal caregiving relationships with residents (Bergland & Kirkevold, 2005; Bowers et al., 2001; Haugan et al., 2013; McGilton et al., 2012). McGilton et al. (2012) and Haugan et al. (2013) examined the relationship between formal caregivers’ relational behaviours on the mood/affect of residents with dementia (McGilton et al.) and without dementia (Haugan et al.) respectively. Positive formal caregiving relationships are associated with less depressive symptoms in residents. Those residents receiving less relational behaviours from formal caregivers tend to experience higher levels of anxiety, fear and sadness, as well as display more anger, than those residents who experience more relational behaviours from formal caregivers.
Two qualitative studies (Bergland & Kirkevold, 2005; Bowers et al., 2001) also explored how ‘close’ formal caregiving relationships benefited residents. For some residents, ‘close’ formal caregiving relationships are considered essential to their emotional wellbeing and life satisfaction (Bergland & Kirkevold, 2005), and for others close formal caregiving relationships are integral to their perception of the quality of care being provided (Bowers et al., 2001). But when residents are cared for by formal caregivers who are less attentive and attuned to them, the research suggest residents are likely experience increased levels of sadness, anxiety and fear, compared to caregiving provided within the context of ‘personal & responsive’ and ‘reciprocal’ relationships (Haugan et al., 2013; McGilton et al., 2012).

What is disconcerting in the Australian RAC setting is the seeming lack of engagement between formal caregivers and residents, with residents being left alone for nearly half of the time, and when attended to are largely ignored by formal caregivers (Edwards et al., 2003). Only minimal interactions between formal caregiver and resident are not conducive to the deepening of the formal caregiving relationship, in which the resident feels heard and understood, and the formal caregiver understand and fulfills the caregiving need.

In answering the final question of this literature review, formal caregiving relationships with diverse aged care populations, revealed a paucity of research in this area. Only one article regarding relationships with younger residents in aged care was identified (Marshall and Baffour, 2011). This noted little engagement between younger residents and formal caregivers, and poor quality relationships. The aged care population group of greatest focus in research was residents with dementia, which was examined in six studies (de Rooij et al., 2012; Edberg et al., 2008; Kokkonen et al., 2014; McGilton et al., 2012; Schmidt et al., 2012; Zwijsen et al., 2014).

**Limitations**

Limitations of the papers examined in this review are reported in Table 4.1, most of these pertained to generalisability of the findings, or sample size used. Only three studies were
undertaken in Australian RAC facilities (Edberg et al., 2008; Edwards et al., 2003; Jones & Moyle, 2016). Aged care policies and funding likely differ significantly between countries, and even states. Since these factors contribute to the work environment and organisational culture, the transferability of findings into an Australian context is difficult.

Further, many of the quantitative studies utilised a cross-sectional approach which hinders establishing causality. Thus, other confounding variables may be influencing the results of these studies. The reliance on observations and self-report measures in many of the qualitative and quantitative studies exposes these studies to potential bias, and any conclusions made from this review are provisional. Many residents were selected for participation by a head-nurse (Edwards et al., 2003), while the recruitment process utilised in many studies was typically opportunistic. Bias in selection and the lack of sample randomisation again in quantitative studies impacts the transferability of the findings.

All but one of the eleven qualitative studies achieved methodological rigor through triangulation from use of multiple methods of data collection (observations, focus groups and interviews) and differing participant groups (residents, family members, formal caregivers and nurses) within each study (Bergland & Kirkevold, 2005; Bowers et al., 2001; Brown-Wilson, Davies & Nolan, 2009; DeForges et al., 2011; Edberg et al., 2008; Jones & Moyle, 2016; Lung & Liu, 2016; Marshall & Baffour, 2011; McGilton & Boscart, 2007; Walsh & Shutes, 2013). Cook & Brown-Wilson’s (2010) study was a re-analysis of transcripts from two previous studies, each one undertaken by both authors. The methods from one of the original studies could not be ascertained, and as such, determining methodological rigor was impeded.

Lack of formalised definitions for concepts such as ‘closeness’, and ‘personally meaningful relationships’ means participants’ perceptions may differ significantly. Thus, for one resident, a ‘close, personally meaningful relationship’ with a formal caregiver, may be very different to another resident. The inherent subjectivity in defining the nature and quality of formal caregiving
relationships is problematic for gaining a comprehensive and consolidated understanding of these relationships. The fact that only seven studies examined either the nature or quality of formal caregiving relationships perhaps reflects the issues researchers face in light of concepts not properly codified.

Implications & Conclusions

The very nature of the caregiving act suggests that some sort of relationship between caregiver and recipient will likely develop as a by-product. Caregiving is fundamentally a relational act between two people, an act from which both giver and recipient can benefit. This is true even within a paid context. For those formal caregiving relationships which extend beyond mere instrumental care, bonds of friendship, support, knowing, reciprocity and care can have a positive impact for all involved. For residents, relationships with their caregivers can improve their mood and sense of wellbeing, as well as decrease anxiety, fear and sadness, likely commonplace when moving from one’s own home. When not impeded by resident, staff or organisational factors, these relationships can provide formal caregivers with an opportunity to express their care for residents in ways congruent with beliefs and residents’ needs. This manner enhances job satisfaction, job commitment and intention to stay, all of which are necessary to facilitate the development and maintenance of beneficial formal caregiving relationships.

Despite the importance formal caregiving relationships play in the life of the resident, the formal caregiver and the general functioning of the facility and the wider organisation, these relationships remain poorly defined and understood. Even worse is the seeming disregard policy, protocol and procedures have for the formal caregiving relationship. The limited studies examining and assessing the quality of formal caregiving relationships begs for more research to be undertaken. This would help with codifying such relationships within policy and practice, and prioritising them within the formal caregiving role.
Beyond better descriptions and identification of the hallmarks of beneficial formal caregiving relationships, is the need for research into diverse populations within the RAC sector. Only one population group, residents with dementia, have been the focus of research, with no studies focusing on CALD residents. Only scant attention has been paid to another population often found in RAC; younger residents with high care needs. The single study identified within this review paints a poor picture of formal caregiving relationships with this population group. The growing number of younger residents entering aged care necessitates further research into this area.

The current literature review presented in this chapter tentatively defines several relationships which appear to exist in the RAC setting. The assessment of these relationships is even more limited, but the research in existence examining the barriers to these relationships is solid, especially for organisational and resident factors. Many of the organisation and resident factors identified in creating barriers to formal caregiving are likely seen throughout RAC worldwide. However, further examination of staffing factors, especially intrinsic beliefs and personality variables, would be beneficial for the recruiting and training of formal caregivers in developing more beneficial formal caregiving relationships with residents.
Chapter Five: The Research Process

As demonstrated in the previous chapter, a review of the literature examining formal caregiving relationships with residents, there are several areas where research is lacking. This included a narrow definition and limited formalisation of the nature of formal caregiving relationships, poorly defined quality indicators of those relationships and limited research into diverse populations within residential aged care. One population that remains largely unexamined is younger people living in aged care facilities. The purpose of this current chapter is to outline a qualitative research method for examining formal caregiving relationships with younger residents in Victorian aged care facilities. Since no previous research has been undertaken from the perspective of the formal caregiver, little is understood of the impact upon formal caregivers and their caregiving role when required to care for younger residents. Exploration of this situation will provide a better understanding of the unique challenges facing formal caregivers in care delivery and in the development and maintenance of formal caregiving relationships with younger residents.

Research Methodology

The qualitative research methodology chosen to examine formal caregiving relationships with younger residents is the Grounded Theory Method (GTM) (Glaser & Strauss, 1967) and Clarke’s Situational Analysis (2003; 2005). The GTM is an ideal research methodology for situations or phenomena that are under-researched as it allows for a more comprehensive exploration and thereby richer understanding of the complexities embedded into the situation to be discovered (Creswell, 1998). The GTM also facilitates the development of a theory that better explains the phenomenon through use of the common themes identified within the data. As reflected in Chapter Four, the development of a caregiving theory is warranted, as no caregiving theory involving the occupational context currently exists. Such a theory could inform Australian
RAC policy so that the needs of this unique population group could be better addressed. It would also allow for the development and implementation of interventions that enrich formal caregiving relationships with younger residents, which may help improve their quality of life.

Use of Clarke’s (2005) Situational Analysis of formal caregiving relationships with younger residents will enable the exploration of non-human elements i.e. staffing issues or policy and procedural requirements, which impact upon the social process within RAC. It will also allow for examination of the various positions of other stakeholders, besides formal caregivers, who influence formal caregiving relationships. This includes managers, residents and their families. A Situational Analysis will, therefore, better illuminate the controversies and discourses inherent within the RAC sector, and highlight those factors impacting upon formal caregiving relationships with younger residents.

**Grounded Theory Method (GTM).** Grounded theory emerged from the field of sociology, and was captured initially in Glaser and Strauss’ seminal work ‘Discovery of Grounded Theory’ (1967). The GTM drew on a symbolic interactionist perspective, combining examination of the patterns and processes in human interaction to aid identification of a shared group reality (Blumer, 1969), with the methodological inquiry of case comparison. GTM is, therefore, suitable for theory generation derived inductively from field data, and is particularly useful to modify existing theories when they no longer reflect the complexity of the phenomenon being examined (Creswell, 1998).

The process of GTM is rigorous to ensure conceptualisation of the investigated phenomenon is empirically established, and since it requires no priori hypotheses the resultant theory is said to be ‘grounded’ in the data (Faggiolani, 2011, p. 12). As the process identifies themes from within the data, which are then clustered together into broader concepts aiding explanation of the phenomenon, GTM moves beyond descriptive objectives to theory generation (Hodkinson, 2008).
The comparison between cases (people, policy, procedure) and the investigated phenomenon, results in probability statements from the data being examined (Glaser, 2001; 2003). These probability statements that illustrate the relationship between concepts, ‘[are] an integrated set of conceptual hypotheses developed from empirical data’ (Glaser, 1998, p.185). Unlike the concept of probability used in quantitative statistical methods, the validity of these probability statements is determined by fit, relevance, workability, and modifiability (Glaser & Strauss 1967; Glaser, 1978; 1998; 1992).

In GTM, the fit is a measure of how closely the concepts ‘fit’ with the incidents they are representing and indicates how comprehensively a researcher has undertaken the constant comparison of the incidents to the emerging concepts. Relevance in GTM refers to the extent to which a study reflects and explores the ‘real’ issues of its participants, while workability concerns how the theory ‘works’ to explain the phenomenon or issue across variances of the phenomenon. Lastly, validity in GTM is also measured by the degree to which its emergent theories of the phenomenon being studied can be changed when new data is compared to a researcher’s existing data. This is known as modifiability. While not interested in determining ‘right’ or ‘wrong’, an emerging theory will have either less or more of a fit, relevance, workability, and modifiability, than a differing theory (Glaser & Strauss, 1967; Glaser, 1978; 1998).

From its original beginnings, GTM has undergone theoretical and methodological debates and revision resulting in variations to its original conceptualisation. An acrimonious split between Glaser and Strauss over methodological differences resulted in the development of two differing paradigms; Straussian and Glaserian. Kelle (2005, p.69) states:

the controversy between Glaser and Strauss boils down to the question of whether the researcher uses a well-defined 'coding paradigm' and always looks systematically for 'causal conditions,' 'phenomena/context, intervening conditions, action strategies' and 'consequences'
in the data, or whether theoretical codes are employed as they emerge in the same way as substantive codes emerge, but drawing on a huge fund of 'coding families.'

Glaser argued researchers should examine the phenomenon without a priori research question or examination of existing information lest it “contaminate, constrain[ed], inhibit, stifle or otherwise impede the researcher's effort to generate categories, their properties, and theoretical codes” (Glaser, 1992, p.23). Strauss believed the use of a specified theoretical framework derived from knowledge of human action was necessary to ensure data is approached and analysed in a systematic manner, thereby ensuring its validity (Kelle, 2005). The divergence of these two paradigms is most evident around the process of coding.

In GTM, categories, codes and coding are fundamental to the process of theory generation. Open coding or substantive coding is the initial conceptualising of abstraction drawn from the written data including transcripts or field notes. Written data is analysed line by line to determine the nature of the problem and it potential resolution. These codes are noted in the margins of the written data. This allows for the emergence of concepts which can be renamed and/or modified. The process of comparing new data against the original codes facilitates the development of a theory explaining the phenomenon being researched (Glaser, 1998; 2001).

Once open coding has been completed and core categories are extracted that best explain the interrelationship between the phenomenon and its players, the use of selective coding is employed to delimit the study (Glaser, 1998; 2001). Data are coded according to the core categories, with other concepts arising from the data disregarded if they have little relevance to the core category. New data are selectively chosen with core categories in mind. This is known as theoretical sampling (Glaser, 1998; 2001).

Once selective coding has occurred, the researcher moves to generating theoretical codes which unify the theory from the categories to emerge from the data (Glaser, 1992). Essentially, theoretical coding is the application of a theory to the model of data being examined and
constantly compared with. This infers data sampling and analysis, and ultimately theory
generations, are neither distinct or disjunctive from each other but are different stages in the
research process that are repeated until new data are seen to modify the generated theory (Glaser,

Strauss and Corbin identified the three core components of any GTM (1997). These
include theoretically sensitive coding of the data to develop strong concepts which aid
explanation of the phenomenon being examined; theoretical sampling – selectively choosing
participants according to the theory being generated and commencing with data analysis at the
very first interview involving the writing down of memos and hypotheses. Lastly, comparing the
phenomena, emerging data and the context to strengthen the developing theory (Strauss & Corbin,
1997).

Constructionist Grounded Theory Method. Since Glaser and Strauss’ (1967) original
conceptualisation of GTM, many researchers have responded to its methodological limitations
incorporating and modifying GTM to reflect a differing philosophical position (Charmaz, 2006).
Modifications to the GTM by Bryant (2002), Charmaz (2006), and Clarke (2005) have generated
GTM with a postmodern, constructivist orientation. This orientation challenges GTM’s espousal
of the neutrality of the researcher, and instead of theory generation from data distinct from the
research and researcher, constructionist GTM advocates data and theories are intrinsically woven
together with the researcher.

This adaptation of the GTM affords the researcher with a capacity for reflexive
interpretation, necessary to generate credible analysis where there may be researcher bias arising
through prior knowledge of the subject manner (McGhee, Marland & Atkinson, 2007). This is
achieved because, unlike traditional GTM that minimises variation within the data to generate one
core category, constructionist GTM seeks to highlight the variability embedded in complex
processes and situations.
Constructionist GTM continues to use the processes of open and selective coding, constant comparison and theoretical saturation found in traditional GTM (Glaser & Strauss, 1967). These processes enable a researcher to move from descriptive analysis to examination and identification of the data to a broader category and then to an over-arching concept. This allows the researcher to examine the similarities and differences within the situation (Charmaz, 2006; Corbin & Strauss, 2008).

The keeping of written memos, or ‘running logs of analytical thinking’ throughout the process of data analysis generates and integrates codes and categories, and aids identification of the links between them. Additionally, the use of written memos also allows researchers to reflect on their own biases, attitudes, opinions and assumptions that might influence data interpretation.

**Situational Analysis.** One recreation of GTM which encompasses a constructionist orientation is Clarke’s (2003; 2005) Situational Analysis. Clarke did away with traditional GTM’s use of basic social processes and utilised Strauss’ social worlds, social arenas, and social negotiations framework. This allowed for the development of three types of analytic maps displaying the complexities embedded in the situation. These maps include Situational Maps, Social World/Arena Maps, and Positional Maps. Situational Maps portray the major human, nonhuman, discursive and other elements within the situation being explored, allowing for analyses of the relationship among them (Clarke, 2003, p. 23). Social World/Arenas Maps depict one or many social worlds, identifying the significant non-human elements such as technological process or policies, groups of collectives (people working together) and the ongoing debates occurring between and within each social world. (Clarke, 2005, p. 25). Positional Maps reveal the major positions held or rejected on key issues embedded within a situation (Clarke, 2005, p. 26).

Collectively, these maps afford a researcher insight into the significant aspects and conditions of a particular situation, embedding the research data firmly into its collective, cultural, social, temporal and organisational context. Additionally, since the goal of Situational Analysis is
to better capture and reflect the complexity and differences found in human situations, minority views, not traditionally represented in GTM, can now be more readily illuminated and examined for their impact on the situation.

Exploration of formal caregiving relations with younger residents in Victorian RAC using Clarke’s (2005) Situational Analysis will highlight the impact of non-human elements on caregiving i.e. staffing issues or policy and procedural requirements, upon social processes inherent in the situation. A Situational Analysis will also permit examination of the various positions held by other stakeholders as well as illuminating the controversies or differences impacting caregiving behaviours in a RAC facility. This allows for greater clarity into the factors impacting upon the formal caregiver and young person relationship. Clarke’s (2003) Situational Analysis use of reflexive processes to ensure quality and the legitimacy of research findings, will allow for any biases the author may have developed from years spent working in a residential facility to be considered and reflected upon.

Procedure

This interview-based qualitative research project received Human Ethic approval through Deakin University, with one subsequent amendment made after approval for the inclusion of interviews with managers. University ethics approval is included in Appendix A. Twenty-five facilities in Melbourne’s outer suburbs were contacted resulting in twelve facilities consenting to participate. A ‘participant information package’ including a plain language statement (PLS) and consent forms were distributed to those facilities granting initial approval for active participant recruitment from among their staff members. A return postage paid envelope containing a form seeking participant’s contact details was also included in order to organise each interview. This separate form containing participants contact details was later detached from the PLS and the
consent form, and removed and destroyed once the interview had occurred. The plain language statement, consent form and contact detail form are included in Appendix B.

Several open-ended questions were posed to participants exploring their experiences working in a residential facility (aged care or purpose-built) and younger residents. These included what made the formal caregiving role easier or more difficult, both generally and when caring for younger residents. Revision of the initial questions occurred during the first several interviews conducted. The ongoing and concurrent thematic analysis of the transcripts from these first several interviews revealed areas of information needed but not yet being elicited from participants. The initial interview guide including a schedule of proposed questions asked is included in Appendix C.

The interviews with participants ranged between 20-45 minutes in duration and were conducted at either Deakin University, Burwood Campus, or at a place convenient for the participant. The interviews were transcribed verbatim after completion of each interview, with memo and note-taking also occurring during and shortly after each interview. The interviewing period lasted approximately four months. While it was originally intended that interviews would be undertaken in a focus-group format, it became necessary to change this formal to in-depth, one-to-one interviews for the data collection process. This was for two reasons; since a number of participants were recruited from the same facility, and were often known to each other, a group interview was found to be inappropriate for the disclosure of honest opinions which may differ between interviewees. Thus, an individual interviewing context within a neutral environment was seen to better optimise understanding of the complex issues, processes and individual motivations. Secondly, the differing work times of participants required an interview method that was flexible in its delivery to better facilitate participation.
Participants

Twenty-six formal caregivers (4 males, 22 females) and two managers (1 male, 1 female) were recruited from ten RAC facilities and two purpose-built facilities. These participants formed a purposive sample, with no additional recruitment deemed necessary as thematic saturation was achieved. Seven of these formal caregivers (6 females, 1 male) and one female manager were employed across two purpose built non-government owned (NGO) facilities for younger people with high care needs. All possessed previous RAC experience. The nineteen remaining formal caregivers, and one male manager were recruited from a combination of two private ‘for profit’ facilities (5 participants: 4 female, 1 male manager), four not-for-profit NGO’s (7 participants: 5 female, 2 male), and four government-run RAC facilities (8 participants: 7 female, 1 male). See Table 5.1 for participant and facility detail summary.

Table 5.1. Summary of facility and participant details

<table>
<thead>
<tr>
<th># of Facilities</th>
<th>Facility Type</th>
<th>Female n =</th>
<th>Males n =</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Purpose-Built NGO</td>
<td>6 (FC)b</td>
<td>1 (FC)</td>
</tr>
<tr>
<td></td>
<td>1 (Manager)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Privately Owned Aged Care Facility</td>
<td>4 (FC)</td>
<td>1 (Manager)</td>
</tr>
<tr>
<td>4</td>
<td>Not-For-Profit NGO</td>
<td>5 (FC)</td>
<td>2 (FC)</td>
</tr>
<tr>
<td>4</td>
<td>Government Owned</td>
<td>7 (FC)</td>
<td>1 (FC)</td>
</tr>
</tbody>
</table>

a NGO denotes facilities run by a Non-Government Organisation  
b FC denotes Formal Caregiver

The ages of the formal caregivers participating varied from 18-66 years, with a mean age of 39 years (SD: 14.65 years). The average duration in the current place of employment was 4.3 years (SD: 9.7 years), and participants had generally worked 7.6 years (SD: 3.4 years) in the RAC sector. Fourteen formal caregivers (50%) had not attained an industry related qualification. Five formal caregivers had gained a Cert III or IV in aged care (18%). Another three attained Cert IV in disability (14%) and two formal caregiver had undertaken a Cert III in community services (4%).
Two formal caregivers had undertaken a diploma course in aged care (7%), with one manager completing a degree (4%) and the other manager undertaking post graduate studies in residential management services (4%). Of the twenty-eight participants interviewed, eleven were from culturally and linguistically diverse (CALD) background and none identified themselves as Aboriginal or Torres Strait Islander. Six participants with a CALD background originated from Asia, two from European countries and three from India.

Of the twenty-six formal caregivers, four were employed in a full-time capacity, nine were on a permanent part-time basis and the remaining thirteen employed as ongoing casual staff. With the exception of the two managers, all formal caregivers had the potential of working a variety of shifts (morning, afternoon and night duty), though most were given a degree of choice and flexibility in their working schedule.

The purpose-built facilities which participated in this study were managed by a sole not-for-profit organisation. These two purpose-built facilities accommodated eleven young people (in total) with high care needs who had previously resided in a RAC facility. The building of these facilities was enabled by funding procured through the Australian government’s Young People in Residential Aged Care (YPIRAC ) initiative (AIHW 2011).

Analysis Methods

The semi-structured interviews were audio-recorded and later transcribed verbatim. Memo/note taking occurred during the interview process and during the data analysis stage. Following a constructionist Grounded Theory Method espoused by Charmaz (2006), the transcribed data were inductively coded word-by-word and line-by-line along focused, axial and theoretical principles. Analytical categories were identified through the constant comparative method underpinning GTM. Through the construction of Clarke’s (2003) Situational Maps, Social Worlds/Social Arena Maps, and Positional Maps, the various positions and relationships were
explored, further broadening data analysis beyond descriptive categories and concepts emerging from coding alone to understand the complexities embedded within RAC. Analysis of data began at the commencement of the interviewing phase in 2013, continuing to the draft stage of the research write up in 2014. Data analysis was managed and expedited using the NVIVO-10 (Castleberry, 2014) software package to enhance theoretical conceptualisation and aid the rigorous analysis of data. Course specific, classroom-based training on NVIVO-10 was undertaken, and a university offered refresher course also completed one year later. One-to-one ongoing qualitative analysis assistance and feedback, coupled with regular supervision from a published qualitative researcher, ensured a rigorous data analytic process was followed.

Summary

The lack of research into formal caregiving to young people within a RAC setting justifies a qualitative, theory generating research paradigm, which is proposed herein. The study described herein affords examination of both the factors shaping the formal caregiving role and relationships with residents already identified through a review of the literature but within an Australian context; and allows for examination and understanding the dynamics of formal caregiving relationships with younger residents, not formally investigated by the current literature. This study also allows for investigation of ‘yet to be’ identified factors stymying quality caregiving to this population group, thus providing a basis to re-evaluate existing policy and procedures inherent in Australian RAC.

Additionally, analysis of the literature undertaken in the previous chapter identifying the factors influencing the formal caregiving revealed the lack of an apparent theoretical model explaining formal caregiving in a paid context. As none of the articles reviewed, extended or synthesised their findings to conceptualise a theoretical framework in which to understand formal caregiving in a RAC setting, this too is needed. As such, a Situational Analysis based on GTM will
allow for an in-depth exploration of formal caregiving relationships with younger residents and in
doing so, lay the foundation for the development of a formalised caregiving relationship theory.
Chapter Six: Caregiving Similarities and the Struggles Caring for Younger Residents

In this chapter and the following two chapters, the findings from interviews with twenty-six formal caregivers and two managers ⁴ about their experiences of formal caregiving to younger residents of aged care facilities will be detailed⁵. Caring for a younger resident is only one small aspect of the larger formal caregiving role which is heavily focused on care of older residents, and on the undertaking of a range of non-care duties.

The use of Clarke’s (2005) Social Worlds/Social Arena Maps (see Figure 6.1) helps to the conceptualise the parameters of this study, allowing for a comprehensive analysis of formal caregiving of younger residents within the larger context in which all formal caregiving occurs. Figure 6.1 demonstrates how the residential aged care (RAC) sector intersects with a myriad of differing social worlds such as residents, managers, organisational culture etc. It highlights an ongoing struggle facing formal caregivers, namely incongruence between the perceived formal caregiving role, and the actual formal caregiving which is expressed within a residential facility.

This chapter will begin by highlighting the similarities in caregiving to both younger and older residents. This will be followed by an exploration of participants’ views about the formal caregiving role and what constitutes good caregiving. This exploration will allow the social world’s stymieing the operationalising of caregiving beliefs into caregiving practice to be revealed. It will also be shown that this conflict is magnified for formal caregivers when caring for younger residents, the reasons for which will be explored comprehensively in Chapter Seven.

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⁴ For anonymity and confidentiality purposes, all comments made by interviewees containing references to residents will use the letter X to denote that resident. The letter X denotes each and all individual residents mentioned by interviewees. However, gender references will be included within the text. The letter Y will be used to denote each and all individual interviewees, while the letter Z will be used to denote references to any and all managers.

⁵ Bracketed numerals (x) after a descriptor indicates the number of interviewees articulating either that descriptor or concept, i.e. caregiving is emotionally draining (3).
Caregiving Similarities: Young and Old in Residential Aged Care

The provision of care by formal caregivers to older and younger residents has much in common, with the goal of the formal caregiving role to provide instrumental and emotional care, along with assistance with any leisure activities. The role also involves undertaking non-care duties related to the running of a facility and the care of its residents. Other similarities observed
within the formal caregiving role is witnessing the inevitable decline of a resident, which in turn, necessitates adaptation of caregiving behaviours to meet the newly emerged needs.

**Instrumental care.** The formal caregiving role is heavily focused on the provision of instrumental care for all residents, with interviewees noting many similarities in providing this form of caregiving to younger and older residents, “they don’t differ much in that sort of stuff [instrumental caregiving], because basically their needs like that are kind of the same”. These duties typically consisted of providing help with a range of ‘activities of daily living’ (ADLs) such as showering, toileting, feeding, dressing, assistance with medication administration, use of independence aids (wheelchair and walking frames), and communication devices. It also included leisure activities such as reading to residents, assisting them with facility activities (arts and crafts, gardening, games), or escorting them to activities outside of the facilities (shopping, doctors’ appointments, concerts, visits to family and friends, or restaurants).

**Leisure activities.** While the provision of instrumental care differed little between younger and older residents, the types of leisure activities varied between each group. Interviewees spoke of how younger residents preferred to engage in activities outside of the facility, such as outings to cafés and restaurants, or the visitation of family and friends. Older residents were seen to prefer to engage in leisure activities offered by the facility, such as card games, music appreciation, or craft activities. “I find the older ones prefer to potter around the place doing some of the in-house activities. But the young guy/girl in here, s/he just wants to be out”.

Activities outside of the facility were acknowledged as being “very infrequent” occurrences, “we are mainly in here all the time helping with ADLs or else doing the non-care stuff we need to do”. They were also seen as being more problematic in their execution. Both managers reflected upon the logistical difficulties incurred when residents wished to leave the facility, noting, “there’s usually more paperwork involved, and more messing around with rostering, lots of pre-planning like booking vehicles or taxis. It’s a nightmare really”. Interviewees too acknowledged the
additional work required by them and management when a resident wished to undertake an activity outside the facility. However, a quarter (7) of participants believed management actively discouraged residents from leaving, “Z is always saying, yes we will organise for X to go and see his/her friend in (X hometown) but it hasn’t happened yet and probably never will”.

Interviewees remarked how family members of younger residents would indicate their desire for relatives visit them, “Why don’t you bring X down to my place, s/he would love to see his/her dog”. These conversations at times evoked anxiety and a sense of helplessness for formal caregivers, “I just nod and say ‘yes we will have to try and organise that for him’, knowing full well it will never happen. That stuff only happens if the manager makes it happen”. The seemingly innocuous event of engaging in an activity outside a RAC facility reflects the clash between multiple worlds; managers, family, formal caregivers, organisational and government policy, each of whom have their own priorities, tasks, functions and goals. It also reflects unspoken dialogues between these worlds in which formal caregivers are reluctant to convey to families the position of managers and policy fails to articulate how ideals, such as community inclusion, be realistically achieved.

Non-care duties. In addition to instrumental care, and assistance with leisure activities, interviewees spoke of undertaking “non-care” duties as part of the formal caregiving role. These included both administrative and housekeeping duties. Administrative duties included case notes, client function documentation (urinary output and fecal charts, food and fluid charts), incident reports, compliance and risk-aversive assessments and documentation (fridge and food temperature monitoring, disability equipment inspection, facility maintenance inspections, occupational health and safety assessments, electrical inspections). Housekeeping duties involved cleaning, meal preparations, and doing the laundry (clothes washing, drying and repair work).

Special occasions or significant events for residents also produced a range of other “non-care” duties such as baking of birthday cakes, decorating the facility for Christmas or a resident’s
birthday, clearing out of a resident’s room after they had died, room preparation for a new resident, building a vegetable garden, or rearranging furniture/decoration of the facility. Though non-care duties differed little when undertaken for either a younger or older resident, several interviewees reported making more of an effort if a “non-care” duty was for a younger resident, “I go the extra mile and make sure all of his/her milestones are celebrated. I don’t do that with other residents. I do it to make it seem more like home, to compensate I guess for him/her being in here”.

**Emotional caregiving.** For formal caregivers, some “non-care” duties such as baking a birthday cake, writing a letter on behalf of a resident, or doing their makeup, was seen as an expression of ‘emotional’ caregiving and considered an essential part of the formal caregiving role,

> I love doing this sort of stuff [non-essential care activities/emotional care] because it makes such a huge impact on them. It brightens their day and makes them feel better, which makes me feel like I’ve done something good, and I feel good. It’s just a pity there’s not enough time to do more of that stuff though.

Emotional caregiving constitutes those behaviours or actions which convey empathy and sympathy or provide encouragement, and validation of an individual’s worth (Fischer & Eustis, 1994). They enhance dignity, autonomy and self-esteem, helping residents to cope with negative emotions while sustaining and enhancing the interpersonal relationship between formal caregivers and residents (Collins & Feeney, 2000; Collins, Guichard, Ford & Feeney, 2006; Fischer & Eustis, 1994). This component of caregiving is recognised by the Australian government as one aspect of the formal caregiving role in Section 2.3 of the Quality of Care Principles (2014) (Federal Register of Legislation, 2016).
Interviewees spoke of other forms of emotional caregiving activities they undertook with both younger and older residents. This included listening to residents, soothing them with words or a touch if they become distressed, and providing instruction or teaching if a resident needed to learn a new skill (i.e. using a TV remote control, writing emails). Other emotional caregiving activities included being empathetic, encouraging independence, providing affirmations and encouragement, acts of kindness, and upholding residents’ dignity and rights.

Formal caregivers and managers differed in their opinions regarding the provision of emotional care within the formal caregiving role with some interviewees regarding it an essential part of caregiving, while others deemed it irrelevant. These opinions can be depicted using a Positional Map as conceptualised by Clarke (2005) (see Figure 6.2). The positions taken by formal caregivers and managers remain flexible as both future experiences and changing contexts may alter an interviewee’s current opinion.

![Positional Map](image)

*Figure 6.2: Emotional Caregiving versus Instrumental Caregiving Instrumental Map*
A Positional Map provides an opportunity to explore those positions not articulated which may help elucidate the situation more fully. This fluidity between positions and interrogation of unspoken positions is one of the advantages of using Clarke’s (2005) Situational Analysis methodology, which argues that more traditional grounded theory methodologies’ reliance on the objective, analytical and systematic research processes fail to capture the messiness, conflict and contradictions embedded in the research topic. The extent to which the interviewees believe the formal caregiving role includes the provision of emotional care is represented on the Y-axis. The X-axis demonstrates the degree to which instrumental care is perceived to be part of the formal caregiving role. As evidenced in this Positional Map, four positions can be seen.

Following Clarke’s reasoning, the Positional Map allows for silences to be articulated. It is clear that no interviewee believed their role was primarily focused on undertaking only non-care duties, nor did any interviewees believe both emotional and instrumental caregiving was contingent on situational, individual and resident variables. Rather, instrumental caregiving was seen by most interviewees as being highly relevant to the formal caregiving role. The most commonly held view (Position B) was that the formal caregiving role focused primarily on instrumental caregiving, and emotional caregiving though deemed relevant for the role, was contingent on situational, individual and resident variables. The belief that the formal caregiving role consisted equally of instrumental and emotional caregiving was the second most commonly held view (Position C) with interviewees reporting finding ways to incorporate emotional caregiving when undertaking instrumental caregiving activities, “I use the time when dressing X and doing his/her hair to touch base with how s/he’s feeling and to give him/her the opportunity to talk [about any issue impacting him/her in a negative way]”. Only a few interviewees (5) believed emotional caregiving was not part of the formal caregiving role (Position A), with even less (1) regarded their role as existing solely to provide emotional care (Position D).
While the relevance of instrumental caregiving within the formal caregiving role is deemed high by most interviewees, it is clear the expression of emotional caregiving behaviours, though accepted as part of this role, is influenced by other variables. These include managerial acceptance of this aspect of caregiving, the interpersonal skills and willingness of formal caregivers and residents to relate in this way, and time availability to do so.

Residents’ decline. Aside from similarities in instrumental and emotional caregiving and non-caregiving duties, interviewees described the other main similarity between caring for a younger or older resident in an aged care facility was witnessing a resident’s decline over time, and the need to then adapt caregiving in response to such decline, “it’s inevitable that they [residents] change. They get older, or sicker, or worse. It’s part of the reason why they need help and it doesn’t matter if they are young or old. They all need help”.

For interviewees’, an adaptation of caregiving included changing both caregiving duties and caregiving behaviours to meet newly emerging needs arising from physical, psychological or the cognitive deterioration of residents. The caregiving duties which often changed in response to a resident’s decline included greater assistance with ADLs or changing the routine in which ADLs are performed (11), use of medical interventions and/or aids such as PEG (percutaneous endoscopic gastrostomy) feeding (4), use of communication devices and physiotherapeutic equipment (12), increasing one’s caregiving knowledge through training or education (5), and completing additional documentation, assessment and reports (17).

Interviewees also reported caregiving behaviours which were often adapted in the face of a resident’s changing needs. These included undertaking caregiving activities at a slower rate to aid residents’ adjustment to such activities (8), listening more to residents (5), providing more opportunities for residents to make decisions (7), increasing physical contact to provide comfort (3), slowing down the rate of speech and delivery of instructions to ensure resident comprehension
(4), increasing the level of positive feedback and affirmation directed towards residents (4), and engaging in more social conversations to facilitate residents’ sense of connection with others (6).

The need to change caregiving duties and adapt caregiving behaviours when a resident declined was common for formal caregivers when caring for both younger and older residents. However, interviewees noted the predictability, rate and impact of residents’ deterioration, along with the adaptation of caregiving practices differed between younger and older residents. Both managers and formal caregivers acknowledged facing a greater challenge in understanding and adapting to a younger residents’ decline because it is often “significantly different to what is seen in the older people in here [residential aged care facility]”. Frequently, it was at this juncture when caregiving skills, knowledge and resources were unable to meet the emerging needs of a deteriorating young person that interviewees witnessed incongruence between their perceived role and actual role.

It’s worse I think for X in here because s/he’s young and compensating for the losses and trying to meet his/her new needs when s/he deteriorates which occurs for a longer period than when our older residents decline. So you are left with constantly being aware of how much more is needed and what can’t be done for him/her, and then you realise this situation might be for years and even decades. It’s a bitter pill to swallow trying to cope with this dilemma.

It was at this time, according to formal caregivers, that family and friends of younger residents would often take more of an active role in caregiving, bringing to the formal caregiving role a new set of expectations and/or caregiving demands. This was also often incongruent with formal caregivers’ beliefs about the situation. Several interviewees noted many of these expectations and demands were unachievable, yet they felt compelled to honour familial wishes, “I reason they know more about X, so I try to also do what they want, because maybe they are right about what s/he needs. But it’s another lot of work which involves negotiating your role yet
again”. Formal caregivers spoke of being pulled in many directions, by policy and procedure, managerial expectation, familial involvement and the resident needs, when the situation of a younger residents’ deterioration occurred, and that “sometimes it feels like the last person considered in this scenario is the young person themselves and what they need”.

**Formal Caregiving to Younger Residents: Caregiving Struggles**

A richer understanding of formal caregivers’ experiences caring for a young person is derived through the full exploration of the residential care arena where formal caregiving occurs in both RAC facilities and purpose-built ones. As reflected in Figure 6.1 there are varied multiple social worlds within the one social arena of residential care being examined herein. The aspect of formal caregiving to younger residents is highlighted in red and shown in Figure 6.1. The multiple social worlds within this arena represent a collection of people and elements (non-human) which act together (Clarke, 2005) and influence each other and the overall social arena of residential care.

Inside the Victorian RAC arena are social worlds which include managers/management systems, older residents, younger residents, family and friends of residents, allied health professionals, nursing and auxiliary staff, and volunteers. Social worlds consist of non-human elements which also interact with and influence the other social worlds within the Victorian RAC arena. These social worlds include: (1) both RAC and purpose-built facilities and the model of care each facility adopts; (2) the Victorian government, including the Department of Human Services and the Department of Health & Ageing, the Australian Commonwealth government, the National Disability Scheme, and the Aged Care Funding Instrument (ACFI); (3) the policies, procedures and protocols of the facility and the wider organisation, stakeholders compliance requirements such as councils, OH&S regulatory bodies, and accreditation governances, and (4) the Victorian and Commonwealth governments legislative demands.
These social worlds interact together influencing the expression of formal caregiving to residents. But according to interviewees, some of these social worlds such as residents’ families, other groups of residents (i.e. residents with dementia or behavioural issues), management systems and governing bodies, the model of care adopted by each respective facility, and ACFI, exert resistive forces which stymie the expression of caregiving in a manner congruent with the views and beliefs formal caregivers hold regarding the nature and purpose of their role. This is seen as a conflict between the perceived formal caregiving role, and the actual role of formal caregiving expressed to residents.

For interviewees, the degree to which formal caregiving beliefs and one’s perceived role was in conflict with formal caregiving actions and a formal caregiver’s actual role undertaken when caring for younger residents, can be represented using a Positional Map (see Figure 6.3). Incongruence between perceived and actual was also evident when caring for older residents, though less so as depicted in Figure 6.3.

![Positional Map](image)

* Denotes position not articulated in the data
a Denotes number of interviewees reflecting this position concerning younger residents
b Denotes number of interviewees reflecting this position concerning older residents

Figure 6.3: Perceived Role versus Actual Role Positional Map
Figure 6.3 demonstrates four positions articulated by interviewees. The view held by most interviewees was Position D, in which caregiving beliefs and one’s perceived role was largely incongruent with the actual formal caregiving role, especially when caring for younger residents. It is likely these interviewees are reflecting the inadequacy of RAC to create an environment for younger people whereby fundamental life needs can be met. Position A & B were the next commonly held views by interviewees. Position A reflected interviewees’ view that their actual role was seldom influenced by their perceived role, and their caregiving actions were not largely influenced by underlying beliefs. A number of interviewees spoke of their fear of losing their job, and that their role was being scrutinised by management. As such, these interviewees felt they should act according to management directives rather than operating from their own personal beliefs, which may ‘get them into trouble’. This opinion was common among formal caregivers who worked in facilities which had seen a number of managers replaced within a several year period. This managerial instability often resulted in formal caregivers that were unaware of and unsure of how to undertake their role. This potentially led to greater adherence to the ‘actual role’ shaped by managerial demands rather than the expression of their perceived role. For those formal caregivers who reflected Position B, some degree of incongruence between their actual role and perceived role was noted at times. Caregiving action was sometimes influenced primarily by an underlying belief system. This was dependent on the resident and the situation.

The view articulated the least among interviewees was Position C, which reflected congruence between one’s perceived role and the actual formal caregiving role expressed. This was only noted by a few interviewees as occurring when caring for older residents. No interviewee expressed the opinion that their perceived role and the actual formal caregiving role was congruent when caring for younger residents. To fully understand the incongruence interviewees observe between their perceived caregiving role and the actual formal caregiving role, it is necessary to recognise interviewees’ beliefs about caregiving and the caregiving role.
Formal Caregiving and the Formal Caregiving Role

The formal caregivers and managers interviewed all express both innate and acquired beliefs about the formal caregiving role and beliefs around what constitutes good caregiving. These beliefs are unique to the individual since the individual and his/her experiences are unique. However, among interviewees, similarities in beliefs regarding the nature and purpose of the formal caregiving role are evident.

The formal caregiving role. For 23 interviewees, the formal caregiving role is analogous to either a parental role consisting of ‘mother’ and/or ‘father’, a ‘social worker’ or health professional relationship in which one party receives help from the other, or a ‘friend’ and ‘confidante’ relational role. The selection of these analogies chosen by interviewees to describe the formal caregiving role are likely drawn from among cultural roles which have a shared meaning to the interviewer, rather than formal caregivers and managers using more abstract models to explain themselves.

Formal caregiving role and the parental role. The conceptualisation of the formal caregiving role as a parental role tended to reflect gender stereotypical views of maternal and paternal ways of relating. Since only five male interviewees participated in this study compared to 23 female participants the use of a maternal descriptor was more commonly employed by interviewees. A maternal descriptor likening the formal caregiving role to “the types of tasks a mum does for her kids, but more than that, the nurturing stuff she does as well” was articulated by nine female interviewees and one male interviewee. Female interviewees remarked on the similarities in their role as a mother and that of a formal caregiver, noting formal caregiving can be regarded as an extension of the maternal role, “it’s very much the same [role of mother and caregiver], looking after, preempting needs, creating an environment that helps them to feel good, comforting and directing, and assisting them to be independent”. The prominent themes around a maternal view of the formal caregiving role included being ‘nurturing’, ‘comforting’, ‘assisting’,

Interviewees adopting a paternal view of the formal caregiving role depicted their role as ‘giving directions’, ‘doing blokey stuff like talking about sports’, ‘being firm’, ‘setting boundaries’, ‘not being too sentimental’, ‘joking around and not being too serious’, ‘protective’, and ‘being strong’. One male interviewee stated, ‘it’s weird, but even though they are older than me, I feel like I’m parenting them and providing a sense of security through us’.

**Formal caregiving role and other professional roles.** Other analogies to the formal caregiving role also used by interviewees include ‘social worker’ (4), and ‘healer’ (1). The use of an analogy of social worker to describe the caregiving role reflects the need to engage in advocacy because of the vulnerability of some residents. According to the Australian Association of Social Workers (AASW), a professional representation body for over 10,000 Australian social workers, social workers typically assist the vulnerable within society to deal with problems of everyday life (AASW, 2017). The AASW (2017) describes the purpose of the social worker role is to have a dual focus on both supporting and improving human wellbeing, and isolating and rectifying any external issues (known as system or structural issues) that may impact on wellbeing or may create inequality, injustice and discrimination.

We do stuff like a social worker does...because our residents are kind of really defenseless and need help with everyday stuff, but not in a way that makes them feel bad about themselves. More about encouraging or I guess empowering them to live the best way they can. But sometimes though we have to go in to bat for them, to argue (with management and family) for what they want. I guess that’s why I think of what we do as kind of social worker stuff.
Aside from a social worker analogy, one other interviewee remarked that her role could be described as one of an emotional/spiritual healer bringing comfort, peace, meaning and resolution of life’s issues,

I think a lot of my job is about bringing comfort to a residents’ emotional world. It’s really about helping them to find healing and peace for the end of their [all residents] life. I think our role is really important because we are the instruments that can help reconcile their whole life together so they find a deeper meaning of their existence and to be able to help them overcome any issues that may stop them from dying a ‘peaceful’ death.

**Formal caregiving role and the relational role.** Conveying the relational element of the formal caregiving role saw one-half of interviewees liken their role to that of friend and confidante. The friendship or confidante analogy reflected a reciprocity within these relationships with several formal caregivers speaking of how their ‘friendship’ with older residents and several ‘young residents’ benefitted both the care-recipient and themselves, “I think us being friends helps normalise X’s (young person) experience here, you know, making it seem more like a real community”. Another interviewer stated, “X is a real source of affirmation and encouragement. S/he makes me feel good about what I do and keeps inspiring me to do more study. I really enjoy being around him/her and s/he’s got some good advice as well”.

For many interviewees, an important aspect of the formal caregiving role was to develop friendships, especially with younger residents. These relationships were seen to provide younger residents with a way to compensate for other relational losses upon entering RAC,

It’s really important to be a friend with X and I guess all the young ones in here. They lose a lot of friends coming into a place like this, so it becomes vital to try and counteract those losses by developing a genuine friendship of sorts.
Collectively, interviewees’ use of either the parental analogy or analogy of social worker, healer, friend and confidante to depict the formal caregiving role reflects perceptions of what caregiving is and the nature of the caregiving relationship. The analogies are neither mutually exclusive nor able to express the entirety and complexity of the formal caregiving role. However, these analogies appear to be fundamentally grounded in the human relational world.

**Good caregiving.** In addition to views about the caregiving role, interviewees also held beliefs around what constitutes good caregiving. For most interviewees, good caregiving was conceived of as a combination of instrumental and emotional caregiving activities that best meet the needs of the individual. Interviewees stressed that the delivery of good caregiving should be flexible to meet individual care needs, “X likes to get up at 7 am, while another resident prefers to get up at 10 am. If we can’t change the timing in which care duties are undertaken, then residents’ preferences have to be ignored”. The lack of flexibility impeded the formal caregiver’s capacity to deliver ‘good caregiving’; one that is appropriate and relevant to each individual resident.

**Good caregiving is individual caregiving.** Flexibility within one’s role was perceived as essential in providing ‘person-centered care’. The inability to provide such care led to a sense of inadequacy; “it’s really frustrating [to have to work within a strict structure of caregiving activities] because it means we don’t have the flexibility to change things to suit each person we care for, which for me, makes me feel bad that I’m not doing my job of caring properly”.

Good caregiving, described by interviewees as ‘ideal’, ‘needed’, ‘essential’, or ‘necessary’ caregiving was regarded as fundamentally meeting the needs of care-recipients. These needs include emotional, physical, relational, social, and medical needs: “caregiving is basically a relationship with a person who needs help with their life and doing it in such a way that they feel cared for and don’t feel worthless because of it”. Thus, good caregiving was seen by nearly a third of interviewees to be holistic, involving the social, physical, psychological and emotional aspects of residents. This was exemplified in interviewees’ use of a maternal analogy: “you look at how a
Good caregiving is relational. Most interviewees (20) saw the development of a ‘friendship-type’ relationship with care-recipients as being foundational for the provision of good caregiving, because “unless you really know someone, you don’t know how to care for them”. This ‘friendship-type’ relationship denoted mutuality and ‘genuine connection’ with another, conveying notions of positive mutual emotional experiences;

I think because we care…like really feel caring towards them, and have a genuine rapport with them, then they respond often with liking us and feeling like they are looked after…it is only from this place that you are then able to better meet their needs, and this then becomes the foundation for good caregiving.

The other five interviewees were “not here to be their friend”. Good caregiving in their eyes was providing instrumental care only to “help them get on with their day”. They did not consider their role to include emotional support or comfort because “that’s what family and friends are for”. Several of these interviewees reflected feelings of occupational burnout, while another spoke of personal life issues, which left her with “little emotional energy to engage anybody [including staff and residents]”. It is likely then for some interviewees who believe emotional caregiving is not part of the formal caregiving role, such a position is the result of self-preservation through strategies designed to conserve one’s emotional resources and energy.

However, several other interviewees articulated the need to maintain “professional boundaries” so as to not become emotionally involved with residents. They spoke of a workplace culture which emphasized the importance of “professional boundaries”, and of being individually reprimanded by their manager for engaging in emotional caregiving activities. Thus, discouraging the role of emotional caregiving by management appears to stymie the expression of emotional
caregiving behaviours. One manager interviewed held such a position and spoke of the implications for him when formal caregivers breached professional boundaries; diminished workplace productivity and distress to residents if and when formal caregivers left. This manager stated;

staff are not meant to develop emotional connections with the residents. It’s unprofessional. It is so important that they remain neutral to those they care for, since any type of emotionality means they are less able to do their job…its more about them, than it is about us. It’s a fine line that some cross and the consequences are messy.

While the culture of the facility and management’s views regarding emotional caregiving were influential upon some formal caregivers, the formal caregiving role and what constitutes ‘good caregiving’ for most interviewees appears deeply grounded in connection to another person. This connection was expressed often in ‘friendship-type’ care relationships, with good caregiving described in terms of trust, advocacy, care, the meeting of needs and the provision of nurturing and emotional support.

**Caregiving Struggles: Incongruence between Perceived Role and Actual Role**

Beliefs about the formal caregiving role and what constitutes ‘good caregiving’ are not static views with interviewees acknowledging their role, the expression of caregiving behaviour and beliefs about caregiving continue to be shaped by three significant influences: motivation for one’s role; the educational and/or vocational training undertaken; and the situational context in which formal caregiving occurs. While some of these influences provide a positive influence on the formal caregiving role and the expression of caregiving behaviours, other influences are embedded with conflicts that generate interviewees’ incongruence between their perceived role and the actual formal caregiving role.
**Positive sources of influence on formal caregiving.** For interviewees, beliefs about the formal caregiving role are shaped by the motivation for that role along with the educational background and training received. These can be considered positive influences on formal caregiving. However, beliefs about the formal caregiving role and what constitutes ‘good caregiving’ are constrained by the situational context where caregiving occurs. This impact can be positive if RAC facilities adopt a care framework which is more closely aligned with individual formal caregiving beliefs. However, if the situational context is embedded with conflicts, which will be explored later in the chapter, then the situational context is seen to hinder formal caregiving.

**Caregiving motivation.** A positive influence upon formal caregiving emerging from interviews with formal caregiver was their motivation to undertake such a role. While these motivations are varied, like caregiving beliefs, many similarities can be observed. For almost half the interviewees’ (13) entry into the formal caregiving role was due to the meaning and satisfaction derived from prior familial caregiving: “I got into this because I was looking after my sister who had cerebral palsy. After she died I realised how much I got from being her carer because I saw how important that role was. So, I got into caring full-time”. This fulfilment and meaning derived from the formal caregiving role were instrumental to some interviewees’ caregiving motivation, “I like my job and because I see that what I do really helps others, I feel good about doing it, and that gives me the energy to keep doing it”.

Not all interviewees who entered the formal caregiving role through prior familial caregiving did so because that caregiving role had provided them with a sense of meaning and purpose. Rather it was preferred over other occupations requiring a similar level of skill, such as factory work, cleaning, labouring, retail or clerical work. Interviewees spoke of entry into aged care work because of a limited capacity to gain employment elsewhere either because of language barriers, learning difficulties or the late age of entry into the role: “It’s ok this job and I don’t mind it.”
English not my first language and I not been able to get work elsewhere unless I work in factory or outdoors. So, I want to be indoors so I did this”(sic). For another, there was no real choice;

I’m 56 and have been doing this for like three years now since my kids have grown up and my mum passed away. Who the hell is going to employ 56-year old who hasn’t really got any other skills but this? I mean I did some office work like 30 years ago but that’s too long now to be relevant and it’s really too late to go to uni, not that I could do it anyway. So I kind of appreciate having been able to get into this work, otherwise I would be unemployed.

It seems for some interviewees, the formal caregiving role is opportunistic rather than deliberately sought and motivation for caregiving is therefore derived from acknowledgement that other choices would be less desirable. Nevertheless, even when entry into the formal caregiving role was opportunistic, interviewees enjoyed at least some aspect of their role: “I like being able to help people, and it’s nice to be appreciated by the people I care for. I didn’t get much appreciation when I was raising my kids, but in here I do”.

Entry into RAC work was for other interviewees a deliberate choice based on “wanting to make a difference in the lives of those who are vulnerable”. This particular interviewee added, “working in this field aligned with my views of social justice and the provision of protection of those who need it...it’s one of the greatest things we can do, to minister to those who are sick or dying”. Interviewees who worked in RAC because of ethical or moral considerations derived satisfaction from their role as it enabled them to live out an existential belief: “this job is an expression of my heart; of what it is to be human”. Caregiving, in this way, was centrally tied to larger existential belief systems.

**Educational and training background.** Alongside caregiving motivation shaping the beliefs and expression of caregiving behaviours, educational background and training are also influencing
factors. For some participants their education and training in RAC work generated a framework that influenced their expression of caregiving behaviour:

It wasn’t until I did my training (Aged Care Diploma) that this reference point kind of developed. Like instead of just seeing myself and my role as doing stuff like ADLs and giving support, it became about how can I promote their dignity and enhance the quality of their life. From then on, whatever I did was about just this, enhancing this [quality of life and dignity].

Training that was delivered within the facility, often to address common issues with specific residents such as those exhibiting behaviours of concern, also provided the platform for interviewees developing new beliefs and shaping existing ones:

We have a few here that are really aggressive…and I used to get frustrated at them, but after I did the training, I realised it was part of the disease they’ve got. It became easier to understand and respond to their behaviour after this.

For other interviewees, education and training challenged existing beliefs about caregiving and the formal caregiving role, “I used to think we were here to do everything but since this [dementia training] I realise I need to give them options to promote their sense of control”. Another formal caregiver added, “It wasn’t until I did my Certificate IV that I realised that the way I interacted with them [residents] was a bit patronising and not very validating. I guess I had assumed they weren’t so capable to understand”.

**Framework of care.** The framework of care adopted by each individual facility is a significant shaper of caregiving behaviour. Several interviewees spoke of how the framework of care within their facility either allowed or discouraged them from expressing caregiving in a manner congruent with underlying beliefs about good caregiving and the formal caregiving role.

In many RAC facilities, a paternalistic model of care is often employed. One-quarter (7) of interviewees felt their capacity to engage in caregiving behaviours which they believe facilitate
residents’ quality of life was hindered by such a model, “I think we tend to foster their [residents] dependence on us because there’s not enough time to give them real choices about how they live. It’s easier if they do what we need them to do”.

This paternalistic model of care within RAC fundamentally diminishes client independence, positioning the caregiver and/or medical staff as the ‘all-knowing’ and unilateral authority (Sandman et al., 2016). However, interviewees consider this framework detrimental to them too because this model generates a hierarchy within the organisational structure which locates them at the bottom,

Basically they [residents] are at the bottom, and we are not far behind. Then there’s the nurses, then management, the board and the CEO. Us at the bottom get little say and have pretty much no power in our job. We know more than those under us [residents], and management know more than us. But we are basically ignored in the whole process and we don’t have the status nursing staff do, so we don’t really matter.

Interviewees describe that being located towards the bottom of the organisational structural hierarchy means they have little say in decisions concerning residents or in shaping their workplace to reduce incongruence between caregiving belief and action, “we aren’t even included in client meetings. It’s like our opinions don’t matter, yet we spend the most time with them”, and “I don’t have an avenue to speak my mind on the things that prevent me from doing a good job”.

This was in contrast to several interviewees who had previously worked in facilities that utilised a palliative care model or incorporated palliative care principles. For these interviewees caregiving action was perceived to be more congruent with their beliefs, because the culture of the facility along with management, endorsed the therapeutic use of self and actively promoted the caregiving relationship, “I am really valued there. My opinions about clients seem to matter and I’m listened to. I feel I do really good work and make a difference to the lives of clients, and that what I do is appreciated”. 
In a traditional palliative care model, enhancement of the quality of life of clients who are terminally ill, and the provision of emotional support to their families is paramount (Dy et al., 2015). This model encourages active care collaboration between health care professionals and clients and their families in making life and health decisions. It also seeks to facilitate the active pursuit of those things which bring meaning and quality of life to a client (Dy et al., 2015). This includes fostering familial involvement and peer relationships, providing activities that yield positive emotions, increasing a client’s sense of control over their life by encouraging decision making, and upholding the dignity and uniqueness of the individual through tailored approaches to caregiving (Dy et al., 2015; Mok & Chui, 2004).

The term palliative care is often used interchangeably to refer to end-of-life care which focuses on alleviating suffering and distress in the final stage of a life-threatening illness (Mok & Chiu, 2004). For some aged care facilities, the principles of palliative care, such as encouraging family relationships, facilitating dignity and enhancing residents’ happiness and sense of mastery, are applied for the entire duration of a resident’s life, rather than during end-of-life care. These principles become the framework by which caregiving behaviours and the aged care culture are directed. Subsequently, palliative care models, which are adopted by RAC facilities, or used within other health care settings, are found to generate increased client and familial satisfaction of care received, as well as improving satisfaction within the formal caregiving role (Ablett & Jones, 2007; Mok & Chiu, 2004).

It is clear from interviewees that beliefs about their role and what constitutes good caregiving arise from a combination of sources, and the framework of care adopted within each facility can either increase or decrease the degree of incongruence formal caregivers experience between their perceived role and their actual role. In the following section, negative influences upon the expression of caregiving behaviour will be explored, with interviewees noting several barriers to the enactment of the formal caregiving role. These include caregiver neutrality, the
invisibility of the caregiving relationship and the powerful yet powerless paradox evoked because of managerial instability, the legacy of high staff turnover, and the burden of bureaucracy upon interviewees.

**Negative sources of influence on formal caregiving.** “What we are meant to do tends to be a lot different to what we CAN (emphasis) do”. For many formal caregivers interviewed, incongruence between the perceived role and actual formal caregiving role stemmed from caregiver neutrality and the invisibility of the caregiving relationship (see Chapter Two for a detailed review of aged care policy including its lack of acknowledgement of formal caregiving relationships).

**Caregiver neutrality.** “I think I’m meant to be a robot in here. Don’t think, don’t feel, just do” lamented one interviewee, with nearly one-half of all interviewees also making references to ‘caregiver neutrality”. Caregiver neutrality is the implied impassive disposition towards care-recipients, which downplays the role of the caregiving care-recipient relationship. It encourages neutral interactions with little emotionality, which some formal caregivers described as their detachment from residents “I feel I’m supposed to act like someone taking your order at Maccas [McDonald’s, fast food outlet], polite, superficial and only there because someone needs to state what they need. That’s it, nothing more, nothing less”.

Very few interviewees believed it was a hallmark of professionalism “I guess I believe I shouldn’t allow them [care-recipient] to become emotionally dependent on me, it goes against what I learnt [in aged care training] about promoting autonomy”. Most interviewees reported that caregiver neutrality was endorsed by their facilities, rather than being something they themselves assumed to be a professional standard, “I’ve been told several times to not get emotionally involved by my boss. He said it was unprofessional. I’m like ‘what the f..k’ when did caregiving become unemotional and disconnected from people?”.
Within the facility, interviewees believed caregiver neutrality was seen as sacrosanct with both managers and formal caregivers acknowledging its existence. However, formal caregivers conceded they had not received training or education about remaining neutral within the caregiving relationship. For interviewees, the endorsement of caregiver neutrality typically emerged through instructions given by management often in response to issues which had arisen within the caregiving relationship. One manager states,

it’s not good to get close to residents. They do die after all, which means I end up with staff who are emotional messes. I don’t think closeness or even a relationship is needed [for caregiving] above and beyond ascertaining what one’s care needs are. It’s not good to get attached, in fact I think it’s downright unprofessional. Staff need to be detached and not get over involved in residents’ lives.

But despite some managers’ endorsement of caregiver neutrality, most interviewees disagreed strongly with this position, because “caregiving is providing care. How can you do that outside of some sort of relationship?”, and,

The most important thing we do is the connection we have with others. It’s not about wiping bums and noses; well it is, but it’s about security and providing comfort and emotional support. That requires connection, it requires relationship, but it’s certainly not achieved by indifference to a person. Instead it comes out of who we are, our capacity to love and nurture. And I don’t understand why this is wrong.

Caregiver neutrality was seen as a particularly detrimental ideology when caring for young residents. Nearly a quarter (6) of formal caregivers believed the formal caregiving role should help compensate the peer losses younger residents experience when entering aged care. This was regarded by formal caregivers as a fundamental aspect of their role when caring for younger residents “more so than anyone else here, becoming their friend [with a young person] in a real
way is so important to us doing our job right. That’s one of their biggest needs and this role can in some way help meet that need”.

**Invisibility of caregiving relationships.** More than half (16) of interviewees also felt that incongruence between their perceived role and the actual formal caregiving role stemmed not only from caregiver neutrality but also because of the invisibility of the caregiving relationship. Caregiving relationships were considered by most interviewees as the bedrock upon which caregiving occurred and as highly visible within a RAC facility. This is in contrast to the systematic lack of acknowledgment and recognition of the importance of these relationships at a government, organisational and facility level, “I think it’s ironic that caring for people involves some sort of relationship and that this industry [aged care] is built on the premise of providing care, yet these relationships have no voice. They aren’t talked about or even considered”. Lack of acknowledgement of formal caregiving relationships is also a contrast to the recognition of informal caregiving relationships which are exhorted both in governmental aged care policy (Aged Care Act, 1997) and, according to several formal caregivers, within aged care facilities.

Despite the call to improve the aged care industry through a formal acknowledgment of the importance and role formal caregiving relationships play in the delivery of quality care to residents (Anglicare Australia, 2010) the existence of paid caregiving relationships continues to remain invisible. Interviewees report feeling they must navigate and undertake these relationships alone because their work environment minimises formal caregiver and care-recipient relationships. Attempts to seek supervision from managers were met with exhortation to remain ‘neutral…and don’t get emotionally involved’. The limited opportunity to be able to ‘debrief and work out stuff’ [within the caregiver-care-recipient relationship]’ within their working environment, left interviewees feeling compromised.
The lack of codification and formal recognition of interviewees caregiving relationships with residents, in both policy and facility procedure, generates conflict between formal caregiving beliefs around what constitutes ‘good’ caregiving and how this should be achieved.

I studied nursing for a while but dropped out because I found it too hard, but I did like two years’ study and one of the things that struck me was their emphasis on ‘the therapeutic use of self’. Which is basically about yourself being present and having genuine interactions with another person and how this can really help the other person. That being present and real just kind of resonated with me. So it has really informed the way I do stuff in here.

And the weird thing is that a lot of the other people here do it as well.

This therapeutic use of self has gained growing acceptance within the health care profession in response to a rejection of previous paternalistic models of caregiving (Norfolk et al., 2007; Taylor, 2011). While a paternalistic model advocates caregivers assume a superior position of power, taking control of the caregiving relationship (Hinojosa et al., 2002), the therapeutic use of self suggests caregivers focus on mutuality and giving support (Taylor et al., 2011).

The ‘therapeutic use of self’ model advocates caregivers intentionally and consciously utilise their own personality to create genuine relationships with care-recipients, which will promote respect, rapport, trust, empathy and sincerity with clients (Norfolk et al., 2007). It also contends that caregivers’ “insights, perceptions, and judgments are [a fundamental] part of the therapeutic process” (Punwar & Peloquin, 2000, p.285), which aims to positively influence a client’s quality of life outcomes and perception of the effectiveness of care received (Taylor et al., 2009: 2011).

Though applied to many of the health-care professions, the concept of therapeutic use of self has yet to be incorporated within the aged care sector, which many interviewees reported typically promotes a more paternalistic framework of interaction: “I feel the system makes them more dependent and less able. They become disempowered when they come to live here because actually it means they resist less and it’s easier for us to do our job”. The very core of a
‘therapeutic use of self’ model advocates for the primacy of relationships within any caregiving context. This view appears to be more congruent with interviewees’ core beliefs around the formal caregiving role and what constitutes good caregiving.

The incongruence arising from caregiver neutrality and the invisibility of caregiving relationships between the perceived role and formal caregiver’s actual role created a level of distress and/or a diminishing of the caregiving relationship for most interviewees. Interviewees’ reported at times feeling anger, despondency, hostility and resentment towards the facility, hostility and resentment toward residents, ambivalence about one’s role, ambivalence towards residents, disengagement from other staff, and disinclination to perform one’s best. This was due to the experience of being unable to act according to one’s beliefs.

This incongruence also diminished the caregiving relationship between formal caregiver and care-recipient. Interviewees reported feeling disengaged from residents, emotionally numb towards them, withdrawing emotionally from them, deprioritising the relationship, caring less over time, and decreasing their time spent performing emotional caregiving activities. Interviewees’ also reported decreased satisfaction derived from formal caregiving relationships and the formal caregiving role itself.

Decreased satisfaction within the formal caregiving role and from caregiving relationships potentially results in a diminished quality of care as residents may derive fewer benefits from these relationships. Five interviewees expressed that this situation is likely worse for young residents for whom relationships with formal caregivers provide a substitute for familial and friend relationships, that are often diminished. It can be postulated that formal caregivers’ decreased satisfaction within their role and from caregiving relationships, when coupled with disengagement from residents, may negatively impact younger residents’ level of security, and any meaning, quality of life and perceptions of quality of care originally derived from those relationships.
‘Powerful yet powerless’ paradox. For interviewees, incongruence between perceived role and caregiving beliefs and the actual formal caregiving role and the expression of caregiving behaviour stems also from the situational context in which formal caregiving occurs. This context is the RAC facility in which interviewees work. Interviewees felt they worked within a ‘powerful yet powerless’ paradox. This is one where formal caregivers believe they have the capacity to positively impact the lives of those they care for, creating a sense of empowerment and mastery within themselves (and care-recipients), but are unable to do so because of the inability to positively impact and change their own working environment. For nearly a quarter (6) of formal caregivers, this produced a feeling of disempowerment and a lack of control over one’s environment.

For twelve interviewees, the situational context creates significant hindrances to the expression of formal caregiving behaviours which are congruent with innate caregiving beliefs. These hindrances include managerial and employee instability, and the burden of bureaucracy, which are known to contribute to staff turnover, discouragement and dissatisfaction within one’s role (Borhani, et al., 2014; Dorgham, 2012; Frechette, 2012). As noted by interviewees, these hindrances also result in the deprioritising of relationships with care-recipients.

The ‘powerful yet powerless’ paradox embedded within the situational context of the formal caregiving role also results in nearly half of all interviewees using self-protective measures to enhance perceived job security. They argued these measures are needed because the situational context in which their formal caregiving role occurs, frequently causes them to ‘worry about job security’. Unfortunately, the use of self-protective measures to enhance interviewees’ sense of job security results in them acknowledging they prioritise non-caregiving duties over direct care and emotional caregiving activities, as well as limiting interaction with residents to ‘preserve one’s emotional energy’. These interviewees add such measures only impair the formal caregiver and care-recipient relationship.
Managerial instability. One of the hindrances to congruent caregiving, interviewees recognise, is managerial instability within the situational context of formal caregiving. Managerial instability refers to frequent changes in organisational and facility management, which often generates alterations to procedure and caregiving processes. These alterations can result in formal caregivers feeling insecure about their role. Since changes in management are a common occurrence within many organisations and businesses, especially within the aged care sector, research shows that this type of change is a significant source of stress for employees (Vakola et al., 2013). Table 6.1 displays the changes in management for each participating facility over the past five years.

Managerial change refers only to those management personnel who formal caregivers reported to or interacted with, or were directly influenced by. This included both facility supervisors and facility managers. Table 6.1 does not reflect changes to management within a company or organisations’ board of directors, regional managers and organisational managers, as these personnel were not typically involved with formal caregivers.

Table 6.1. Number of Managerial Changes Per Facility from 2007-2012.

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*These facilities were under construction and not yet operational.
One of the reasons for employee turnover, decreased role satisfaction, and staff absenteeism within the aged care sector, has been found to link with a failure of management to assist employees to adjust to their new position (Vakola et al., 2013). This was found to be true for formal caregivers (16) who reported experiencing increased stress and job anxiety, decreased job satisfaction and an increased desire to gain new employment, when the facility in which they work experienced changes to the management structure.

To navigate managerial changes requires specific organisational strategies be employed to help employees adjust to these changes and alleviate any occupational stress (Shirey, 2013). Key models of assisting employees with adapting to change have been formulated over the past several decades and include Kotter’s 8-step change model (Kotter, 1996), Lewin’s 3-stage Model of Change (Kritsonis, 2005), and Prosci’s (2012) Change Management Methodology. While beyond the scope of this study to examine in detail all the nuances of each model, key similarities can be noted within all change models. These include establishing why change is required and then articulating a new vision, encouraging staff’s adjustment through emphasising past employee achievements proceeded by continually recognising employees’ current steps in the change process, consolidating these changes by highlighting the connection between new behaviours and organisational success and the continued positive reinforcement of employee efforts.

Half (13) of all formal caregivers, as well as the two managers interviewed, reported that their organisation had done little to prepare or assist them when management structures changed within their facility;

One day we got told we were doing this wrong and that wrong, even though we had done it a certain way for ages before…we just kept getting into trouble [with new management] but there was no explanation, just reprimands and constant memos on the board telling us we were doing it wrong.
For interviewees, this lack of preparation and assistance with change creates an environment of threat whereby they begin to feel uncertain within their role, and unsure with respect to the security of their job;

It was a horrible time because so many of us thought we might get the sack. We just kept hearing about all the things we were doing wrong and it made you doubt what you knew. It made you question everything that you used to do and know before.

Many interviewees acknowledged changing their occupational focus when this occurred, directing their focus, energy and effort inwards towards self-preserving activities rather than focusing outwards and directing care towards residents. One interviewee explained, “you begin to just shut down towards other people and focus on getting through yourself. I felt I stopped caring about the residents as I felt I had to begin fighting to keep my job”.

Formal caregivers voiced how the inward focus on self-preservation was the catalyst for delineating between ‘essential’ and ‘non-essential’ duties. However, essential duties were considered those readily seen and easily monitored by management for their completion, such as filling in charts and undertaking domestic duties. ‘Non-essential’ duties were those that could not be recorded or monitored, and primarily included one-to-one caregiving activities; such as listening to, spending time with and comforting residents;

You don’t get into trouble if they see that the client files have been filled in, so that’s what you focus on first, keeping out of trouble by dotting the ‘i’s and crossing the t’s’. But it comes at a cost of not doing the real stuff, the actual caring for people.

The ‘real stuff’ for this interviewee is the emotional caregiving activities which enhance the relationship between formal caregiver and resident. This priority differs from management which emphasises completion and documentation of non-caregiving tasks and instrumental caregiving activities, so as to meet compliance and stakeholder demands necessary to procure aged care funding.
Instability in management is therefore seen by interviewees as a significant hindrance in being able to express caregiving behaviour in a manner that is congruent with one’s beliefs about the formal caregiving role and what constitutes good caregiving. Instability in management can promote an environment of threat that generates feelings of powerlessness and decreased mastery over one’s environment for formal caregivers; the legacy of which is that formal caregivers must deprioritise the caregiving relationship in order to ensure employment security.

**Instability of workforce.** In addition to managerial instability, which often contributes to the instability of the aged care workforce, employee turnover was also seen to hinder interviewees’ capacity to express caregiving behaviour that is in line with their core beliefs. Interviewees explained that new formal caregivers are often unable to perform in the same capacity as existing staff because they lack knowledge about residents’ needs and preferences, and have yet to learn the facility procedures. As such, this lack of knowledge increases the workload of existing formal caregivers who “take on more to make up for what they’re [new staff] not doing or can’t do at the moment”. This increased workload results in less time for personal engagement with residents and a reprioritisation of focus away from residents onto the teaching and assistance of new staff.

The managers interviewed not only acknowledged the impact new staff had on the workload of existing formal caregivers but spoke of how the loss of accumulated knowledge about residents’ needs and preferences negatively impacted the quality of care residents receive;

Yes it’s a hard adjustment time for the old staff and for residents when someone new starts. There is a lot of indirect learning and knowledge which falls to the existing staff to teach the new ones about. This means they are less able to do their role [providing instrumental and emotional care] properly and it also means that the residents have to get to know someone new. And often the quality of care is less for a time being as new staff adjust. It’s ok if it’s one or two new staff but if there’s been a mass of new staff, everyone feels it and it’s really stressful for all involved.
Formal caregivers also reflected on how changes in staff negatively impact residents and diminish the quality of care they receive. This is a source of frustration which is often directed towards the facility if formal caregivers deem them responsible for staff turnover.

A number of formal caregivers (21%) also reported feeling sad for residents when staff leave, sympathising with them over the loss of relationships but feeling hopeless to change the situation, “it’s hard when staff leave. The old people don’t cope with change very well anyway and if they have become attached to them [formal caregiver] it’s really tough for them to lose that person and then get used to someone new”. For these interviewees, their sadness was amplified when caring for young people in a RAC facility, since “their loss is worse because it happens more often. They are here for much longer than older residents, and they need these relationships more. So the young ones have multiple griefs to go through. It’s heartbreaking to see”.

The legacy of employee turnover within the RAC sector is an increased workload for existing formal caregivers and an often diminished quality of care for residents. For interviewees, the increased workload focuses their attention and effort away from the resident and the caregiving relationship towards the teaching and adjustment of new staff. However, the diminished quality of care that ensues, and the distress residents experience when staff leave, negatively impact upon the formal caregiver. Interviewees become increasingly aware that residents’ fundamental needs are not being met, and that they themselves are unable to do anything to rectify this. Fortunately, this negative impact upon formal caregivers is only temporary while new staff adjust to their role. This cannot be said for the impact upon residents and the caregiving relationship that ceases to exist once a formal caregiver leaves.

**Burden of Bureaucracy.** While disruptions to the formal caregiving role and the caregiving relationships is time limited when new staff commence, the burden of bureaucracy is ever present, with many interviewees noting it was a continual interference to the caregiving relationship. The burden of bureaucracy is the demands non-caregiving duties place on the formal caregiving role
that, for interviewees, result in having to negotiate between these duties and direct caregiving
duties, especially emotional caregiving activities.

Two thirds (17) of formal caregivers interviewed felt that compliance and stakeholder non-
caregiving duties required them to prioritise these demands over ‘direct caregiving duties’.
Consequently, nineteen interviewees felt that the caregiving relationship is ultimately diminished
because of this reprioritisation. These interviewees felt impeded in expressing caregiving action in
a manner consistent with caregiving beliefs that upheld the importance and cornerstone of the
caregiving relationship.

Well, there’s lots of behind the scene stuff, you know, paperwork and stuff I think is kind
of boring and what’s the point of it? All that sort of stuff means you don’t spend as much
time with the residents and that’s sometimes sad, because they, kind of need sometimes
more one-on-one time with you. But in the end it’s all about accountability rather than the
people. That’s stuff is measurable not the relationship.

One manager also reflected on the tension that the burden of bureaucracy generates within
both their role and the formal caregiving one. The need to ensure continual funding results in
facility management having to emphasise the completion of compliance and stakeholder demands
above effort directed towards developing, maintaining and promoting caregiving relationships
within the facility;

I recognise the cost of all this work which is less time doing more meaningful work such as
being with residents. But my hands are tied. If it doesn’t get done, then we lose funding
which means even less services can be offered and even more loss of quality of life for
residents.

This emphasis further renders caregiving relationships invisible within facility and
government policy, and creates an even wider chasm between caregiving behaviour and caregiving
beliefs. The result is increasing incongruence and dissatisfaction within the formal caregiving role, which further hinders caregiving relationships.

Conclusion

Interviewees’ beliefs about their role and what constitutes good caregiving develop from a foundation of education, training, ongoing experience and the framework of care adopted by each facility. Against the backdrop of a residential aged care facility, the capacity to express those beliefs in caregiving action is contingent on the situational context of those facilities. Both management and staff instability, along with the burden bureaucracy places on the formal caregiving role, are significant hindrances to the expression of caregiving behaviours, either through increasing the workload of existing formal caregiving or directing caregivers’ focus and emotional and mental energy inward in order to deal with the occupational threat.

The ‘powerful yet powerless’ paradox embedded within this situational context sees formal caregivers understand the power of relationships within a therapeutic use of self. Yet because of inherent conflicts such as caregiver neutrality and the invisibility of caregiving relationships within the RAC sector, formal caregivers are largely powerless to express caregiving behaviour in a manner congruent with fundamental caregiving beliefs. Attempts to resolve such incongruence resulted in the prioritising of certain caregiving activities over others, and the diminishing of the caregiving relationship. This in itself increases the degree of incongruence between caregiving beliefs and caregiving action, facilitating job dissatisfaction and generating a host of negative emotions in which formal caregivers must deal with.

Though RAC primarily exists to meet the needs of older people, young people also reside in such facilities. While caregiving is often similar between young and old, formal caregivers’ incongruence between the perceived and the actual caregiving role is magnified when caring for a young person. The reasons for this will be explored in the following chapter examining the differences in providing care to younger residents compared to the care of older residents. Chapter
Seven will explore the two differences identified by interviewees, which relates to ‘the ethical issue of young people in residential aged care’ and the impact of ‘identification’ with them.
Chapter Seven: Differences and Difficulties Caring for Young People in Aged Care

In Chapter Six, the similarities in caring for younger residents and older residents of residential aged care (RAC) facilities were discussed. Highlighted were interviewees’ struggle to express caregiving behaviours and caregiving actions in a manner congruent with fundamental beliefs about the formal caregiving role and what constituted ‘good caregiving’ for individual residents. Exploration of the struggle facing formal caregivers’ revealed conflicts embedded in the RAC sector stymying the capacity to care congruently within one’s personal belief systems. Caregiving neutrality, the invisibility of formal caregiving relationships, managerial and employee instability, and the burden of bureaucracy were identified as contributing to formal caregiver incongruence.

In the current chapter, exploration of the differences caring for younger residents in an aged care facility compared to older residents is discussed. This exploration will reveal two fundamental differences interviewees observe; the ethical issue of younger residents in RAC and the impact of formal caregivers’ identification with these younger residents. Initially, the ‘ethics of younger residents in aged care’ will be discussed using a Positional Map (Figure 7.1) to diagram the respective positions interviewees hold regarding the in/appropriateness of RAC facilities for younger residents. Figure 7.1 will also show interviewees’ positions on the in/appropriateness of alternative accommodation for younger residents with high care needs; purpose-built facilities. Also included in this section of the chapter will be the differences in caregiving experiences with younger residents across differing caregiving contexts; RAC versus purpose-built facilities.

In the second section of this chapter, the other fundamental difference in caregiving experiences between younger and older residents will be examined. This is the phenomenon of ‘identification’. Many young residents are of the same or similar age to the formal caregivers who provide their care. For formal caregivers, this adds a layer of complexity to the caregiving relationship formed with younger residents and is a significant shaper of the caregiving behaviour.
directed towards them. Identification will be examined in detail in the section titled ‘I can’t help but think, what if this was me?’

Caregiving Differences: The Ethics of Young People in Residential Care

While the type of care younger residents require is very similar to the care for older residents, the context in which this care occurs elicited strong opinions among the formal caregivers interviewed. Most interviewees consistently spoke of the inappropriateness of RAC for younger residents, deeming it ‘not good’. The ethics of younger people in residential care will be discussed using a Positional Map (Figure 7.1). This map reflects the respective positions interviewees hold regarding their level of acceptance of RAC facilities and purpose-built facilities for the accommodation of younger residents with high care needs.

![Positional Map](image)

*Positions depicted in the map are the result of quotations from interviews.

RAC means Residential Aged Care Facilities

PBF means Purpose Built Facility

In Figure 7.1, the X-axis represents the acceptance or lack thereof for the RAC placement of younger people. The Y-axis represents acceptance or non-acceptance of younger residents living in purpose-built facilities. Four positions can be seen, with the most commonly held view
(Position C) that RAC is inappropriate for younger residents, but the appropriateness of purpose-built facilities was contingent on residents’ need and living preferences, the quality of staff employed and the resources provided by the purpose-built facility. More than a third of interviewees held the view (Position D) that RAC was inappropriate for younger people. These interviewees regarded purpose-built facilities as being better equipped to meet the life and care needs of younger residents.

The two least common views, Position A & B, regarded aged care facilities as an appropriate living situation for younger residents, with Position A making direct reference to the inappropriateness of purpose-built facilities. Position B contended that under certain circumstances, purpose-built facilities may be more appropriate than an aged care facility. These circumstances included younger residents becoming too disruptive to older residents, or if their care needs necessitated specialised caregiving which formal caregivers within an aged facility could not provide. Analysis of the interviewees’ transcripts who asserted Position A & B omitted any mention of the life needs of younger residents, aside from instrumental caregiving.

Caregiving for these interviewees appeared to be more heavily focused on completing instrumental caregiving duties (toileting, feeding, bathing), rather than providing emotional care, with both interviewees advocating for ‘caregiver neutrality’. Caregiver neutrality, explored fully in Chapter Six, is the view that caregivers should not develop any emotional attachment towards a care-recipient. Thus, the position held by these interviewees appears to be based on a very narrow concept of caregiving, one which preferences instrumental caregiving activities above emotional caregiving ones. As such, the completion of instrumental caregiving activities is more likely achievable within the context of RAC.

‘Not good’ for younger people. The accommodation of younger residents within aged care facilities was considered inappropriate by 82% of interviewees. Many of these described such placement in terms of ‘not good’, including ‘not good’ for the younger resident, ‘not good’ for
their family and friends, ‘not good’ for older residents and ‘not good’ for formal caregivers. One interviewee remarked, “it’s wrong, wrong, so frigging wrong. They just shouldn’t be in here. It’s no place for anyone who is young. There’s no life for them here”. Statements such as these were commonly expressed in interviews.

RAC was deemed as ‘not good’ for younger residents by many interviewees because of the significant limitations to developing new social connections and maintaining old ones, as well as difficulties in engaging in social activities and living a meaningful life. Frequently noted by interviewees were comments regarding the social isolation the younger residents they cared for feel, particularly the limited peer interaction available to them.

Social isolation observed by formal caregivers is frequently noted in research examining the life quality of younger people in RAC. A study by Winkler et al. (2010) comparing younger people with an acquired brain injury (ABI) living in shared supported accommodation (SSA) with those in residential aged care (RAC), found both groups of younger residents were typically visited by a friend less than once per year (40% in SSA and 56% in RAC) with 82% of younger residents seldom or never visiting friends in their home (Winker, Sloan & Callaway, 2007). Visitations from family were a more common occurrence, with familial visits ranging between 62.2 times per year for younger residents in SSA and 102.5 times in RAC (Winker et al., 2007). The difference in frequency of family visitation is attributed to familial compensation for the perception that younger people in RAC are lonelier and are inhibited in forming relationships with other residents, and that they experience more boredom because the environment fails to meet their life needs (Winkler et al., 2007).

Several interviewees acknowledged that friendships did occur between younger and older residents, but interviewees raised questions regarding the degree of satisfaction derived from such relationships. Generational differences in knowledge and a lack of common ground were seen to prevent the formation of deeper relationships between younger and older residents;
I mean, come on, how much can you have in common with someone who’s forty years older than you...I don’t really get close to the oldies because they live in a different world than what I know, so I can imagine it’s the same for (X) [the younger resident in the interviewee’s RAC facility].

The comment made by this interviewee highlights an overarching theme among interviewees when caring for a younger resident, namely their ‘identification’ with their client. This identification can be conceived of as tacit knowledge, an inherent understanding of younger residents, their needs, the life-stage they are in, their wants and desires, which go beyond the codified knowledge of the individual. For some interviewees, identification with a younger resident enhanced caregiving motivation, “I guess because I understand him/her, I have a feel for what s/he needs beyond just typically ADLs and stuff. I know him/her better than other clients, and it’s why I do the little things that make his/her life a bit better”.

But for many other interviewees, identification with the younger resident became onerous, as caregiving beliefs and intentions became increasingly thwarted by caregiving duties and bureaucracy. This tension between what many interviewees wanted to do and felt they should be doing for the younger residents they cared for, and what could realistically be undertaken in a RAC facility, produced feelings of anger, powerlessness, helplessness, resentment, frustration, and emotional numbness. The phenomenon of ‘identification’ in formal caregiving relationships with younger residents was not identified by interviewees in their relationship with older residents. The theme of identification will be explored in more detail later in this chapter since, for many interviewees, it was a significant shaper of caregiving relationships and caregiving expression.

Besides a lack of commonality, the superficiality of relationships formed between younger and older residents was also attributed to the likelihood such relationships would be cut short because of death or the significant decline of the older resident. Eleven interviewees spoke of the ever-present reality of impending death within the RAC facility. One interviewee remarked;
I reckon it’s hard getting to know someone and getting close, to then have them die or watch them get sicker. I know the young [person] in my place, well s/he’s 38, and s/he said to me ‘s/he is tired of death being around him/her’, and I know that stops him/her now from even attempting to have some sort of relationship with anyone. In the beginning s/he tried, but 8 years on, s/he’s had enough’.

Other interviewees maintained aged care was not appropriate for younger residents because of limited social activities in which a person could engage, and the inability of facilities to provide an environment that is meaningful to them.

It’s really not so good for him/her being in here. S/he’s pretty bored and gets agro [aggressive] really easily because of it. There’s really nothing for him/her to do, and to be faced with nothing to do that’s worthwhile, day in and day out. Well, I couldn’t handle it. Interviewees also spoke of their distress at seeing the younger residents they provided care to become more withdrawn as the months and years passed;

It breaks my heart to know that (X) doesn’t come out of his room much anymore. It so sad to see how down he is now [compared to when s/he first arrived], and worse is there’s not really a damn thing I can do about it.

‘Not good’ for older residents. While the placement of younger people into RAC was deemed by many interviewees as being inappropriate and ‘not good’ for any younger resident, five interviewees also contend the situation is also ‘not good’ for older residents. These interviewees felt some of the behaviours and life needs of a younger resident conflicted with the lifestyle and needs of older residents;

When (X’s) mates come over, they are noisy, laughing and carrying on and they watch um violent movies in his/her bedroom which are played at full bore. The old ladies in the rooms next to him/her complain and whine for days afterwards when his/her mates have
been over because they’ve had to nap in the common room rather than their bedroom, and plus they (X’s friends) are often here till late, so their bedtime routine is disrupted.

This interviewee highlighted a common acknowledgement by 54% of interviewees that aged care facilities often lacked a private space in which younger residents could engage in socialisation activities with their peers or family.

Besides conflicts between two differing lifestyles and life needs, three interviewees believed the placement of younger residents into aged care was ‘not good’ for the older residents because the disability or neurodegenerative disorder of the younger resident was too confronting or distressing for them. Two formal caregivers retold of the increasing distress several older residents experienced during the deterioration of one younger resident with Huntingdon’s Disease (HD) in their facility. One interviewee spoke of the repeated angry outbursts projected onto her by an older resident as the younger person’s mental and physical health declined,

She would start yelling at me, ‘why the hell can’t you do something, he’s dribbling all the time and he stinks of wee, and I don’t see why I should have to be around him,…I didn’t think she liked him until he died and then she was inconsolable for months blaming us for his death.

This example perhaps illustrates the complex shared world of relationships and interactions within a RAC setting in which situations within its walls are not isolated and independent of each other, rather these situations have the potential to impact upon all those within this shared world.

Interviewees also spoke of older residents’ difficulty comprehending the symptomatic manifestations of a younger residents’ disease or disability, highlighting a larger issue of managing competing resident’s needs. In particular, several interviewees spoke of one younger resident with an acquired brain injury whose disinhibited behaviour caused regular conflict on the ward. One formal caregiver remarked,
when (X) went off [angry outburst] or did something inappropriate, a couple of the older one’s would get up on their high horse and say like “that’s no way to speak or behave…he should know better at his age”. Despite me telling them many times that sometimes a stroke in the front of the brain causes changes to how a person is, they couldn’t get it.

Several interviewees commented on the emotional impact felt and expressed by some older residents to the presence of a younger person in a RAC facility meant more work for formal caregivers as they attempted to ‘keep the peace’ between residents. One interviewee stated “I have enough to do already, but placating this one and soothing this one just adds more work to do…of course of which we aren’t really trained to deal with. I feel like I’m always putting out emotional spot fires”. Interviewees spoke of how, over time, repeated exposure to these types of situations generated feelings of frustration and annoyance with particular residents, which led to a disinterest in engaging with the residents involved.

Balancing competing needs between residents, staff and systems are often sources of conflict within the formal caregiving system. Edberg et al. (2008) found navigating competing needs including resident needs versus their family needs, the needs of one resident with another, residents’ needs versus the wellbeing of staff, and residents’ needs versus the ‘system’, was a source of significant strain among nursing staff. While the psychological outcomes of such strain was not examined in Edberg’s et al. (2008) qualitative study, the link between job strain, mood, and job satisfaction has been established. Healy and McKay’s (2000) study of nursing stress found a negative correlation between job satisfaction and job strain (stressors within the work environment including lack of support, conflict, workload, inadequate staffing levels and insufficient time), and a positive correlation between job strain and lowered mood. Examination of strategies nurses used to cope with job strain in Healy and McKay’s (2000) study revealed the use of avoidance coping (behavioural efforts to escape or avoid the problem) was associated with increased negative moods.
According to interviewees, repeated exposure to incidences of competing needs, which generated feelings of powerlessness to change particular situations, resulted in their use of avoidance coping. In light of Healy and McKay’s (2000) findings, this behavioural response is problematic for formal caregivers in respect to lowering their mood, and the resident-caregiver relationships. Interviewees described their avoidance coping as both physical and emotional withdrawal from residents involved in these situations,

When it’s like that [situation] I will back away from it all and go and do something else or get someone else on shift to take over. It’s the only way I can get rid of the emotionality of the situation in a less harmful way.

For this interviewee the capacity to reorganise one’s shift duties or enlist another staff member to undertake the care needs of residents in order to withdraw is contingent on the rapport staff have with each other, the flexibility to re-arrange shift duties, and managerial acceptance of shift flexibility. Indeed, in Murphy’s (2007) examination of nurses’ perceptions of factors negatively impacting quality of care in RAC, being bound by routines that were inflexible, and which deprioritised residents’ and staff needs, was associated with perceived poorer delivery of care. Further, facilities which promoted innovation and provided support in making changes to practice were associated with the provision of higher levels of care (Murphy, 2007).

Aside from physical withdrawal, several interviewees spoke of emotional withdrawal from residents when involved in situations involving younger and older residents in which they felt powerless or helpless to do anything. While this was often for the duration of the shift, as interviewees attempted to ‘regain composure and objectivity’, two formal caregivers spoke of their emotional withdrawal from several residents which continued for months after an incident passed. This included engagement in only superficial conversation, conversation that was limited to caregiving needs only, caregiving interactions that remained largely silent, and the ‘glossing over’ of resident subtle requests for emotional support, such as a pat on the hand and a ‘you will be ok’
when a resident became teary, rather than deeper probing of the issue. These interviewees, full-
time formal caregivers working regular day-shifts, had multiple exposures to incidents of a similar
nature (conflicts in competing needs) and spoke of the lack of support from other workers and
facility staff, “it just keeps on happening. The same issue time and time again. And there’s nothing
I can do except just shut it out so I can get on with my job. It’s not worth the stress otherwise”.

Support from other workers and facility staff, including management, is perhaps the
cornerstone to equipping formal caregivers with the support they need to engage in effective
caregiving behaviours and aid resolution of conflict within a facility. Wilson, Seymour and
Aubeeluck (2011) examined the challenges facing staff providing end-of-life care to people with
progressive long-term neurological conditions. This multi-method design involving 180
interviewees across six neurological care centers found collaborative relationships within the care
team enabled staff to draw on the expertise and experience of other staff members to help them
manage and cope with difficult situations that arose during the caregiving relationships with
clients. Once again, flexibility in organising the ‘to do’ list of facility duties, and managerial
support for shift flexibility continues to also underpin the extent to which collaborative
relationships among staff are effective in aiding the resolution of conflicts between young and
older residents. Flexibility and adequate support from other team members may also facilitate less
use of physical and emotional withdrawal coping strategies from formal caregivers when faced
with situations that are disempowering.

‘Not good’ for family and friends. The placement of younger residents into aged care
facilities is considered by interviewees as being ‘not good’ for younger residents as well as older
residents for whom such facilities were designed. Nearly one quarter of interviewees also
considered RAC facilities were ‘not good’ for the family and friends of younger residents citing a
lack of private space to entertain, the confrontational aspect of aged care for relatives and friends,
the lack of capacity to entertain children or facilitate a parental role (in residents who had their own children), and discordance between the facility and visitors’ schedules.

Similarly to those interviewees who believed older residents found the disability or neurodegenerative disorder confronting, three interviewees contended family and friends of younger residents often found the mental and physical health issues of older residents confronting or distressing. Two interviewees attributed a decline in visitors one younger resident received because of the discomfort their friends and family repeatedly encountered when visiting;

Aged care places like this can be scary when you don't work here. You see what it’s like to get old and frail. It reminds you of what’s coming. And it’s worse because there’s no place for them [family and friends] to not be around it.

The lack of private space in which young people could entertain family and friends was again most often cited by interviewees as contributing to family and friends’ distress when confronted with the nature of RAC,

I don’t think he should be here, it’s not a good place, and well, I think his kids are maybe kind of scared when they visit. You know we have some oldies that well, one of them in particular goes off like a banshee, and well, that freaks us out, so you can imagine how (X’s) six and three-year old feels about being around that.

Acknowledgement of the difficulties young people experienced in maintaining peer relationships was commonly articulated by interviewees from both RAC and purpose-built facilities. In particular, 43% of interviewees stressed the importance of making younger residents’ friends feel welcome in order to increase the likelihood of their return; “I think if they feel welcome here and like they’re not intruding, they will more likely keep coming back”. This comment highlights several interviewees’ beliefs about ‘good caregiving’ which included facilitating a welcoming environment for residents including their family and friends.
Formal caregivers’ recognition of younger residents’ deficits in peer relationships reflects Winkler et al.’s (2006; 2007; 2010; 2011) findings from research into the quality of life of younger residents in Australian RAC facilities. Winkler et al. (2006) note 44% of younger residents receive visits from a friend less than once a year, with 47% travelling outside of the RAC facility less than once a year (p.104). Deficits in peer relationships among younger residents is also acknowledged by the Senate Community Affairs Reference Committee (2005), citing that such deficits in peer relationships, coupled with lack of privacy, inability to exercise autonomy, and the witnessing of multiple deaths within a facility, increase the risk of depression among younger residents. It is clear that many interviewees recognise the importance of these peer friendships, especially for the mental health and wellbeing of younger residents, and subsequently, facilitation of these relationships has become incorporated into their caregiving role.

Formal caregiver opinions are not unfounded in relation to younger residents’ mental health and wellbeing, and the role peer relationships play. For example, Snowdon and Fleming (2008) and McCabe et al. (2006) find 40% of RAC residents met the DSM-IV criteria for depression, much higher than seen in the general population. While quantitative research examining the prevalence of mental health issues among younger residents has not been undertaken, research does indicate younger residents experience a much lower quality of life than the general population (Winkler et al., 2010; 2011). It is likely then that prevalence of mental health issues, such as depression, among younger residents is also higher than seen among their peers not living in a RAC facility.

Aside from recognition of the difficulty younger residents have in maintaining peer relationships, three interviewees also felt RAC facilities provoked anxiety for some family and friends as the environment was not conducive to either entertaining children or to facilitating younger residents’ parental role. One interviewee noted,
This one guy has a couple of young kids who are SO [emphasis] active and they basically try to run amok whenever they can. His wife gets so stressed trying to attend to her husband while trying to keep the kids under control. I’ve seen it also, it happens when his brother’s and sister’s visit with their kids. Kids are noisy and that’s um normal really, but it’s not appreciated in here so I think it creates a barrier to visiting them.

Some formal caregivers also noted the RAC facility had a negative impact upon engagement in normative parental activities young people with dependent children experience. Once again, purpose-built facilities were perceived by those formal caregivers working there as being better for the undertaking of parental engagement with children because these facilities afforded more flexibility and opportunity to do so. One interviewee reflected on the different environment between the two types of facilities:

I know I muck around with my kids, like chase them around or play hide and seek or build a table fort. But (X) can’t do that in here, it’s a no-no, especially when the family is restricted to (X’s) bedroom. But at my other place where I work [purpose-built facility] that sort of stuff would be less of an issue as the place is bigger and you can get outside easier. Plus the staff there are used to working somewhere that’s more like home and so they roll with it better.

This comment perhaps suggests that the living environment plays a role in shaping norms around acceptability of behaviour and caregiver responses to the behaviours of residents and their visitors.

Several interviewees also regarded the routine of the facility as being in conflict with the schedules of visiting family and friends, making visitors of young people (and potentially visitors of older residents) feel unwelcome;

Weekends are ok but during the week when people visit after work, it’s our busiest time with mealtime and stuff and the ‘med run’ [nursing staff’s scheduled distribution of medication] and it’s sort of chaos all mixed together when you throw in kids, or friends or
families... I mean I try to help out and get them a coffee but they [visitors] pretty much get ignored. I feel bad especially because I think they feel like they are intruding. It’s not good for making them want to come again.

Once again, this comment highlights a sense of personal responsibility formal caregivers and their managers feel in providing an environment that facilitates the meeting of residents’ needs beyond caregiving ones.

‘Not good’ for formal caregivers. The placement of young people into a RAC facility is considered by many formal caregivers as being ‘not good’ for younger residents, their family and friends, and the older residents calling the facility home. The lack of private space, confronting behaviours of other residents, and fundamentally different life needs and lifestyles of the young and old makes accommodating a younger resident in a RAC facility less than ideal. However, interviewees also considered the placement of young people into the RAC facility where they worked as being ‘not good’ for themselves either.

More than a third of interviewees (10) expressed frustration over the lack of information about the disorder or disability a younger resident was suffering from, with several stating they ‘wouldn’t even begin to know where to get that information from’. This complaint was common even among formal caregivers working in facilities built purposely for younger residents. The managers interviewed also stated they felt inadequate to provide information to caregivers about a younger resident’s respective disorder above and beyond what was readily available via the internet. One manager commented, “I can relay this information in a rote sort of way, but that doesn’t even begin to capture all the nuances and intricacies that manifest. It’s that stuff, that information and direction my staff are really looking for. But I don’t have it to give it to them”.

However, four interviewees spoke of independent research they had undertaken in order to better understand the young people they cared for. One formal caregiver had contacted the Australian Stroke Association hoping to gain a greater understanding of the impact a stroke has on
a person, while another formal caregiver had emailed Huntington’s Victoria and the Australian Huntington’s Disease Association for information and support in caring for a younger resident who was rapidly deteriorating. This formal caregiver stated, “I just thought if no one really understands here what’s going on, then to do my job properly I will have to find out what’s going on. So I did”.

While four formal caregivers undertook independent research to enable them to understand the condition of the younger resident they were caring for, more than half of interviewees (54%) felt they lacked sufficient training and caregiving skills to adequately care for a younger resident, especially when that resident had a degenerative condition. For some interviewees, this resulted in feeling helpless and incompetent to provide the appropriate kind of care required,

I kind of feel really useless with this one [younger resident with a neurodegenerative condition] as (X) has gone downhill really quick and we are left flailing in the mud trying to help. I can’t even pronounce what (X) has, let alone understand what it is, and sadly no one seems to know anything.

Feeling inadequate and lacking in appropriate caregiving skills is a commonly cited complaint among staff working with clients who have low-prevalence neurodegenerative conditions. Wilson, Seymour and Aubeeluck (2011) found the unpredictability of the disease trajectory and the relative infrequency with which people with neurodegenerative disorders come into care, meant formal caregivers needed to ‘re-learn skills’ each time they encountered a new resident. Indeed, the relatively small number of young people residing in aged care in Australia means that management, aged care facilities and formal caregivers themselves will often gain only very limited experience in providing care to this group of people.

While regular staff may develop specialised skills through regular contact with one younger resident, the variety of presentations and disorders found among this population may mean these caregiving skills are not completely transferable to another younger resident who
enters care. The same is true of purpose-built facilities, though accommodating all young people with high care needs, the presentation of the disorder and disease progression will likely vary significantly between residents. Further, the significant staff turnover within the residential care sector and the high use of casual staff means that many formal caregivers who come into contact with a younger resident may have had no, or only limited, experience dealing with this specific population group. This is problematic as the sharing of expertise has been found to be invaluable and often relied upon heavily to provide a high quality of care and navigate the challenges associated with caring for those with neurodegenerative conditions (Carter et al., 1998; Wilson et al., 2009)

Management of both RAC and purpose-built facilities are likely to also lack exposure to individuals with neurodegenerative conditions. More than one-third interviewees (10) spoke of the lack of guidance and support from management around adapting caregiving behaviour to the changing needs of young people. One interviewee stated,

to be honest, I’m pretty sure our manager doesn’t really have a clue about (X) and what’s going on. [Manager] has given me totally incorrect advice before when I asked about (X) so I’m a bit reluctant to go to management. Just because they are higher up doesn’t mean they know more.

Though the physical and cognitive decline of older residents often necessitated the adaptation of caregiving behaviours by formal caregivers, interviewees reflected both they and management seemed better equipped and informed on how to respond since such declines were regularly experienced in the aged care sector. However, with younger residents, the physical and cognitive decline often did not follow a similar pattern to those of older residents and were frequently intertwined with increasing negative behaviours and/or a deterioration in mental health and wellbeing.
Interviewees spoke of not having an appropriate interpretative lens or reference point from which to understand a younger resident’s emerging symptoms,

I don’t know what’s normal when it comes to (X). I don’t know if this [behaviour or symptom] is part of (X’s) condition or from something else. Worse is that I don’t know how I’m supposed to respond, and neither does anyone else. It’s a real big guessing game. Another interviewee remarked,

You can’t do it because a young person in here is an anomaly, it’s not the norm so no one is really prepared for what to do, or really knows how to best respond [to them]. Instead we just do what we do with the old people. But that frame of reference, that reference point is inappropriate. It’s a bit like trying to understand a letter written in Spanish using a German dictionary. You gonna get it wrong, a lot [emphasis].

Interviewees also noted how the type of condition a younger resident had influenced the level of interaction and degree of relationship formed. A contrast was noted by formal caregivers working in the purpose-built facilities between young people with an ABI, and those with Multiple Sclerosis (MS), HD or Motor Neurone Disease (MND). Interviewees spoke of the increased capacity for a relationship with someone who was suffering with an ABI rather than a neurodegenerative condition because there was no significant deterioration in their condition, “you kind of get used to what (X) can do. You adjust and that becomes the norm, but with the other one (resident MND), you never know what each day will bring”. Similarly, residents with MS, though having a degenerative condition, often experience periods of remission or deteriorated at a slower rate than those with HD or MND. For two interviewees this was seen to provide a greater opportunity for a relationship to develop.

Interviewees in RAC perhaps have less capacity to contrast between young people, since the exposure to a younger resident in an aged care facility is much less frequent. However, one interviewee in a RAC facility who had cared for two young people at different times reflected how
the young person’s disease or disability influenced the level of emotional engagement. This interviewee spoke of a greater sense of hopelessness caring for a younger resident with MND than caring for the younger resident who had an ABI,

I think it’s because X was going to die and there was nothing much I could do. He had deteriorated so quickly and it was just heartbreaking to watch. So I didn’t really get involved because it was too painful. But with X (other resident), it’s different. She will probably live another thirty years and X’s outlook is much better. I feel I can [emphasis] contribute something useful to her life.

The prognosis an individual with a neurodegenerative condition has is implicated in the degree to which health care professionals engage with patients. Carter et al. (1998) found nurses believed they could offer clients with MS a greater level of care than those with MND because of the chance of remission. Nurses also reported greater confidence in their capacity to care and convey hope to patients with MS because of the possibility of remission. With regards to interviewees’ position that RAC in ‘not good’ for formal caregivers, it cannot be ruled out that the younger resident’s condition and the extent to which a formal caregiver perceives they can contribute to the care and wellbeing of that younger resident’s life, is influencing such views.

**Purpose-built facilities and the younger resident.** Of all the interviewees participating in this study, seven formal caregivers and one manager worked in a purpose-built facility and all had experience providing care to a younger resident within the RAC environment, either historically or concurrently. Despite several interviewees contending that RAC is appropriate for younger residents with high care needs, only one interviewee believed purpose-built facilities were not always a suitable alternative accommodation for every young person. This interviewee articulated difficulties caring for one particular younger resident,

(X) doesn’t fit in here and he disrupts the other guys and girls who live here. He does my head in so I guess I would rather see him elsewhere. Plus I don’t think it’s always THE
(emphasis given) best place, like this one, for every younger resident. I think [RAC facilities] other places can sometimes offer more structured routines which help with some of the issues we have to deal with.

These difficulties concerned the undertaking of activities of daily living. The younger resident’s preferences for waking up and meal times were different to other residents, and catering to those preferences hindered other facility routines and schedules. This often impacted other residents. The resident’s preference for waking in the afternoon meant showering and the preparation of the first meal of the day fell to the afternoon staff to undertake. However, during the weekdays several other residents were regularly away from the facility which in turn required facility staff to transport them home. Often this left only one formal caregiver in the facility to care for the remaining residents and to prepare the evening meal. This left little time to accommodate the younger resident’s preferences. The interviewee stated,

It actually makes it harder because here it’s about a more home-like place and we are supposed to make sure the people we look after live the way they want to, like getting up when they want, and going out when they feel like it. Which is fair enough but the thing is, there’s not that type of flexibility in what we do, and there’s not like lots of staff to help to get everything done. The morning shift has to get all the residents out of bed, showered and fed and then cart them to where ever they need to be for that day. But (X) wants to sleep in till all hours. It’s his right but we [staff] cop it from the afternoon staff and management just because all our duties haven’t been finished.

The situation articulated here highlights a significant issue facing the residential care sector, which includes aged care and purpose-built facilities, namely the challenge of providing a person-centered care approach in the face of under-resourcing (staff and finance) and increasing compliance requirements and regulation. While purpose-built facilities are typically smaller and can offer a living facility that better approximates a home-like environment, purpose-built
facilities still remain embedded in the same socio-political milieu which governs both the
disability and RAC sector.

For some interviewees, the nature and environment of purpose-built facilities promoted
greater congruence between formal caregivers’ perceived role and the actual role undertaken. It
provided them with the ability to adapt the facility’s environment and one’s caregiving behaviour
to suit the ‘individual rather than the masses’. This reduced conflict between caregiving beliefs
and actions, and promoted a sense of job satisfaction. Interviewees gave examples of modifying or
creating meals to suit individual palates or buying a particular brand of washing powder because
(X) gets itchy when other brands are used’, sitting with a client when s/he is in bed to help
her to fall asleep, and reading the morning paper to another client who had done so for the
past twenty years before needing care.

One interviewee remarked,

I love knowing that doing this [sitting with client as X falls asleep] brings her the comfort
and security s/he needs, and that what I do REALLY (emphasis) means something to
someone else, that it makes a real difference in someone else’s life. It’s really satisfying to
me because I feel that ultimately that’s what my job is really about.

Purpose-built facilities were also seen as affording formal caregivers with increased client
contact, “less clients definitely means more time with each one, and it means, I guess it feels more
like you are doing a better job, or that you are actually doing what you are supposed to be”. They
were seen to facilitate family and peer interactions with the provision of private entertaining
spaces in which to interact with family and friends. Interviewees noting these spaces were often
lacking within aged care facilities.

However, interviewees remarked that younger residents did not have the same level of
interactions with their peers compared to the social life of formal caregivers;
They don’t seem to really have many friends that drop by. You should see my place on the weekend. It’s nothing like that. There’s probably more mums and dads that visit, and maybe a brother or sister, but as for friends, yeah they’re still pretty much alone.

This sentiment is echoed in Winkler et al.’s (2010) study which found little difference in the number of visits from friends for young people living in shared accommodation versus RAC, despite shared accommodation providing greater privacy. It suggests there are other barriers to social engagement between a younger resident in a RAC facility or purpose-built facility and their friends.

**Summary.** One of the two differences interviewees noted caring for younger residents compared to older ones, was the opinion of the inappropriateness of RAC facilities for this population. RAC facilities were regarded as ‘not good’ for young people, their families, other older residents, and formal caregivers themselves. Limited opportunities for social interactions, minimal peer interactions, and the diminished capacity to live a meaningful life deemed RAC as being unsuitable to meet the unique and changing life needs of younger residents. Though purpose-built facilities were seen as a better option, and more likely to meet younger residents’ life needs, these facilities remain impacted by systemic issues within the residential care sector; under-resourcing in staff and resources that hinder the delivery of individualistic person-centered care.

**Caregiving Differences: Identifying with Young People in Residential Aged Care**

I stood alone in X’s room and looked around. It was probably four meters by four meters in size. I looked at the few photographs, of places and smiling faces, of her in times free of the disease killing her. A few remnants of a past life, a mug with a photo on it, a few knick knacks here and there on top of a pine table that probably was from home. I looked around and this is what X’s life had become. Four walls with a few memories of a life that no longer is. What if this was me and this is what my life now amounted to? I think I would
rather be dead than live this existence here in this place. That realisation made me more
determined to do everything I could to make X’s life a bit better. To make everyone’s life
here a bit better. Because for here but the grace of God go I.

This poignant comment made by one of the interviewees reflected a commonly expressed
sentiment by many interviewees and articulates the other difference formal caregivers observe
when caring for younger residents compared to older ones. Indeed, these comments collectively
formed a very significant theme identified in the interviews undertaken; interviewees sense of
identification with younger residents in both a RAC context and purpose-built facilities. For
interviewees, this identification is conceived of as an inherent understanding of the totality of a
younger resident and their life beyond solely instrumental caregiving needs. This identification
extended to interviewees’ innate sense of a younger resident’s life stage, needs which might arise
during this stage, what their life is currently lacking, and the importance of relationships with
others, especially intimate relationships.

**Life stage.** Interviewees reflected upon ‘life stages’ with comments and descriptions such
as ‘the season one’s life is in’, ‘the time for this is now’, ‘look at X’s peers, this is what they’re all
Fundamentally, interviewees conceptualised ‘life stages’ as being distinct epochs of time identified
by a seemingly common and normative life activity or endeavour such as dating, settling down and
having children, building one’s career, planning for retirement, and winding down the pace of life
after retirement.

A life stage is in reality not fixed in terms of when it will occur i.e., an individual may
choose to remain single and childless, while another decides to retire in their mid-forties.
However, interviewees’ conception of the ‘life stages’ a younger resident they care for currently is
in as likely reflecting their own current life stage or one which they have undergone or can identify
with. As one interviewee articulated;
We’re the same age pretty much, and I know my life is pretty much about my kids, [getting] them to little aths [athletics program for children], and dancing and soccer, and all that school stuff. X has got kids as well so we are in the same boat, except X can’t do that stuff. So I reckon how much more it would suck to X to be missing out on that stuff.

For nearly quarter of all interviewees (7), identifying and understanding the life stage a younger resident was in was seen as beneficial for preempting their life needs to better give a younger resident that which they needed beyond instrumental caregiving,

X is only 21, the same age as my daughter. I know how much she wants her freedom and how she is trying to make an identity for herself, and I so understand her need for people her own age to help her define who she is. That’s normal, but in here [RAC facility] it’s harder to gain what you need for that time in X life. So I have little chats with X about life, like what a mum does, and try to give X more autonomy when I’m caring for X in the day-to-day. I try and encourage X to maybe join some groups coz I know that’s what X needs right now.

Understanding of these life stages also enabled interviewees to more easily identify with the areas of life a younger resident was missing out in. For formal caregivers, identifying what is lacking in a younger resident’s life was frequently associated with the awareness that such needs could not be met by them or the facility. Interviewees spoke of these needs as ‘life’s purpose or mission’, ‘fun’, ‘hobbies’, ‘dating’, ‘being a mum or dad’, ‘having a family’, ‘setting and achieving goals’, ‘learning about one’s self’, ‘exploring the world’, ‘education’, ‘being a part of a community’, ‘feeling like your life matters’, ‘sense of purpose and meaning’, and ‘being connected to others’. These comments typically reflect aspects of quality of life which were described in Chapter Three as a combination of the satisfaction one gains from work, relationships, leisure activities, goals and hobbies (Diener & Lucas, 1999; Diener, 2000; Headey, et al., 1993; Seligman, 2011), the meaning of one’s life (Halama & Bokosova, 2009; Mascaro & Rosen, 2006;
McKnight & Kashdan, 2009), and the quality of connection to others (Frisch, 2006; Seligman, 2011).

Awareness of a younger resident’s needs and the inability to meet those needs or facilitate the environment to make better provision to meet those needs often generated anger and frustration among interviewees from both RAC and purpose-built facilities. However, interviewees working with young people in the purpose-built facilities spoke of their work environment permitting a greater capacity and flexibility to meet residents’ needs. As one formal caregiver noted, “it is easier here than in an old aged home because we can organise more appropriate social stuff, like concerts and stuff, and we can give them more choice in things like food and what they want to do”.

Similarly, the manager of one purpose built facility noted how it was easier to create an environment that was more enriching for young people with the hope this environment would better meet their ‘social and life needs rather than just caregiving ones’. The manager noted, though all residents were young, there were differences in the individual life stages which generated complexity in creating the ideal environment for which all residents would benefit. This complexity was unlike RAC facilities which typically only accommodated one or two young people at a time. However, the nature of RAC appears to thwart formal caregivers’ attempts at meeting the social and life needs of any younger resident, generating frustration and anger.

The importance of relationships. Irrespective of the facility type, most interviewees consistently noted the importance of peer relationships and the subsequent lack of relationships for many of the young people they cared for. The importance of peer relationships for younger residents cannot be understated. In an Australian Senate review into the adequacy of RAC for those under 65 years, the Senate found that the lack of peer relationships was negatively impacting younger residents’ quality of life and exacerbating “pre-existing mental health issues...[ contributing to the development of] grief, loss, and depression” (YPINH, 2015, p.23).
Formal caregivers in purpose-built facilities had a greater capacity to structure their facility and the day-to-day shifts to better meet some of the needs of the residents. This, in turn, created a positive feeling of usefulness, productivity and pride in one’s work for several of the interviewees. However, many formal caregivers and the manager of a purpose-built facility spoke of a continual awareness and sense of helplessness to facilitate or provide the type and depth of relationships they perceived a younger resident needed,

I can be a friend to X, a good friend in fact, but I can’t be his lover or partner. I can’t meet those needs, nor would I want to but to think that X will never have that, that breaks my heart.

Interviewees noted a lack of relationships for young people included not only the lack of intimate relationships but also ‘best friend’ relationships, ‘sporting buddy’ relationships, ‘work colleague’ relationships, ‘mentoring’ relationships and ‘community’ relationships. They also noted young people typically had a limited capacity to fully engage in other types of relationships in which they were a part of. These relationships included being a ‘husband or wife, or mother or father’, ‘leader[ship] relationships, and ‘aunt, uncles, niece or nephew’ relationships.

Interviewees’ opinions about young people’s relationships is also reflected in the literature examining the life quality of young people in RAC (Winkler, Sloan, & Callaway, 2007), in research comparing RAC and purpose-built facilities (Winkler et al., 2010), and within government reviews (YPINH, 2015). In line with the current findings, this research consistently shows that young people’s relationship network is significantly compromised and often lacking compared to peers with no care needs. As such, formal caregivers express distress over witnessing the lack of, or compromise to the relationships young people experience.

As reflected in the quote at the start of this section, identification for interviewees appears to be grounded in empathy and based on their capacity to project themselves into the current life circumstance or ‘life stage’ in which the younger resident for whom they care. More than empathy
and projection, identification for interviewees represents a powerful shaper in the expression of caregiving behaviour. Interviewees retold stories of adapting their caregiving behaviours and, at times, their attitudes toward younger people in order to better facilitate the meeting of their life needs.

For interviewees, this typically involved decreasing assistance in order to foster independence and providing choice where possible to enhance a younger resident’s sense of control over their life. It also involved asking younger residents their advice regarding areas of expertise. This helped to convey a sense of their worth and usefulness. Formal caregivers also undertook research to inform younger residents of opportunities for social and community participation. They also provided younger residents with teaching opportunities for the learning of life skills such as cooking and shopping. One night shift worker who worked in a purpose-built facility spoke of using the quieter evening shift to help one younger resident to learn to cook,

Basically I prepare the lunch and dinner for the next day, and well one day, X came up to me and said he would really like to learn how to cook. From that shift onwards, he would help me to prepare the meals, chopping the veggies and meat and adding spices and stuff. X went on to suggest things we could make and over time he became very good at cooking. It made me feel like what I was doing, just ordinary mundane stuff, was actually really important and useful to other people. My role went from just a worker to a teacher and X and I benefitted from that.

This comment made by a formal caregiver highlights how formal caregiving relationships can be mutually beneficial to both residents and caregivers. This aspect of caregiving is explored in Shaver et al.’s (2010) work on the benefits of prosocial behaviour, such as demonstrated in a formal caregiver’s willingness to teach a younger resident how to cook.

Shaver et al. (2010) argue prosocial behaviours within caregiving relationships are advantageous to both caregiver and care-recipient for they provide positive outcomes to the care-
recipient, and positive rewards for the caregiver (pp. 78-79). Engaging in prosocial behaviour is seen to promote feelings of connection with another, a sense of self-efficacy and increased positive feelings about oneself (Shaver et al., 2010), as was the case for the formal caregiver teaching a younger resident how to cook. They are also associated with higher levels of mental health for the caregiver (Schwartz et al., 2003).

**The emotional impact of identification.** Empathy for younger residents in an aged care facility, along with a natural inclination formal caregivers have to compare their life against that of these younger residents, means that for interviewees’ this identification generates a host of either positive or negative emotions. Unfortunately, attempts to deal with negative emotions can stymie the formal caregiving relationship formed with a younger resident.

**Positive benefits of identification.** For some interviewees, identification with a younger resident of an aged care facility generated greater depths of tolerance and compassion. This was especially beneficial for mitigating the impact upon the formal caregiver and younger resident relationship when a younger resident engaged in socially inappropriate behaviour, such as angry outbursts, “I guess I understand what’s going on underneath X’s anger so it doesn’t affect me as much. I’m very aware of his/her losses and that it a powerful motivator to understanding why X can behave the way s/he does”.

Several other interviewees felt their identification with a younger resident also increased the level of their caregiving motivation. This resulted in either actively seeking to strengthen the rapport they had with that younger resident, or to enhance the caregiving relationship between one another,

I believe what we do and the relationship we have is so important because it gives these young people normal age friendships. I know if I was in here then I would probably be seeking out friendships with those who care for me. So I guess it reminds me to always try and build rapport and improve our connection.
The downside of identification. Not all interviewees positively benefitted from identification with a younger resident in a RAC facility. Identification was also a powerful evoker of an array of negative emotions. Identification enabled interviewees to sympathise with young people leaving them to speculate about their life quality and what was lacking. Identification also facilitated the existing conflict over incongruence between interviewees’ perceived role and the actual formal caregiving one.

Identification, sympathy and perceived life quality. The capacity to project oneself into another person’s reality to understand how their situation is impacting them, forms the basis of identification. For most interviewees though, this identification connects them with feelings of “sadness”, “hopelessness” and the “unfairness of life” when caring for a younger resident. One interviewee remarked:

There is much sorrow here when we speak of X. I think you can’t help but be overwhelmed by the sadness and the injustice of X’s life in here. These feelings can start to get you down if you don’t know how to deal with them properly.

The emotional toll of caregiving, as described by the interviewee above, is often reflected in the literature examining caregiving (Alderman et al., 2014; Camacho, 2016; Northouse et al., 2012), especially its contributory role in burnout among those in caregiving roles (De Rooijs et al., 2012; Schmidt et al., 2010; Testad et al., 2010).

Identification and conflict within the caregiving role. While most interviewees typically accepted the reality, there would always be a degree of incongruence within their role. This incongruence is exacerbated and more recognisable and problematic when caring for a younger resident. Interviewees noted far less conflict arising within their role when caring for older residents,

I guess it’s different because this is the last stop for them [older residents] and they’ve done life’s living. It’s done and dusted, so apart from making them comfortable and treating
them with dignity, they don’t really need much more other than the normal types of care we do. I mean it would be good if we could spend more time because that’s important, but other stuff that we try and do with the young ones, that’s not needed.

In the context of caring for a younger resident, identification reflects to formal caregivers what ‘good caregiving’ is or should be to meet unique and diverse needs of a younger resident, but at the same time, it also reveals how lacking the residential care sector is in providing formal caregivers with the capacity to do so. Half of all interviewees spoke of this conflict around knowing what is truly needed to care for a particular younger resident, including meeting their life stage needs, and knowing what could be realistically achieved. One interviewee commented;

There is a huge gulf that I and probably nobody else can or will ever close. What I know needs to be done, what is really needed to make that real difference [to the lives of a younger resident] but can’t be because of the where and why and the here and the now of this place. I live in the face of what isn’t, in the face of what is lacking, rather than feeling any pride of what is, and what has been given or done [in reference to meeting caregiving needs].

Another interviewee reflected,

it’s never enough. Not by a long shot. The level of needs beyond dressing and feeding is overwhelming. I don’t know where to start, and whatever I do just falls into a dark abyss of “not even close” [to meeting all needs].

Many interviewees expressed feelings of ‘hopelessness’, ‘helplessness’, ‘powerlessness’, ‘anger and frustration’, ‘inadequacy’, ‘incompetence’, ‘injustice’ and feeling ‘defeated’. Other interviewees spoke of feeling apathetic, “I just don’t give a damn anymore…not the job nor the people”. While most of the fourteen interviewees who cited feeling hopeless, frustrated and angry blamed the facility management and wider organisation for these emotions, two formal caregivers
blamed themselves for the incongruence between perceived role and the actual formal caregiving role, I think I should just be able to do more to help them, I’m sure there are things I can do” and “I think I’m not really much good at this job, even though I love it, I think I suck at it. I know I would do better if I was better at it”.

In addition to interviewees’ attribution of negative emotions to either their facility or organisation and towards themselves, two formal caregivers and one manager attributed their anger, frustration and resentment to the young people themselves. One commented “if X didn’t get so angry and violent, I would be able to work with him more and help him get what he needs. But as he is, I can’t and I won’t. X has to learn what life’s about”.

Blaming a younger resident may help to minimise any formal caregiving distress that arises from a formal caregiver’s inability to care in a manner congruent with their beliefs.

**Resolving negative emotions.** The experience of negative emotions appeared to lessen for interviewees who had a supportive manager who expressed empathy and was able to understand the difficulties within the formal caregiving role. Interviewees acknowledged the positive benefits of being in a facility where both staff and management were willing to acknowledge formal caregivers’ concerns and feelings and listen to their frustrations. The capacity of other facility staff to “allow [formal caregiver] to vent [negative emotions] or talk about how the role was having a bad impact on [other areas of life] helps get rid of some of these feelings”.

Aside from reducing negative emotions, interviewees from one purpose-built facility and several RAC facilities who commented their manager was ‘supportive’ of them in their role also noted the decreased occurrences of conflicts between perceived role and actual role;

We might get a bit agro because of the amount of work that just gets more and more, but our manager is always helping us out. Z either sympathises or lets us know that she understands what we are going through. Z is never judgmental if we can’t do it all. This helps heaps because other managers aren’t that understanding.
Indeed, several of the managers who were considered ‘supportive’ by interviewees had themselves previously been formal caregivers before changing roles. One interviewee commented, “Z understands a lot of what we face because she’s been through it before, you know, before she did this role’.

It is likely supportive managers with previous experience in the formal caregiving role identify with formal caregivers, remembering their past experiences of conflict between facility and organisational expectation and caregiver capacity. This identification shapes their expression of leadership, in a similar way to which identification with young people shapes the expression of caregiving behaviour for formal caregivers.

A lack of support from management and other colleagues was cited by nearly half of all interviewees as the catalyst for becoming overwhelmed by negative emotions when caring for younger residents. For several of these formal caregivers, attempts to resolve distressing negative emotions resulted in the emotional withdrawal from that younger resident. Emotional withdrawal included numbness toward the person, apathy regarding the quality of their relationship, ambivalence about the person, and a decreased personal interest which typically manifested in reduced emotional caregiving duties and a preference for instrumental caregiving ones;

I’m not sure why, but I’ve become really distant to X now. Not at first, but now he doesn’t stir up any feelings of any sort. I’m kind of dead with him. I just do the basics now, not the stuff that tires me out like I used to [emotional caregiving]. I used to make sure we would have fun, but now it’s get in and get out.

Another formal caregiver commented,

I’ve tried and tried to do my best, and got nowhere. You can’t fight the system. I can’t waste any more time and effort on trying to make a difference. It’s burnt me out and now there’s nothing left to give.
Two other interviewees also alluded to currently experiencing burnout within their role. Burnout is a combination of emotional exhaustion, depersonalisation and reduced personal accomplishment (Maslach, Jackson & Leiter, 1996). These interviewees spoke of reducing their levels of emotional engagement and emotional caregiving duties undertaken with residents. But the ramifications of emotional withdrawal from the caregiving relationships are far reaching.

Though it can be seen as a self-preservation act, emotional withdrawal potentially decreases the satisfaction derived from one’s role as the gap between ‘what one should do’ and ‘what one can do’ widens. Emotional withdrawal may blind formal caregivers to younger residents’ needs which could realistically be met. This also provides them with less opportunity to derive satisfaction from their role and further reduces a younger resident’s peer interaction, likely reducing the benefits derived through the formal caregiving relationship.

**Summary.** Identification is a unique aspect of formal caregiving relationships with younger residents, and one of the noted differences when comparing caregiving of younger residents to older populations. Interviewees cite they typically lack this sense of identification when caring for older residents. A lack of identification could be implicated in Knight and Mellor’s (2007) qualitative work examining older resident’s experiences of aged care. Their study revealed older residents found aged care to be ‘good enough but not the life of choice’. Though care was adequate and appreciated, older residents’ wellbeing was impacted by “loneliness amid company, loss of autonomy, privacy and independence, feelings of vulnerability, not feeling at home and the need to comply to survive” (p.76). The study showed that residents articulated wants and needs for living a life of quality, differed from the wants and needs perceived and articulated by formal caregivers.

Knight and Mellor (2007) study suggests formal caregivers may be less able to identify, preempt and satisfy the life needs which emerge in old age because they themselves are younger. Indeed, the RAC sector is designed, managed and governed by individuals who have yet to retire and
experience ‘old age’, and a lack of identification may explain why aged care facilities are ‘good enough but not the life of choice’.

In this dissertation, formal caregivers’ identification with younger residents had the capacity to preempt and meet their unique and changing life needs. While this was beneficial for some interviewees in positively shaping the formal caregiving role, identification also generated a host of negative emotions which disrupted a formal caregiving relationship with a younger resident.

Conclusion

This chapter explored the differences for formal caregivers and managers caring for younger residents compared to older residents. Interviewees noted the inappropriateness of placing younger residents in an aged care facility. The most common position articulated by interviewees was to consider this placement as ‘not good’. This included ‘not good’ for the younger resident, their family and friends, older residents with the aged care facility, and formal caregivers themselves.

The second difference interviewees noted between caring for a younger resident compared to older residents is the impact of ‘identification’ with that younger resident. Many of the young people in residential care are of the same or similar age to the formal caregivers who provide their care and this identification with a younger resident appears to add a layer of complexity to the caregiving relationship.

As a shaper of caregiving behaviour towards young people, identification motivated some interviewees to better meet the identified and preempted needs of a younger resident. It generated greater depths of tolerance and compassion while increasing caregiving motivation, strengthening caregivers’ rapport and enhancing the caregiving relationship. But for others, identification created conflicts between expectations and formal caregivers’ capacities. Many interviewees found
themselves navigating between an ever-present reality of ‘that which one wishes to do or believes is the right thing to do for a younger resident’, and ‘that which can be done for them’.

Within this conflict, identification produced intense negative emotional reactions including grief, anger, numbness, emotional disconnection, hopelessness, helplessness and despair. While some directed their anger and frustration towards the facility and wider organisation, others blamed their experience of negative emotions on themselves and were left with a sense of inadequacy and incompetence about their caregiving capabilities. At times, identification with a younger resident generated such intense negative emotions that interviewees withdrew from emotional caregiving and the formal caregiving relationship with the younger resident. This was detrimental to the formal caregiver, the satisfaction of their role, the quality of care given, and fundamentally, the quality of life of the young people through whom a relationship with interviewees provides some level of peer and social interaction (Wilson, Seymour and Aubeeluck, 2011).

In the following chapter, formal caregiver’s identification with a younger resident will be further elaborated upon, revealing a shared world of commonality between the lives of interviewees and that of younger residents in aged care. This shared world between formal caregiver and younger resident is a world of paradox, where both are the ‘same yet different’, ‘visible yet invisible’, and ‘powerful yet powerless’.
Chapter Eight: Formal Caregiver, Young Person and their Paradoxical Shared World

In the previous two chapters, interviewees’ experiences of caring for younger residents in the residential aged care (RAC) sector were detailed. These chapters examined the caregiving similarities and differences between caring for younger and older residents. For interviewees, the inappropriateness of placing younger people into a RAC facility, and interviewees ‘identification’ with younger residents were two obvious differences. Formal caregivers spoke of experiencing incongruence between their perceived role and the actual formal caregiving role undertaken. This stemmed from conflicts embedded within the RAC sector such as caregiving neutrality, the burden of bureaucracy, and a ‘powerful yet powerless’ paradox. These conflicts shaped both the expression of caregiving behaviours and the formal caregiving relationship developed with younger residents.

In this chapter, the shared world between formal caregiver and younger residents will be explored. The identification noted in the previous chapter, which sees formal caregivers project themselves into the world of a young person, also provides the foundation upon which formal caregivers compare and recognise similarities within their world and that of the younger resident. This can be described as the ‘shared world of paradox’, whereby the formal caregiver and younger resident are both the ‘same yet different’ and ‘visible yet invisible’.

‘Same Yet Different’ Paradox

Within the arena of the RAC sector, the formal caregiver and young person, despite having very different roles within this context, are in many ways in a similar situation as each another. More than half (61%) of all formal caregivers reflected upon both their inability and younger residents’ incapacity to positively influence their environment in a way that was beneficial. Interviewees drew comparisons between their situation and that of younger residents, revealing they have little capacity to organise their work shift according to what best suits them.
and the residents. Similarly, a younger resident’s day is organised for them around ADLs, medication and meal times,

it’s a system in a sense that is imposed to ensure we complete all the tasks that need doing, and it’s quite prescriptive with little room for variance. But the flow on effect is that for the people in here [residents], their day is also quite regimented because it has to accommodate us and what we need to do.

Similarly, interviewees reflected how both they and younger residents have little or no say in changing workplace culture to better support the needs of the formal caregiving role, and younger residents. As one interviewee stated, “it’s ironic that we are both in a similar situation. I can’t get things changed to make my life or X’s easier, and s/he can’t do that to make his/her life better”.

Interviewees spoke that any change in workplace culture would need to consist of “being listened to more”, “having my concerns being considered legitimate [and resolved]” (1), “implementation of my strategies for X”, “less rigidity around things that have to be done” (5), “asking us and them [younger residents] what they need”, “the facility prioritising them [residents], us and what we do”, “recognition and valuing of our [formal caregivers] role and contribution”, “prioritising people over profit”, and “greater collaboration between us, young people and management”.

Interviewees reflected both they and the young people whom they care for are either never or rarely consulted within the RAC sector on how their role and their life could be improved within this context, “it would be nice if we were included in the case meetings, so we could be heard and the things we struggle with could also be heard”. Further, interviewees noted both they and younger residents have minimal capacity to physically change their environment. Lack of alternative accommodation results in younger residents experiencing limitations in finding other places to live. Similarly, formal caregivers noted they too experience limited opportunities to change employment or their role.
As highlighted in Chapter Two in an overview of the Australian aged care workforce, many formal caregivers have limited options to move out of the RAC formal caregiving role. Limited education and training, hindrances to upskilling or reskilling, minimal previous experience in other occupations or work experiences in sectors of minimal qualification, low pay and high levels of casual positions which often necessitate the working of two jobs, all compound attempts to change roles. Further, staff movement within the RAC sector is often only sideways, such as to a different facility, rather than upwards or outwards into a different role (King et al., 2012). Therefore, formal caregivers, like younger residents are ‘stuck in that place’, with only a limited ability to enact real change.

Finally, formal caregivers’ comparisons with younger residents in a RAC facility also noted both they and younger residents often grappled with the same conflict. This conflict is the incongruence between facility/organisation and their own expectation and the actual caregiving capacity, or need of a young person. Thus, both formal caregiver and younger resident find themselves in a situation where there exists a stark contrast between ‘what one needs and wants, and what one can get’.

Despite these similarities, interviewees acknowledged that several differences do exist between them and the situation a younger resident is in. One interviewee explains;

As bad as it gets on shift, as much as I might get pissed off by the system, as frustrated as I get that whatever I do just isn’t enough, I take a step back and remind myself [that] I get to go home. I get to leave and that I can walk away. They don’t, they can’t and they probably never will. It gives me perspective again, to keep going despite how hard it is or how bad it feels.

Interviewees spoke of how dealing with the issues embedded within the RAC facility is limited to only one aspect of their life, the employment context, while a young person’s entire life is
largely consumed by the RAC facility in which they live. However, interviewees note taking ‘emotional baggage’ home with them:

the capacity to not be able to care and do my job in the way I see it needs to be done, kind of haunts me even when I get home. I find it hard to switch off, because my job is a big part of my life and my sense of self. That sense of unfairness almost like sticks to me.

Formal caregivers may gain reprieve at the end of a shift from the reality and emotional legacy of incongruence between their perceived role and the actual formal caregiving role. However, they will also continue to be repeatedly exposed to such incongruence during the course of their career because of a limited capacity to change roles. This is in a similar manner to a younger resident who faces a long period of their life living and experiencing incongruence between what they need and what they can obtain, and having little power to change such situation.

‘Visible Yet Invisible’ Paradox

In addition to formal caregivers noting they are the ‘same yet different’ to the younger resident, interviewees expressed they are both ‘visible yet invisible’. For younger residents, their presence is highly visible within a RAC facility, standing out because a young person in an aged care facility is such an anomaly. Formal caregivers too are equally visible within such facilities as their role is enacted within the very walls of a RAC facility, and therefore they are seen by other staff, visitors, and residents. Both formal caregivers and young people are visible to one another, forming and maintaining the caregiving relationship as both continue to share the world of ‘same yet different’. Formal caregivers noted ‘identification’ with a young person, along with the positive and negative impact such identification has on the caregiving relationship making it highly visible to both parties, and visible to the wider RAC facility. However, the formal caregiver and younger resident, as well as the formal caregiving relationship, remain completely invisible
within the legislation governing the RAC sector. Equally, both formal caregivers and younger residents remain invisible within the policy and procedures of the aged care facilities despite such high visibility within these facilities. In Chapter Two, the review of aged care policy made no mention of formal caregivers, the caregiving role, and caregiving relationship. Also absent from aged care legislation is the presence of younger residents within the aged care sector. One interviewee commented, “we don’t exist really, nor do they [young person]. We don’t exist to the powers that be”.

The invisibility of the formal caregiving role in policy is contrasted to the public opinions espoused by family and friends, and resident’s family and friends regarding the very importance of their role. Several interviewees noted the value and esteem that their role evokes amongst the general public. This is in stark contrast to many interviewees’ perceived lack of value and esteem their role is given by the organisation and wider government policy.

The invisibility of formal caregiver and younger resident along with the absence of these voices within the government, the RAC sector, and individual facilities potentially reflects the lack of power formal caregivers and younger residents have. For more than half of all interviewees, a lack of power was identified and cited as a major hindrance in expressing caregiving in a manner congruent with their personal caregiving beliefs, “there’s nothing much we can do to make this place better for us and especially the residents, especially the young guy/girl in here. I constantly feel defeated and powerless”. For many interviewees, powerlessness referred to their inability to change the situation, and to create an environment that met both formal caregiver and residents’ needs, and better facilitated the formal caregiving relationship.

Many interviewees felt the absence of their voice to shape policy and protocols hinders their capacity to express caregiving behaviour that is greater aligned with individual beliefs regarding what constitutes caregiving. This incongruence is magnified and felt most acutely when caring for
a young person because ‘identification’ highlights the unique caregiving needs that are not easily met within the current RAC policy and care frameworks.

**Conclusion**

The unique finding from this situational analysis of formal caregiving experiences of caring for younger residents in an aged care context is the impact of ‘identification’. Formal caregivers’ identification with younger residents has the capacity to exacerbate embedded conflicts within the residential aged care sector, especially those that increase incongruence between the perceived formal caregiving role and the actual role undertaken. Attempts to resolve or manage the emotional consequences of incongruence, identification, and the systemic conflicts within the RAC sector shape caregiving behaviour and the caregiving relationship. As a result, formal caregivers experience a host of negative emotions that can impact upon their own mental health, quality of life, satisfaction derived from the formal caregiving role, and the quality of care given.

While interviewees’ identification is positive in identifying, preempting and potentially advocating about a young person’s life and their caregiving needs, this identification also facilitates interviewees to draw parallels between their life and the lives of young residents within an aged care facility. This form of identification is the ‘shared world of paradoxes’ where both formal caregiver and younger resident are the ‘same yet different’, and ‘visible yet invisible’. Both remain limited and hindered in their capacity to work or live in a manner which they need or desire. Formal caregivers and younger residents are the ‘same yet different’ as both are faced repeatedly with the same conflict of knowing what is needed and living with the reality that what is needed cannot be obtained from within one’s environment. Overlapping the ‘same yet different’ theme is also a shared world of ‘visible yet invisible’. Formal caregivers and young residents are both ‘visible yet invisible’ within the RAC sector, though for differing reasons. Both remain invisible and voiceless within government policy and the organisation framework itself. This
invisibility and absence of voice facilitate the powerlessness of both formal caregiver and younger resident.

Against the RAC sectors backdrop of managerial instability, the invisibility of the caregiving relationship, significant employee turnover, carer neutrality, frameworks of care that enhance incongruence, and the socioeconomic status of interviewees, formal caregivers attempt to care for younger and older residents. Often unseen, unheard and under the radar of policy and the RAC sector, formal caregivers face enormous hurdles, both emotionally and occupationally in the delivery of care; the legacy of which impacts negatively upon the very caregiving relationships for which the role exists. For younger residents, whose peer networks are limited because of the nature of RAC, these caregiving relationships likely afford the meeting of social and life needs, and help mitigate the substantial loss of quality of life when entering an aged care facility. Therefore, any hindrance to caregiving, the caregiving relationship and the formal caregiving role, not only impacts the formal caregiver, but also impacts upon the quality of care provided and the quality of life experienced by younger residents.
Chapter Nine: Discussion and Conclusion

In the final chapter of this dissertation, the justification underpinning the examination of formal caregiving relationships with younger residents is revisited. With a paucity of research into these relationships, coupled with an absence of a formalised caregiving theory within a residential aged care (RAC) setting, this thesis provides the unique and in-depth exposé needed. The choice of research methodology extends the current body of knowledge that underpins the proposal of a theoretical model of caregiving, in the context of younger residents in aged care. The key elements of this theory are presented as suggestions for enhancing the formal caregiving role and formal caregiving relationships with younger residents. These include: the application of the concept of ‘therapeutic use of self’ to the formal caregiving role, adoption of a broader palliative care model which better enshrine the tenets of person-centered care into the RAC sector, and the inclusion and prioritisation of formal caregiving relationships in both policy and procedure. The limitations of the Situational Analysis conducted and theoretical implications that have resulted from this thesis are also detailed. The chapter will conclude with suggestions for future research.

Justification for the Examination of Formal Caregiving Relationships

The formal caregiving role is fundamental to RAC service provision with formal caregivers meeting the therapeutic care needs and personal needs, along with assisting with the ADL required by those who are frail, have a disability, chronically ill and older people (Family Caregiving Alliance, 2014). They also unwittingly meet relational needs of residents.

For interviewees who took part in the Situational Analysis for this dissertation, the formal caregiving relationship developed with residents, especially younger residents, formed the basis upon which the formal caregiving role is organised. Clearly identified was that the essence of formal caregiving is deeply grounded in the relational context and the shared world of caregiver and care-recipient. For a younger person living in a RAC facility, the formal caregiving
relationship provides respite from the harsh reality of aged care, and invites them into a world of peer ‘normalcy’, albeit an often temporary, and at time fabricated, one. Yet these relationships are absent in aged care legislature, and remain largely unexamined within academia.

This dissertation provided an in-depth analysis of current Australian RAC legislature, as examined in Chapter Two. This was coupled with a review of the literature pertaining to quality of life in RAC, and a systematic review of the research examining formal caregiving relationships, presented in Chapter Three and Four respectively. What is known through this research is that formal caregiving relationships can provide benefits to residents, such as helping promote younger residents’ quality of life and subjective wellbeing (Chang et al., 2010; Cohen-Mansfield et al., 2010; Lee et al., 2009; 2010; Song et al., 2015). These relationships may also improve mood (Chang et al., 2010; Cohen-Mansfield et al., 2010; Lee et al., 2009; 2010; Song et al., 2015), and facilitate coping with physical deterioration and the progressive loss of life functioning which many younger residents face. The potential benefits to younger residents begs for the proper and effective utilisation of the formal caregiving relationship. To do this, these relationships needed to be thoroughly explored and understood. Equally important was the identification of those factors that hindered formal caregiving relationships with younger residents.

**Overview of the Situational Analysis of Formal Caregiving Relationships**

The Situational Analysis on which this dissertation is based provides the first exploration of formal caregiving relationships with younger residents within Victorian residential aged care (RAC) facilities. Transcripts from the in-depth interviews conducted with twenty-six formal caregivers and two managers from ten RAC facilities and two purpose-built ones, were coded and examined in detail. Using Social World/Social Arena map (Figure 6.1) the complex relationships between formal caregivers, younger residents, and the Victorian RAC sector were explored. The use of positional maps enabled the various perspectives interviewees held regarding their role (Figure 6.2), the degree to which their caregiving beliefs could be operationalised (Figure 6.3) and
the appropriateness of RAC for younger residents (Figure 7.1) to be properly identified and highlighted.

The unique contribution this Situational Analysis makes to understanding formal caregiving relationships with younger residents is to highlight how caregiving is fundamentally a bi-directional human system of relational acts juxtaposed within an aged care system that seems to omit much of that which makes us human. This tension plays out in multiple ways within the formal caregiver and younger resident’s world; role incongruence, a powerful yet powerless paradox, and the visible and invisible paradox. Yet it is the internalised identification of the younger resident by the formal caregiving role that highlights most keenly this tension between the human system of relational acts upon which caregiving is based, and the aged care system which appears to prioritise policy, protocol and procedure above people. Indeed, this is argued in Todres et al (2009) call for the humanisation of care and the need to value those aspects that make us human. Without the proper capacity of the governing framework overseeing the RAC sector to fully recognize, understand and make central the emotional world, and the human needs and human limitations of those within the RAC sector, formal caregiving to younger residents will continue to be inadequate.

This Situational Analysis reveals that caregiving to younger residents highlights and crystalises for the formal caregiver any incongruence between caregiving beliefs and behaviours found within their formal caregiving role. The incongruence experienced by formal caregivers arises from their inability to care in a manner consistent with intrinsic beliefs and caregiving motivations, or in response to the perceived needs of a resident. This is the result of a ‘culture of care’ within the RAC sector that both negates the importance of formal caregiving relationships, and stymies their development and continuance. This is despite the fact that for most interviewees, formal caregiving relationships are central to the formal caregiving role.
Role incongruence is also more acute in formal caregiving relationships with younger residents because of formal caregivers’ ‘identification’ with them. Like the formal caregiving role, ‘identification’ also provides an organising framework directing formal caregiving behaviours towards younger residents. It affords the formal caregiver with a reference point in which to gauge a younger resident’s life and caregiving needs. It is based upon the central question ‘what if this was me, what would I want or need in order to have a life that is meaningful?’ The ‘culture of care’ prevalent in RAC appears to hinder the operationalising of a formal caregiver’s answer to these questions, and in doing so exacerbates the role incongruence from the ‘culture of care’.

Both De Forge et al. (2011) and Banajeree et al. (2015) highlight the existence of role incongruence among formal caregivers. The ‘culture of care’ within RAC is heavily organised around compliance and onerous bureaucracy, which require care processes to be standardised and measured to ensure effectiveness and accountability. This comes through sacrificing the human relational aspect of formal caregiving, which is less able to be conceptualised, and even less able to be standardised (Banajeree et al., 2015; DeForge et al., 2011).

Interviewees in the Situational Analysis highlighted the impact that the ‘culture of care’ has on the formal caregiving role and formal caregiving relationships with the younger residents. The ‘burden of bureaucracy’ and ‘managerial and workforce instability’ encouraged the formal caregivers interviewed to delineate and prioritise certain caregiving activities over others. Interviewees spoke of prioritising those caregiving activities that are seen and recorded, such as food and fluid charts, above caregiving activities that were relationship building and enhancing (i.e., spending time reading to residents).

The Situational Analysis examining formal caregiving relationships with younger residents revealed the delineation and prioritisation of some caregiving activities over others, is influenced by the backdrop of ‘caregiver neutrality’, the ‘invisibility of caregiving relationships’ and a ‘powerful yet powerless’ paradox embedded within Australian RAC. Individually and collectively,
these factors encourage and reinforce formal caregivers’ decision to deprioritise relationship building and enhancing caregiving behaviours and activities. DeForge et al. (2011) and Banajeree et al. (2015) examined only the ‘culture of care’ and its impact on the formal caregiving role. The Situational Analysis undertaken as part of this dissertation was able to reveal that the cost to formal caregivers in making such delineations in caregiving activities, especially when caring for younger residents, is high. Formal caregivers grapple with a host of negative emotions that are both distressing and detrimental to job satisfaction, and to their emotional wellbeing. Attempts to manage these emotions often finds resolution in the diminishing of the formal caregiving relationship. This is derived through strategies encouraging emotional disengagement.

One such disengagement strategy employed by some formal caregivers was to blame a resident for their current situation of having to live in a RAC facility. This strategy allows for the formal caregiver to project any negative feeling derived from role incongruence solely onto the resident. As one interviewee said,

it’s really X’s fault we are placed in this situation. He was stupid enough to drink and drive and land in here. So what, if I can’t do my job properly, he has to pay the price for his actions’.

Another disengagement strategy interviewees employed was to reduce their level of interactions with a younger resident. Interviewees spoke of limiting conversation to only that which is relevant to instrumental caregiving, “I just do the basics now, not the stuff that tires me out like I used to [emotional caregiving]. I used to make sure we would have fun, but now it’s get in and get out”. Both of these disengagement strategies inhibit the development of a shared world of knowing, whereby both formal caregiver and younger residents begin to understand and appreciate each other’s humanity and uniqueness. Disengagement strategies that diminish formal
caregiving relationships are also at odds with many interviewees’ expressed core beliefs about the formal caregiving role, namely its emphasis on the human relational context of caregiving.

A further unique contribution the Situational Analysis undertaken for this dissertation has made to an understanding of formal caregiving relationships with younger residents is the role and impact of ‘identification’. Identification is the capacity to project oneself into another person’s world. In caregiving to younger residents, identification is an inherent understanding of the totality of that younger resident and his/her life. It exceeds the mere knowing and meeting of just instrumental caregiving needs, to give the formal caregiver an innate sense of the younger resident’s life stage. It encompasses the pre-empting and recognition of any needs that might arise during that life stage, as well as identifying deficits in their life. It also highlights the fundamental importance of relationships for the younger resident. Formal caregivers thus utilise an understanding of their own life, their current life stage, and the needs arising from that stage, to better understand a younger resident’s unique situation.

This identification can positively influence formal caregivers, enhancing their caregiving motivation and desire to provide ‘good caregiving’. Identification also produces greater tolerance and compassion towards a younger resident. It enables them to see the reality of a younger resident’s life, and the daily struggles they face. It also helps formal caregivers ‘overlook’ a younger resident’s negative behaviour, such as aggression or hostility that may undermine the formal caregiving relationship.

The price of formal caregivers ‘identification’, of their ability to see the myriad of complex needs of younger residents, is the acute awareness of having to provide caregiving in an environment largely incapable of meeting those needs. The Victorian aged care sector is besieged with issues that cause the needs of younger residents to be overlooked. In the review of Australian RAC governances undertaken for this dissertation, several key factors were identified which contribute to a RAC environment which is unsuitable for younger residents. These factors include:
limited financial resources, the presence of two separate funding sources (state and federal), key
omissions within legislature, staff shortages and use of casual/temporary or agency staff, a high
turnover in staff, a lack of trained staff in the appropriate caregiving of younger residents, poor
understanding of disease trajectories, and limited alternative age-appropriate accommodation
(Parliament of Australia, 2007). Many of these issues identified in this dissertation’s review of
Australian aged care policies, are also reflected in the literature examining barriers to formal
caregiving (Banerjee et al., 2015; Burgio et al., 2004; Cook & Brown-Wilson, 2010; DeForge et
al., 2011; Edberg et al., 2008; Jones & Moyle, 2016; Lung & Liu, 2016; Schmidt et al., 2012;
Testad et al., 2010)

Formal caregivers must continually work within a tension of ‘what needs to be done and
should be done?’ and ‘what can actually be done?’. For some formal caregivers, this dissonance
will erode their caregiving motivation, making them reticent about developing and maintaining
formal caregiving relationships with younger residents, especially in a way that reflects core
beliefs about the formal caregiving role. This is detrimental to both formal caregiver and younger
resident.

Towards a Formal Caregiving Relational Theory: Key Recommendations

Younger residents are both an anomaly and a minority group within the Australian RAC
sector. There are more than 6000 people under the age of 65 living in Australian RAC facilities.
Six hundred of these are under 50 years of age (AIHW, 2014a). Their presence elicit social and
political discussions about the appropriateness of such accommodation, while their life and care
needs often differ to those of older residents. The qualitatively different caregiving needed to meet
the life and care needs of younger residents is identified in the Australian Nursing Federation’s
submission to the Australian Senate’s review of younger residents in RAC facilities (Parliament of
Australia, 2007). It is also articulated by the formal caregivers and managers interviewed for this
study.
In both the literature analysed for this dissertation, and the interviews undertaken for the Situational Analysis, the role and necessity of formal caregiving relationships, especially in the care of younger residents, is paramount. Interviewees’ concepts of the formal caregiving role are largely conceptualised around notions of relating, such as found in a ‘confidante’, ‘friend’, ‘mother’ or ‘father’. Relationships are regarded as the bedrock upon which formal caregiving occurs, and fundamental to the provision of ‘good caregiving’. Unsurprisingly, literature too reflects the importance of relationships. Relationships are considered a foundational aspect to quality of life, and within the RAC sector, positive formal caregiving relationships are correlated with improvements in residents’ mood (Haugen et al., 2013; McGilton et al., 2012), their sense of thriving (Bergland & Kirkevold, 2005), and the perception of the quality of care being provided (Bowers et al., 2001).

The population of younger residents within Australian RAC typically lead lives “characterised by loneliness and boredom” with more than one-third unable to participate within the community (Winkler, Farnworth et al., 2006, p.105). Research reveals younger residents have very limited engagement with peers, they experience extensive social exclusion and face many obstacles and difficulties when attempting to participate in the community (Muenchberger et al., 2011; Winkler et al., 2006; 2007; 2010; 2011). Consequently, younger residents in Australian RAC have higher levels of depression than the general population, express feelings of distress over their inability to have choices, and frustration at the lack of control over their life (Strettles et al., 2005; Winkler et al., 2006; 2007; 2010; 2011)

Formal caregiving relationships are well placed to influence many aspects of a younger resident’s world that can enhance life quality. Even though formal caregivers have a paid role in these relationships, the nature of formal caregiving remains firmly embedded in a social human relational context. Beyond meeting just peer relational needs, formal caregiving relationships with younger residents also provide a conduit for improving life quality by promoting choice and
autonomy through decision-making opportunities. These relationships also enable mastery over a younger resident’s environment through the support and advocacy provided by formal caregivers. However, the basis of such things rely predominantly on the comprehensive understanding of the younger resident. This is only gained through the ongoing relationship process between formal caregiver and younger person that allow each one’s individuality to be understood.

The very nature of RAC is not only dismissive of relationships within the formal caregiving role; it also hinders the deep knowing of an individual (Edwards et al., 2003; Jones & Moyle, 2016). Some barriers to these formal caregiving relationships have already been identified through previous research, including: resident’s behaviours of concern, especially among those with dementia (Edberg et al., 2008; Schmidt et al., 2010; Zwijsen et al., 2014), the presence of formal caregiver burnout and mental health issues (De Rooij et al., 2012; Kokkonen et al., 2014; Testad et al., 2010), communication difficulties (Walsh & Shutes, 2008) and the organisational culture of a facility (Banajeree et al., 2015; Bishop et al., 2008; DeForge et al., 2011). Others are unique to this dissertation and Situational Analysis, such as ‘caregiver neutrality’, ‘role incongruence’ and ‘identification’.

The Situational Analysis undertaken also reveals the ‘invisibility of formal caregiving relationships’ in RAC, along with the invisibility of the formal caregiver and the younger resident; both of which have very little voice, and hence power, to change their environment to better meet caregiving needs. The voices of these relationships remain silent in the making of aged care governances. Fundamentally, formal caregiving relationships remain largely unacknowledged or endorsed by government legislature, RAC culture and organisational policy.

Improvements in the RAC sector must begin with the formalisation and codification of the formal caregiving relationship. By incorporating these relationships into legislature and policy, they can be seen and regarded as an integral component of quality care. Since government legislature and mandates influence the focus and direction of organisational policy, the inclusion
of formal caregiving relationships as a fundamental aspect of caregiving can help guide organisational policy to prioritise these relationships.

For formal caregiving relationships to be effectively utilised in enhancing younger residents’ lives, formal caregivers’ prioritisation of these relationships requires two things: A ‘culture of care’ which promotes these relationships (currently more evident within facilities adopting a palliative care model), and formal caregivers’ understanding and operationalising of the ‘therapeutic use of self’ within the formal caregiving role.

As DeForge et al. (2011) and Banerjee et al. (2015) have shown, the ‘culture of care’ shapes formal caregiving behaviour. A broader adoption of a palliative care model into residential aged care would facilitate a care environment that would focus on the enhancement of the quality of life of residents, an area deficient for younger residents. In this model of care, the formal caregiving role and the formal caregiving relationship are central to the enactment of the palliative care approach because of its capacity to provide emotionally supportive caregiving to both families and residents, and to tailor caregiving to the individual needs of residents (Dy et al., 2015).

A palliative care model enshrines the very ideals of a person-centered care framework that has been shown to contribute positively to the lives of residents in an aged care facility (Edvardsson et al., 2008). The central aims of a person-centred care framework are to support the rights, values and beliefs of residents, provide them with unconditional positive regard, and encourage each resident to remain actively involved in the process of self-determination (Edvardsson et al., 2008). This framework holds paramount the importance of the relational context in which the carer and care-recipient are entwined. At its core, emotional caregiving behaviours remain the expression of this conceptual care framework. Words of encouragement, genuine affection, sympathy and empathy, and the honouring of the uniqueness of a person fulfill the directives and principles of person-centered care (Fischer & Eustis, 1994).
A person-centred care framework is ultimately predicated on the concepts of respect, autonomy, empowerment, communication, and shared decision making, which is mediated by the care relationship (Pol-Grevelink et al., 2012, p. 220). This framework is also associated with improvements in the mood of residents, and their level of self-determination (Edvardsson et al., 2008). Studies have shown that RAC facilities which operate under the tenets of a person-centered care framework note that residents report increased feelings of wellbeing, and more positive relational interactions and relationships with formal caregivers (Edvardsson et al., 2008).

Since caregiving to younger residents is qualitatively different to caregiving of older residents, the capacity of formal caregivers to provide individualised and flexible caregiving is more likely to meet the unique life and care needs of a younger resident. In turn, a formal caregiver’s ability to do so enhances their satisfaction and motivation to provide quality caregiving. A palliative approach to RAC incorporating person-centered care would better facilitate the active pursuit of those activities that bring meaning and quality of life to a client (Dy et al., 2015). This includes fostering familial involvement and peer relationships, and providing activities that yield positive emotions. For the formal caregiving role in a RAC setting, the adoption of palliative care principles encourages formal caregivers to increase a resident’s sense of control over their life through active and collaborative decision-making. This is relevant to formal caregiving with younger residents whose quality of life is compromised by reduced autonomy. It also allows formal caregivers to better uphold the dignity and uniqueness of the individual through an individualised approach to caregiving (Dy et al., 2015; Mok & Chui, 2004).

Research confirms the benefits of employing a palliative care model in a RAC facility as it generates increased client and familial satisfaction of care received, as well as improving satisfaction within the formal caregiving role (Ablett & Jones, 2007; Mok & Chui, 2004). A palliative care approach to RAC which endorses a person-centered care framework would help diminish role incongruence within the formal caregiving role, since it advocates for the importance
of both relationship and uniqueness of the individual and their needs. This model of honouring individuality and a resident’s uniqueness, and encouraging role flexibility to meet resident’s needs, would better create caregiving environments that improve and enhance a younger resident’s quality of life.

A palliative care approach to RAC which endorses a person-centered care framework would also allow for the ‘humanisation’ of the aged care sector, as exhorted by Todres et al. (2009). Humanisation is understood as valuing those aspects that make us human, with the recognition that humanising care emerges when these human aspects within caregiving are emphasised (Todres et al. 2009). Unfortunately, the aged care sector’s emphasis on ADLs, and its use of health-related measures of care quality tends to prioritize the human physical body over the human emotional world, along with those aspects in life which enhance the human emotional world, such as relationships with others.

The failure of the Australian aged care legislation to include the voices of formal caregivers, residents’ experiences, and formal caregiving relationships has only further ‘dehumanised’ care and enhanced the objectification of residents and the homogenisation of formal caregiving work (Todres et al., 2009, p. 68) This objectification is evident in RAC tendency to label residents and their care needs in favour of residents’ perception and prioritisation of their own needs. While, homogenisation, the adherence to systematic and codified caregiving standards, precludes individual preferences and hinders formal caregivers’ capacity to shape caregiving to meet younger residents’ unique needs (Todres et al., 2009)

The adoption of a palliative care approach grounded in a person-centered care framework would provide a foundation for more ‘humanised’ care, which ultimately better meets the needs of younger residents, and promotes the formal caregiving role. At the grass roots level, for a palliative care approach to be enacted, formal caregivers must understand their own importance within the formal caregiving role. This is conceptualised as a ‘therapeutic use of self’.
This idea has gained acceptance within the health care profession in response to the medical sector’s paternalistic models of caregiving (Norfolk et al., 2007; Taylor, 2011). A paternalistic caregiving model assumes that doctors, nurses and even formal caregivers have a superior position of power compared to the care-recipient (Hinojosa et al., 2002). The ‘therapeutic use of self’ rejects this notion suggesting caregiving should focus on mutuality and support (Taylor et al., 2011).

The ‘therapeutic use of self’ model advocates caregivers intentionally and consciously utilise their own personality to create genuine relationships with care-recipient, relationships which will promote respect, rapport, trust, empathy and sincerity with residents (Norfolk et al., 2007). In a RAC setting, a formal caregivers use of the ‘therapeutic use of self’ would allow their own “insights, perceptions, and judgments’ to be an integral part of the formal caregiving relationships” (Punwar & Peloquin, 2000, p. 285), with the ultimate aim of positively influencing a resident’s quality of life, care outcomes and their satisfaction with the care delivered (Taylor et al., 2009: 2011). The very core of a ‘therapeutic use of self’ model advocates for the primacy of genuine relationships within any caregiving context. This view is more congruent with interviewees’ core beliefs around the formal caregiving role and what constitutes good caregiving.

Limitations and Suggestions for Future Research

This dissertation into formal caregiving relationships with younger residents was undertaken in RAC facilities in Victoria. Residential aged care facilities were purposively selected within the outer suburbs of Melbourne, and no rural or regional facilities were sampled. Comparisons between metropolitan and rural or regional facilities, and aged care facilities from other states would enhance findings from this study, and better establish their generalisability.

The Victorian RAC sector currently accommodates the second largest number of residents under the age of 65 years (AIHW, 2011) and is different to RAC in other states (except Western
Australia) in that it has the largest number of privately-owned and government-owned facilities. Victorian RAC also has a second layer of bureaucratic complexity and demands as it is funded by both the state and federal government. Additionally, Victorian RAC is governed by both federal legislature as detailed in the Aged Care Act (1997) (Federal Register of Legislation, 2017) and state legislature in the ‘Beyond Compliance’ initiative. The extent of the impact of this additional legislature and bureaucracy cannot be properly determined without comparative analysis of aged care facilities in other states.

Of the facilities participating, four were owned and managed by the Victorian government, two were privately owned by one operator, and two were purposely-built and managed by one not-for-profit, non-government organisation which also managed two other RAC facilities that participated. The other two remaining facilities were owned and managed by a different non-for-profit, non-government organisation. The sample of operators of the RAC facilities participating in this study cannot adequately represent all the operators in Victoria, or Australia. Organisational ideals and focus, which often translates into caregiving policy and practice, likely differs across organisations and businesses. The limited sampling of operators in this study warrants future research which broadens the selection of organisations recruited. This would better determine how the culture of care, promoted by organisational ideals, shapes formal caregiving to younger residents.

Despite assurance of confidentiality, the opinions given by interviewees may not adequately represent their true beliefs. Interviewees’ statements may have been impacted by fear of occupational reprisal or from the desire to portray oneself in a more favourable light. It is also difficult to ascertain whether having a researcher who has had four years’ experience in the residential care sector had an impact on interviewees’ responses.

The Situational Analysis conducted as one part of this dissertation interviewed both formal caregivers and managers on their experiences of relationships with younger residents. The
inclusion of younger residents in future research would provide a richer understanding into formal caregiving relationships, especially in understanding the benefit younger residents derive from these relationships. The inclusion of younger residents in future research would also aid identification of those influences and barriers to formal caregiving relationships experienced by younger residents themselves. This perspective was unable to be explored within the Situational Analysis undertaken.

Finally, at the time RAC providers were contacted for participation in this study, the NDIS had not been rolled out in the areas in which recruitment took place. Research conducted after the complete roll out of the NDIS for younger residents is therefore warranted, as the NDIS influence on formal caregiving and RAC services cannot be determined at this point.

Conclusion

The presence of younger people under the age of 65 years, in Australian RAC facilities has sparked both social and political debates, with research indicating the quality of life for these people is compromised. This dissertation’s review of Australian aged care legislature reveals a lack of recognition of younger residents and their unique life and care needs. Aged care policies also fail to recognise the formal caregiving role and formal caregiving relationships, the basis upon which RAC services are provided.

In the systematic review of existing research on formal caregiving relationships, it is clear that formal caregivers encounter many barriers to developing caregiving relationships that are meaningful and beneficial to both caregiver and resident. This is despite the fact that these relationships could potentially enhance the quality of life and wellbeing of younger residents. As with Australian aged care policy, much of the literature around formal caregiving pertains to older residents, with no examination afforded to younger residents in RAC. In the absence of research examining formal caregiving to younger residents, this dissertation sought to fill this gap.
A Situational Analysis of the experience of twenty-six formal caregivers and two manager’s caregiving relationships with younger residents revealed several unique findings not identified in the current literature. Formal caregivers can better identify with younger residents, having the ability to see and pre-empt their unique life and care needs. The inability to meet those needs within the formal caregiving role causes distress, which is managed by some interviewees through the diminishing of any formal caregiving relationship formed with younger resident. The Situational Analysis also reveals that caregiving to younger residents often highlights the incongruence between caregiving beliefs and actions within formal caregivers role. This dissonance must also be managed, and often results in formal caregivers enacting disengagement strategies that diminishes the formal caregiving relationship.

Changes to the Victorian RAC sector, including: the adoption of a palliative care approach, the ‘therapeutic use of self’ by the formal caregiver, and the recognition and prioritisation of the formal caregiving role and formal caregiving relationships, would better enable RAC to meet the needs of its residents. While the relocation of more than six thousand younger residents is largely untenable at this point in time, the use of RAC’s largest resources, its formal caregivers and formal caregiving relationships, could be used more effectively to enhance the quality of life and wellbeing of younger residents.
References


Parliament of Australia. (2015). Report: Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in


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## Appendix A

### Abbreviations & Acronyms

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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ACFI</td>
<td>Aged Care Funding Instrument</td>
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<td>ACW</td>
<td>Aged Care Workforce</td>
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<tr>
<td>ADLs</td>
<td>Activities of Daily Living</td>
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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>AIHW</td>
<td>Australian Institute of Health And Welfare</td>
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<td>ASHS</td>
<td>Adult State Hope Scale</td>
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<td>BDI-II</td>
<td>Beck’s Depression Inventory - II</td>
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<td>CALD</td>
<td>Culturally And Linguistically Diverse</td>
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<td>CES-D</td>
<td>Centre for Epidemiological Studies Depression Scale</td>
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<td>DASS</td>
<td>Depression, Anxiety &amp; Stress Scale</td>
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<td>DOH</td>
<td>Department of Health</td>
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<tr>
<td>DSS</td>
<td>Department of Social Services</td>
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<td>GTM</td>
<td>Grounded Theory Method</td>
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<tr>
<td>HACC</td>
<td>Home and Community Care</td>
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<td>HHS</td>
<td>Hearth Hope Scale</td>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>LMS</td>
<td>Life Meaningfulness Scale</td>
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<td>LRI-R</td>
<td>Life Regard Index – Revised</td>
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<td>LTC</td>
<td>long-term care</td>
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<tr>
<td>NDIA</td>
<td>National Disability Insurance Agency</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NSR</td>
<td>Negative Social Relationships</td>
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<td>PPMS</td>
<td>Perceived Personal Meaning Scale</td>
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<td>PSRACS</td>
<td>Public Sector Residential Aged Care Service</td>
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<td>PSS</td>
<td>Perceived Stress Scale</td>
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<td>QOL</td>
<td>Quality of Life</td>
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<td>RAC</td>
<td>Residential Aged Care</td>
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<td>RBS</td>
<td>Relational Behaviour Scale</td>
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<td>SCORE</td>
<td>Strengthening Care Outcomes For Residents</td>
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<td>SMS</td>
<td>Spiritual Meaning Scale</td>
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<td>SRS</td>
<td>Supported Residential Services</td>
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<td>YPIRAC</td>
<td>Young People In Residential Aged Care</td>
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Appendix B.

Deakin University Ethics Application

Deakin University
Faculty of Health
Human Ethics Advisory Group - Health

Request for Modification Form

1  Project Details

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<td>Care workers experiences of caring for diverse populations in the aged care sector.</td>
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<tr>
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Please note that if you expect to complete any data collection or analysis after the date of expiry of approval, you are required to complete Section 7.

- Researchers’ Details

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<th>Associate Professor Tess Knight</th>
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<td>School / Centre</td>
<td>Psychology</td>
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<tr>
<td>Campus</td>
<td>Burwood</td>
</tr>
<tr>
<td>Contact phone number</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:tess.knight@deakin.edu.au">tess.knight@deakin.edu.au</a></td>
</tr>
</tbody>
</table>
Title and name of Principal Investigator / Supervisor | Associate Professor Craig Olsson
---|---
Faculty | Health
School / Centre | Psychology
Campus | Waterfront
Contact phone number | 5227 8428
Email | craig.olsson@deakin.edu.au

(Please copy and paste table for all additional researchers)

Title and name of Co-investigator / Student | Eve Bottrill
---|---
Institution (if not Deakin) | 
Faculty | Health
School / Centre | Psychology
Campus | Burwood
Contact phone number | 0425 735 541
Email | ebo@deakin.edu.au

3 Details of proposed modification(s) to project (e.g. change of sample size, addition of research instruments, change to research team)

The proposed modification pertains to the inclusion of managers/management staff of residential aged care facilities.

4 Reason(s) for proposed modification(s) to project
The reasons for such modifications is to enable a better understanding of the impact younger residents have on the residential aged care facility. This includes examination of changes management initiate upon a young person’s entry into a facility, and the challenges management face when a young resident enters residential aged care.

Do the modifications relate to data collection? YES

Double-click on the appropriate box and select “checked”.

If yes, please answer the questions below.

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<td>Is there collection of identifiable <em>personal</em> information?</td>
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<tr>
<td>Is the collection of identifiable <em>sensitive</em> information?</td>
<td>NO</td>
</tr>
<tr>
<td>Is the researcher obtaining identifiable personal information from another organisation?</td>
<td>NO</td>
</tr>
<tr>
<td>Has the individual whose information it is, consented to the collection, use or disclosure of identifiable personal information?</td>
<td>Not applicable</td>
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6 Attachments

Please attach all documentation relevant to the proposed modification (e.g. Plain Language Statement(s), Consent Forms, questionnaires etc.)

Please ensure that any changes to previously approved documents are made using track changes.

7 Request for extension

Please complete the following section if you expect to complete any data collection or analysis after the date of expiry of approval.
Please note that following the initial three-year approval period, an extension of one additional year can be granted. If you wish to request a further extension, you may do so but approval is at the discretion of the Chair and/or the Committee.

8 Other comments

10 Signatures

(Please copy and paste table for all additional researchers)

Please note that if an investigator is being added to or removed from the research team, they must also sign this form

Please complete and return to:

Secretary HEAG-H
Dean’s Office
Faculty of Health
Level 3, Building E
221 Burwood Hwy
Burwood VIC 3125

Enquiries should be directed to: 
Telephone: (03) 9251 7174
Email hbsethic@deakin.edu.au
Appendix C.

Plain Language Statement, Consent Form & Participant Contact Details

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO:

Date: 17/09/2012
Full Project Title:

Professional caregivers experiences of caring for diverse populations in residential care facilities

Principal Researcher: Dr. Tess Knight
Student Researcher: Eve Bottrill
Associate Researcher(s): Associate Professor Craig Olsson

I am seeking disability support workers and personal care attendants/assistants to participate in a study exploring the experiences of working with diverse population groups in the aged care sector. This study will examine how disability support workers and/or personal care attendants adapt caregiving to the specific needs of people with an intellectual disability, degenerative neurological condition or an acquired brain injury.

Participants will be recruited from different aged-care facilities around Melbourne and the outer suburbs. Individuals willing to participate will be allocated to a focus group with 4-5 other disability support workers and/or personal care attendants. These focus groups will be conducted primarily at Deakin University, Burwood Highway, Burwood. Participants will be asked a series of questions such as ‘how different is caring for a young person (under 50) with a neurodegenerative condition than caring for an aged person? What are the difficulties you have experienced when a young person is admitted into aged care?

Each focus group will be of a 60 minute duration and will be audio-recorded to enable transcription
and analysis of the content of the focus group discussions. All identifiable data (including names & organizations) will however be omitted from these transcriptions. It is important that participants respect the confidentiality of information provided by other participants.

All participants have the right to withdraw their consent prior to the convening of their allocated focus group. Since the focus groups will be audio-recorded, it is not possible for a participant to withdraw comments made during the focus group. However, if a participant wishes, their comments will be omitted from analysis and not included in the final results. Each participant will have the option of receiving a electronic summary of the final results either by contacting the researcher or informing the researcher they wish to receive the results.

This study will yield important information on current caregiving practices and the appropriateness of these practices for caring for diverse population groups within residential aged care. The information obtained from the focus groups/interviews will be used to develop a training manual that addresses the specific issues facing caregivers when working with diverse populations in their aged care facility.

There are no expected risks to participants. However, the researchers are aware that for some individuals the topics discussed may cause distress, such as, recognition of a lack of control in their work place. Should this occur, participants are encouraged to call Lifeline 131114 or Grief Line (03) 9935 7400 or HopeLine 1300 364 673 for free telephone counselling. Alternatively, individuals should contact their General Practitioner for a referral to an appropriate health professional.

This project does not have any financial sponsor nor declarations of interest from other researchers, sponsors or institutions.

For further information regarding this project please contact;

Eve Bottrill ebo@deakin.edu.au
Tess Knight tess.knight@deakin.edu.au
Craig Olsson craig.olsson@deakin.edu.au

**Complaints**
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Manager, Research Integrity, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 9251 7129, Facsimile: 9244 6581; research-ethics@deakin.edu.au

Please quote project number [HEAG-H 124_2012].
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO:

Organisational Consent Form

(To be used by organisational Heads providing consent for staff/members/patrons to be involved in research)

Date: 17/09/2012

Full Project Title: Professional caregiver’s experiences of caring for diverse populations in residential care facilities

Reference Number: HEAG-H 124_2012

I have read and understand the attached Plain Language Statement.

I give my permission for ........................................ of ........................................ to be invited to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal the participants’ identities and personal details if information about this project is published or presented in any public form.

I agree that

1. The institution/organisation MAY / MAY NOT be named in research publications or other publicity without prior agreement.

2. I / We DO / DO NOT require an opportunity to check the factual accuracy of the research findings related to the institution/organisation.

3. I / We EXPECT / DO NOT EXPECT to receive a copy of the research findings or publications.

Name of person giving consent (printed)
Signature .......................................................... Date ........................................ Please return to;
Eve Bottrill
Deakin University- School of Psychology
221 Burwood Highway,
Burwood, Victoria 3125,

Telephone: 9251 7129, Facsimile: 9244 6581
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO:

<table>
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<td>(To be used for participants who wish to withdraw from the project)</td>
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**Date:**

**Full Project Title:** Professional caregiver’s experiences of caring for diverse populations in residential care facilities

**Reference Number:** HEAG-H 124_2012

I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University.

Participant’s Name (printed) ………………………………………………………………………

Signature ………………………………………………………………………Date …………

**Please mail or fax this form to:**

Eve Bottrill
Deakin University- School of Psychology
221 Burwood Highway,
Burwood, Victoria 3125,
Telephone: 9251 7129, Facsimile: 9244 6581
Participant Contact Details

Thank you for agreeing to participate in this study examining your experiences of caring for diverse populations, specifically younger residents, in a residential care facility. For ease in organizing focus groups and/or interviews please provide your name and contact details, and nominate the days and times most convenient for you. Please place this form in the provided reply-paid envelope, together with your signed plain language statement and consent form.

Name:.................................................................................................................................

Contact details:.....................................................................................................................

Preferred mode of discussion:

FOCUS GROUP        INTERVIEW

Please circle your preferred time and day for a focus group or a one-to-one interview:

MON   TUES   WED   THUR   FRI   SAT   SUN

• Early AM (Before 9am)

• AM (9-12pm)

• PM (12-5pm)

• EVENINGS (5pm onwards)

Kind regards,

Eve Bottrill (Candidate, Doctor of Psychology (Clinical))

Deakin University
School of Psychology
221 Burwood Highway
Burwood, VIC 3125
Telephone: 9251 7129
Facsimile: 9244 6581
Appendix D.

Initial Interview Guide with Demographic Questions

Semi-structured, in-depth interview question list:

Introduction
Welcome and thank you for making the time to meet with me. The questions being asked are deliberately broad. However, several of them have some qualifiers. I anticipate that answering these questions will take between 20-45 minutes to complete.

My background
I have spent a decade and a half working within the disability field, of which included four years working in a residential facility for people with neurodegenerative diseases.

Focus of the research
The focus of this research is on formal caregiving to younger people in Victorian residential aged care facilities.

Purpose of the interview
The information gathered from these focus groups and interviews will help to understand formal caregiving to younger residents within a residential setting, as well as identify any barriers to the formal caregiving process. This information can then be used to make suggestions for ways that formal caregiving can be enhanced so as to improve the quality of life of residents, and the provision of care received.

PLS and consent form
The consent form highlights the issue of confidentiality and notes where I can be contacted.

<table>
<thead>
<tr>
<th>Demographic information:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
</tr>
<tr>
<td>2. Gender</td>
</tr>
<tr>
<td>3. Nationality</td>
</tr>
<tr>
<td>4. Years of experience as a formal caregiver or manager</td>
</tr>
<tr>
<td>5. Number of years in current facility</td>
</tr>
<tr>
<td>6. Type of facility currently working in</td>
</tr>
<tr>
<td>7. Working a second job</td>
</tr>
<tr>
<td>8. Educational background/attainment</td>
</tr>
<tr>
<td>9. Employed as fulltime, part-time or casual</td>
</tr>
<tr>
<td>10. Number of changes in management (facility managers and unit supervisors) at your current facility during your time there.</td>
</tr>
</tbody>
</table>

Questions: Qualifiers:

1. Tell me about your experiences working in a residential aged care facility? What makes your role harder to undertake? What makes your role easier to undertake

2. Tell me about your experiences working with a younger person living in the residential facility you work, or have worked in? What makes your role harder to undertake when working with a younger person? What makes your role easier to undertake when working with a younger person?

3. What are the similarities in providing care for a younger resident and an older resident?
<table>
<thead>
<tr>
<th>4. What are the differences in providing care for a younger resident and an older resident?</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Is there anything you wish to add?</td>
</tr>
<tr>
<td>• Thank you for taking the time to meet with me</td>
</tr>
<tr>
<td>• Please feel free to email any questions you may have at the email address at the bottom of the PLS.</td>
</tr>
<tr>
<td>• If you wish to have a summary of the finding or a copy of the final thesis please contact me on <a href="mailto:ebo@deakin.edu.au">ebo@deakin.edu.au</a>.</td>
</tr>
</tbody>
</table>
Appendix E.

Overview of Key Legislates of the Aged Care Act (1997)

Five key bills constituting the Aged Care Act (1997);

Aged Care Act (1997)
Aged Care (Accommodation Payment Security) Act 2006
Aged Care (Accommodation Payment Security) Levy Act 2006
Australian Aged Care Quality Agency Act 2013

Amendments made to the Aged Care Act (1997);

Accountability Principles 2014
Aged Care (Transitional Provisions) Principles 2014
Approval of Care Recipients Principles 2014
Approved Provider Principles 2014
Classification Principles 2014
Committee Principles 2014
Complaints Principles 2014
Extra Service Principles 2014
Fees and Payments Principles 2014 (No.2)
Grant Principles 2014
Information Principles 2014
Quality of Care Principles 2014
Records Principles 2014
Sanctions Principles 2014
Subsidy Principles 2014
User Rights Principles 2014
Appendix F.

Core Principles/Objectives of the Aged Care Act (1997)

1. ‘To provide funding of aged care that takes account of; the quality of the care, type of care and level of care provided. The governances must also ensure access to care that is affordable by, and appropriate to the needs of the people who require it. Additionally, it is necessary the Act detail appropriate outcomes for recipients of the care and ensures accountability of the providers of the care for the funding and for the outcomes for recipients.

2. To promote a high quality of care and accommodation for the recipients of aged care services that meets the needs of individuals;

3. To protect the health and wellbeing of the recipients of aged care services;

4. To ensure that aged care services are targeted towards the people with the greatest needs for those services;

5. To facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location;

6. To provide respite for families, and others, who care for older people;

7. To encourage diverse, flexible and responsive aged care services that are appropriate to meet the needs of the recipients of those services and the carers of those recipients; and facilitate the independence of, and choice available to, those recipients and carers;

8. To help those recipients to enjoy the same rights as all other people in Australia;

9. To plan effectively for the delivery of aged care services that:

10. To promote the targeting of services to areas of the greatest need and people with the greatest need, avoiding duplication of those services, improving the integration of the planning and delivery of aged care services with the planning and delivery of related health and community services;

11. To promote ageing in place through the linking of care and support services to the places where older people prefer to live’.
Appendix G.

*Overview of the Supported Residential Services Act (Private Proprietors, 2010)*

Supported Residential Act (Private Proprietors, 2010).

- Administration & Registration
- Information for prospective residents and residential and services agreement
- Accommodation and personal support standards
- Medication
- Staffing
- Complaints
- Reporting and records
- Fees and money and property of residents
- Notices to vacate
- Monitoring and enforcement
- Election to the community visitors’ board.
## Appendix H.

**Table 4.1. Summary of Reviewed Articles (Alphabetical According to First Author)**

<table>
<thead>
<tr>
<th></th>
<th>Author, date Country</th>
<th>Sample &amp; Recruitment</th>
<th>Design Methodology</th>
<th>Outcome Measure/ Key Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Banerjee et al., (2015) Canada</td>
<td>9 Focus groups comprising 141 RN’s, 139 LPN (licensed practical nurses) 415 FC</td>
<td>Qualitative – Feminist Epistemological Focus groups &amp; survey questionnaire</td>
<td>Regulations took time away from carework. Caregivers don’t have a voice at the policy level. Little decision making capacity. Difficulty treating residents with respect and dignity that is deserved.</td>
<td>Findings are limited to the setting in which study was conducted. Aged care policies for Australia may be different to those of Canada.</td>
</tr>
<tr>
<td>2</td>
<td>Berkland and Kirkevold (2005) Norwegian</td>
<td>Field observations and open-ended interviewes with residents (purposive sample)</td>
<td>Qualitative – Descriptive Exploratory</td>
<td>Relationship with FC essential to thriving for some residents. Kind and helpful FC rather than relationship with FC essential to thriving.</td>
<td>Exploratory nature means findings may not generalize into other settings.</td>
</tr>
<tr>
<td>3</td>
<td>Bishop et al., (2008) USA</td>
<td>Survey to 255 FC QOL questionnaire given to 105 residents from 18 RAC facilities</td>
<td>Mixed model</td>
<td>Support from management influence intention to stay in FC role. Greater FC commitment to role was associated with increased resident QOL and greater satisfaction in FC relationship.</td>
<td>RAC were selected on the basis of residents reports of being a ‘good’ facility.</td>
</tr>
<tr>
<td>4</td>
<td>Bowers et al., (2001) USA</td>
<td>Interviews with 26 residents</td>
<td>Qualitative – Grounded dimensional</td>
<td>Residents considered good caregiving in one of three ways: Care-as-service/Instrumental care Care-as-relating/quality of relationship with FC. Care-as-comfort/Emotional caregiving</td>
<td>Small sample size hindered external validity of study. Cross-sectional design means opinions may change over time.</td>
</tr>
<tr>
<td>5</td>
<td>Brown-Wilson et al., (2009) England</td>
<td>Participant observations (256 hours), focus groups &amp; Interviews with 16 residents, 25 FC, 18 family members.</td>
<td>Qualitative – Constructivist approach</td>
<td>3 types of relationships: Pragmatic relationships, Personal and responsive relationships, Reciprocal relationships.</td>
<td>Focus on positive relationships with FC and opinions my change in light of negative relationships</td>
</tr>
<tr>
<td></td>
<td>Author et al., (Year)</td>
<td>Country</td>
<td>Methodology</td>
<td>Findings</td>
<td>Observations</td>
</tr>
<tr>
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<tr>
<td>6</td>
<td>Burgio et al., (2004) USA</td>
<td>192 residents, 178 FC observations over 10-day period (randomly sampled). FC administered Job Satisfaction Index (JSI), And Maslach Burnout Inventory (MBI)</td>
<td>Quantitative</td>
<td>Residents rated their level of care (defined as personal appearance and hygiene) higher when cared for by formal caregivers who worked in a full-time permanent capacity $F(1, 186) = 3.94, p = .048$. Residents whose care was provided by formal caregivers on a rotating shift expressed less satisfaction in the level of care they received $F(1, 186) = 3.94, p = .048$. Increased job satisfaction and lower levels of burnout were also seen among formal caregivers who were permanently employed, compared to those on rotating shifts $F(1, 173) = 6.38, p = .0124$.</td>
<td>Observations were undertaken via random sampling. Observation for the entire time may yield different results.</td>
</tr>
<tr>
<td>7</td>
<td>Cook &amp; Brown-Wilson (2010) England</td>
<td>Reanalysis of transcripts from two studies to understand social engagement between FC, residents and their families. (Document analysis) Study A: biographical investigation on residents experiences in RAC. Study B: Constructivistic study/thematic analysis into understanding shared meanings between residents, their families and FC.</td>
<td>Qualitative- cross-study analysis two studies.</td>
<td>Functional and relational relationships were seen between resident and FC. Functional – focus on instrumental caregiving Relational – focus on sharing of stories and reciprocity. Continuity of staff enhanced relationships between FC and residents, which led to familiarity and increased trust of FC.</td>
<td>The methods of only one study could be ascertained and therefore the methodological rigour of the other cannot be ascertained.</td>
</tr>
<tr>
<td>8</td>
<td>DeForge et al., (2011) Canada</td>
<td>Participant observations, semi-structured interviews and focus groups with FC</td>
<td>Qualitative – Critical ethnographic</td>
<td>FC felt “afraid to care” for residents. FC report great incongruence between complying with the rules and doing what they felt was right. FC felt “unable to care” for residents as compliance demands undermined caregiving capacity.</td>
<td>Generalizability of results into an Australian RAC setting.</td>
</tr>
<tr>
<td></td>
<td>Study</td>
<td>Country</td>
<td>Sample Size</td>
<td>Study Design</td>
<td>Measure(s)</td>
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<tr>
<td>9</td>
<td>de Rooij et al., (2012)</td>
<td>Holland/Netherlands</td>
<td>80 Formal caregivers (FC)</td>
<td>Quantitative</td>
<td>Global Health Questionnaire (GHQ-12)(mental health) Utrechtse Burnout Scale (UBOS-C)</td>
</tr>
<tr>
<td>10</td>
<td>Edberg et al., (2008)</td>
<td>Australia/Sweden/UK</td>
<td>35 FC participated in focus groups.</td>
<td>Qualitative</td>
<td>FC relationships with residents with dementia is characterized by strain arising from ‘being unable to reach’ residents’. Communication difficulties and the struggle to determine residents needs generated feelings of caregiver inadequacy and guilt FC. Inability to provide comfort and alleviate a resident’s distress created strain within the FC role. Residents’ emotional and psychological needs often overwhelmed FC.</td>
</tr>
<tr>
<td>11</td>
<td>Edwards et al., (2003)</td>
<td>Australia</td>
<td>2848 observations of resident and FC interactions</td>
<td>Quantitative</td>
<td>Residents were alone for 40% of the time. FC responded positively to residents dependant behaviors. FC did not respond to independent resident behaviors. When FC attended to residents, they more likely did not engage in any verbal or non-verbal communication, nor did they provide any physical contact.</td>
</tr>
<tr>
<td>12</td>
<td>Haugan et al (2013)</td>
<td>Norway</td>
<td>202 residents completed several survey including; Nurse-Patient Interaction Scale (NPIS), Hospital Anxiety and Depression Scale (HADS).</td>
<td>Quantitative</td>
<td>Residents who had more positive interactions with formal caregivers reported less depressive symptoms than residents who experienced negative interactions with formal caregivers. The directional paths from nurse–patient interaction to depression displayed a significant negative relationship (γ1,1 = −0.37).</td>
</tr>
<tr>
<td></td>
<td>Jones &amp; Moyle (2016) Australia</td>
<td>Interviews of 39 FC</td>
<td>Qualitative exploratory</td>
<td>A significant path from depression to anxiety ($\beta_{1,2} = 0.55$) mediated effect (by depression) on anxiety.</td>
<td>Mean participant age was 86 years who completed 130 questions. Participant fatigue may have biased results despite measures to counteract this i.e. taking breaks.</td>
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<td>13</td>
<td>Kokkonen et al., (2014) England</td>
<td>75 FC completed several questionnaires including: Experiences of Close Relationships - Revised (ECR-R). Approaches to Dementia Questionnaire (ADQ). Inventory of Geriatric Nursing Self-Efficacy (IGNSE). Maslach Burnout Inventory (MBI).</td>
<td>Quantitative cross-sectional survey.</td>
<td>FC who reported more attachment-related anxiety had higher levels of emotional exhaustion ($r = 0.26, p &lt; 0.05$), as did those with attachment-related avoidance ($r = 0.27, p &lt; 0.01$). Higher levels of burnout were found among those formal caregivers who had an insecure attachment (anxious or avoidant). Attachment-related anxiety was also correlated with lower levels of geriatric nursing self-efficacy ($r = -0.33, p &lt; 0.01$), and less person-centred attitudes including recognition of personhood ($r = -0.32, p &lt; 0.01$). FC who had high levels of self-efficacy had less emotional exhaustion ($r = -0.20, p &lt; 0.05$), a decreased sense of depersonalization ($r = -0.28, p &lt; 0.01$) and reported a greater sense of personal accomplishment ($r = 0.37, p &lt; 0.01$). Both attachment-related anxiety ($r = 0.30, p &lt; 0.05$) and avoidance ($r = 0.20, p &lt; 0.05$) was correlated with higher levels of depersonalization among formal caregivers. However, in hierarchical</td>
<td>Staff participation was from only one organization. Therefore, the generalizability of the results are limited.</td>
</tr>
<tr>
<td></td>
<td>Study 1</td>
<td>Study 2</td>
<td>Study 3</td>
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</tr>
</tbody>
</table>
| **15** | Lung & Li (2016)  
Hong Kong | Unstructured interviews with 18 FC and 15 residents.  
Qualitative | Residents who perceived the formal caregiving role to be primarily concerned with the delivery of instrumental care, did not seek emotional caregiving from FC. Residents’ who viewed FC as busy also constrained their requests for support to that concerning with only instrumental caregiving activities. FC who viewed their role as providing instrumental care only did not seek to establish closer interactions with residents and minimized their involvement with residents who expressed negative emotions. When FC and residents viewed the formal caregiving role as the provision of both instrumental care and emotional support, reciprocal and trusting relationships were established. In turn, residents noted feeling more secure in the provision of care received when such relationships developed. | Finding may not generalize into an Australian context. |
| **16** | Marshall & Baffour (2011)  
USA | Demographic information and semi-structured interviews with 15 younger residents (YR) in a LTC facility.  
Qualitative- GTM | YR reported limited social support and increased family disconnection. YR had limited leisure activities and inadequate finances to remain engaged with their community. YR had poor relationships with FC. FC did not engage with YR. | Generalizability of findings due to small number of participants. Other YR declined to participate because of confidentiality, therefore, differing opinions may have emerged if there were no issues of confidentiality and if those YP who didn’t participate consented to. Length of stay and level of disability not explored and this may change opinions expressed. |
<table>
<thead>
<tr>
<th></th>
<th>Author(s)</th>
<th>Sample Description</th>
<th>Research Design</th>
<th>Findings</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>McGilton &amp; Boscart (2007) Canada</td>
<td>Interviews with 32 FC and 25 residents and their families.</td>
<td>Qualitative component of a larger study examining relationships within RAC.</td>
<td>For residents, having a confidante who listens and is reliable, pre-empt their needs and acts in their best interest were hallmarks of closeness with a staff member. Families perceived closeness within the formal caregiver-resident relationship based on staff's caring attitude, sense of concern and the personal attention given to the resident. Staff defined closeness within their relationship with residents by the degree of connectedness they felt.</td>
<td>The concept of ‘closeness’ is yet to be formally defined.</td>
</tr>
<tr>
<td>18</td>
<td>McGilton et al (2012) Canada</td>
<td>38 residents with dementia, 35 FC. Direct observations &amp; self-rating scales including; Relational Behavior Scale (RBS), Dementia Mood Picture Test (DMPT), Apparent Affect Rating Scale (AARS).</td>
<td>Quantitative – repeated measures design</td>
<td>Significant negative correlations were found between formal caregivers’ relational behaviors and residents’ mood and affect. Residents who received less relational behaviors from formal caregivers experienced increased levels of anxiety, fear and sadness, and displayed more anger. Residents ‘anxiety/fear’ was negatively correlated with the total RBS scores during morning care in all three facilities (Facility A: ( r = -0.49, p = 0.004 ); Facility B: ( r = -0.59, p = 0.006 ); and Facility C: ( r = -0.52, p = 0.034 )). Residents ‘sadness’ was negatively correlated with the total RBS scores in Facility A (( r = -0.57, p = 0.001 )), Facility B (( r = -0.58, p = 0.007 )), and Facility C (( r = -0.69, p = 0.002 )). Likewise, ‘anxiety/fear’ was negatively correlated with the total RBS scores in Facility A (( r = -0.64, p &lt; 0.01 )), Facility B (( r = -0.70, p = 0.001 )), and Facility C (( r = -0.86, p &lt; 0.001 )).</td>
<td>Influence of observer may have impacted resident and FC interactions. Some residents did not complete the DMPT resulting in a loss of statistical power. Small sample size.</td>
</tr>
<tr>
<td></td>
<td>Author(s) and Year</td>
<td>Location</td>
<td>Participants and Methods</td>
<td>Design</td>
<td>Findings</td>
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<tr>
<td>19</td>
<td>Schmidt et al., (2012) Germany</td>
<td>731 Nurses and FC completed several questionnaires including; Residents challenging behavior (RCB), Nurses’ General Health (EuroQol- EQ-5D), Burnout Index (Copenhagen Burnout Index- CPI), Work ability (Work Ability Index-WAI)</td>
<td>Quantitative – cross sectional design</td>
<td>Age of the nurses &amp; FC was significantly associated with RCB distress ($\beta = 0.12; p &lt; 0.001$). The FC in the ‘high’ RCB-related distress group reported significantly higher burnout values (age-adjusted mean = 56.5), lower general health scores (age-adjusted mean = 59.0), lower work ability scores (age-adjusted mean = 35.6) compared to FC scoring in the ‘low’ RCB-related distress.</td>
<td>No measurement of frequency of challenging behaviour which may be correlated also to FC distress. Use of only one organization may limit findings.</td>
</tr>
<tr>
<td>20</td>
<td>Testad et al., (2010) Norway</td>
<td>197 FC completed the following instruments; Cohen-Mansfield Agitation Inventory-Long form (CMAI), CMAI-disruptive, Functional Assessment Staging (FAST), General Nordic Questionnaire for Psychosocial and Social Factors at Work (QPSNordic), Perceived Stress Scale (PSS), Hopkins Symptoms Check List (HSCL), Ursin Health Inventory (UHI)</td>
<td>Quantitative- Cross sectional survey</td>
<td>Age and shiftwork correlated significantly with the outcome variables on health and well-being; age and PSS ($p &lt; 0.029$), SHC ($p &lt; 0.012$) and shiftwork and SHC ($p &lt; 0.041$). QPSNordic subscales of leadership ($p &lt; 0.002$), mastery of work ($p &lt; 0.008$) and control at work ($p &lt; 0.004$), were each significantly associated with HSCL.</td>
<td>Cross-sectional nature of the study makes it difficult to determine causality. Subjective rating of residents agitation may not reflect true levels of agitation.</td>
</tr>
<tr>
<td>21</td>
<td>Walsh &amp; Shutes (2013) UK/Ireland</td>
<td>Individual semi-structured interviews with 34 migrant FC. Focus groups with 41 residents.</td>
<td>Qualitative-constructivist framework</td>
<td>Determined several different FC relationship types with residents; ‘Need orientated’ which focused on instrumental care. ‘Familial or friendship’ which contained feelings of familial attachment, love and responsibility. ‘Reciprocal’ type relationships which are based on relational interaction involving the reciprocal exchange of personal stories and information. These relationships aided the personalization of care to better suit the individual resident.</td>
<td>Findings may not generalize into an Australian context.</td>
</tr>
</tbody>
</table>
‘Discriminatory’ relationships characterized by racial discrimination by resident. FC language barriers impeded the formation of ‘familial or friendship’ and ‘reciprocal’ type relationships between FC and residents.

| 22 | Zwijsen et al (2014) | 432 residents with dementia. Nurses completed the following measure about residents; Global Deterioration Scale (GDS), Nursing Home version of the Neuropsychiatric Inventory (NPI-NH), Distress scale of the NPI-NH measuring caregiver burden from residents neuropsychiatric symptoms. | Quantitative- cross sectional survey | When frequency and severity of symptoms were combined; Agitation/aggression had the highest mean FC distress score (2.3 ± 1.4), Irritability/lability also produced higher mean FC distress scores (2.0 ± 1.4). | FC expressed ambiguity around the concept of ‘distress’, and the lack of formal definition means self-report evaluations of distress may be biased. Causality is difficult to establish because of use of cross-sectional methods. |
Appendix I.

Messy Situational Map of Formal Caregivers, Younger Residents and RAC
Appendix J.

Table. Ordered Situational Map: Personal and Organizational Barriers to Formal Caregiving Relationships with Younger Residents

| Individual human elements/actors | Formal caregivers (FC)  
<table>
<thead>
<tr>
<th></th>
<th>Managers of RAC and PB facilities</th>
</tr>
</thead>
</table>
| Collective human elements/actors | Body of Allied Health Professionals  
|                                  | Aged Care Funding Instrument  
|                                  | Department of Human Services  
|                                  | Department of Health/ Ageing and Aged Care  
|                                  | Wider Organization: vision, mission and management  
|                                  | Health and Safety regulatory bodies |
| Nonhuman elements/actants        | Governmental Policy & Procedures  
|                                  | Organizational Policy and Procedures  
|                                  | Facilities operational procedures and regulations  
|                                  | Stakeholder accountability, risk & compliance demands  
|                                  | Models of care adopted in RAC  
|                                  | Stability/instability of facility/organisation management  
|                                  | Type of facility |
| Implicated/silent actors/actants | Young people in RAC  
|                                  | Older residents of RAC  
|                                  | Family and friends of young people in RAC  
|                                  | Family and friends of older residents in RAC  
|                                  | Nursing and auxiliary RAC staff  
|                                  | Volunteers |
| Key events in situation          | Young People with Disability in Aged Care Initiative  
|                                  | National Disability Insurance Scheme  
|                                  | Amendments to the Aged Care Act (2007)  
|                                  | Senate Debates re: appropriateness of young in RAC  
|                                  | Managerial Instability |
| Discursive constructions individual and/or collective human actors | Inadequacy of aged care model for young people  
|                                                                 | Inappropriateness of RAC for young people  
|                                                                 | Defining caregiving  
|                                                                 | Centrality of emotional caregiving  
|                                                                 | Changing caregiving and life needs of young people  
|                                                                 | Organizational structural inequality  
|                                                                 | Inadequacy of resources for meeting young people needs  
|                                                                 | Prioritization of instrument care over emotional care work  
|                                                                 | Identification with young people  
|                                                                 | Caregiving beliefs verses caregiving actions  
|                                                                 | Caregiving behaviour shaped by beliefs and reactions  
|                                                                 | Same yet different  
|                                                                 | Powerful yet powerless  
|                                                                 | Invisible yet visible  
|                                                                 | Lack of knowledge  
|                                                                 | Differences in YP condition or disorder |
| Discursive constructions of nonhuman actants | Burden of Bureaucracy as dehumanizing for clients & FC  
|                                                                 | Model of care and how its shapes caregiving  
|                                                                 | Policy and procedure and how it shapes caregiving  
|                                                                 | Managerial Instability |
| Political/Economic/Legal elements | Increased compliance demands  
|                                  | Lack of mandated staffing ratios  
|                                  | Government compliance and risk aversive practices  
|                                  | Stakeholder obligations  
<p>|                                  | Managerial Instability |</p>
<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ambiguities in interpretation of Aged Care guidelines</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Sociocultural/symbolic elements</strong></td>
<td>Work as meaningful&lt;br&gt;Work as a validation of identity as ‘a good person’&lt;br&gt;Caregiving is an act of love and connection</td>
</tr>
<tr>
<td><strong>Temporal elements:</strong></td>
<td>Neurodegenerative deterioration and changing care needs&lt;br&gt;Insufficient time for all caregiving duties&lt;br&gt;Staff turnover and loss of knowledge of young person&lt;br&gt;Working two jobs</td>
</tr>
<tr>
<td><strong>Spatial elements</strong></td>
<td>Type of facility&lt;br&gt;Dementia wards&lt;br&gt;Purpose built facilities&lt;br&gt;Resource availability&lt;br&gt;Ratio of young people to older residents in RAC&lt;br&gt;Ratio of FC to residents</td>
</tr>
<tr>
<td><strong>Major issues/debates (usually contested)</strong></td>
<td>Caregiver neutrality&lt;br&gt;Invisibility of caregiver in policy&lt;br&gt;Invisibility of young person in policy&lt;br&gt;Importance of FG and resident relationships&lt;br&gt;Perceived caregiving role verses actual role&lt;br&gt;Role of emotional care work as part of formal caregiving&lt;br&gt;Role of family and friends&lt;br&gt;FC beliefs of role of family/friends verses actions towards&lt;br&gt;Formal caregiving as only instrumental care&lt;br&gt;FC as powerful yet powerless&lt;br&gt;FC and young people who are the same yet different&lt;br&gt;FC and young people who are both visible yet invisible&lt;br&gt;Role of management in shaping FC beliefs and actions&lt;br&gt;Impact of structural inequalities upon formal caregiving&lt;br&gt;Impact of structural inequalities upon FC&lt;br&gt;Structural inequality as a shaper of caregiving behaviours&lt;br&gt;Identification with young people&lt;br&gt;Emotional impact of identification&lt;br&gt;Managerial instability and its role in FC defence reactions&lt;br&gt;Defence reactions and the YP and FC relationships&lt;br&gt;The impact of BOC on the YP/FC relationship&lt;br&gt;Inadequacy of training and knowledge&lt;br&gt;Anomaly of YP in RAC&lt;br&gt;Ethnicity of FC and potential barriers to communication</td>
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<tr>
<td><strong>Related discourses (historical, narrative, and/or visual)</strong></td>
<td>Prioritization of profit over people&lt;br&gt;Burnout and job satisfaction&lt;br&gt;Individual facility guidelines and policies</td>
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<tr>
<td><strong>Other key elements</strong></td>
<td>Role of family and friends&lt;br&gt;Qualification, ethnicity of FC&lt;br&gt;Gender dominance of female FC&lt;br&gt;Vocational background of managers</td>
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<tr>
<td><strong>Negotiations</strong></td>
<td>FC to YP&lt;br&gt;FC to managers&lt;br&gt;FC to older residents&lt;br&gt;FC to FC&lt;br&gt;FC to family and friends of YP and older residents</td>
</tr>
<tr>
<td>Managers to stakeholder and wider organization</td>
<td></td>
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<td>Managers to government regulatory agencies</td>
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<td>Managers to YP</td>
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</table>
# Appendix K

*Transcript exemplar demonstrating data analysis from open coding to theory contribution.*

<table>
<thead>
<tr>
<th>Excerpt</th>
<th>Open</th>
<th>Axial</th>
<th>Selective</th>
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<tbody>
<tr>
<td>1. Families will often say something like, ‘Why don’t you bring X down to my place, s/he would love to see his/her dog’.</td>
<td>1. Quality of life.</td>
<td>1 &amp; 2 Relationship with family</td>
<td>1, 2 &amp; 3 Relationship with Family and management</td>
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<tr>
<td>2. I just nod and say ‘yes we will have to try and organise that for him’, knowing full well it will never happen.</td>
<td>2. Defeated. Demoralized. Unhappy staff. Too hard.</td>
<td>2 &amp; 3 Negotiations with family and management</td>
<td></td>
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<td>3. That stuff only happens if the manager makes it happens.</td>
<td>3. Obstacles. Lack of power. Management.</td>
<td></td>
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<td>4. I wish that that sort of stuff could happen more often.</td>
<td>4. Expectations</td>
<td>4, 5, 6, Negotiations between perceived role and actual role</td>
<td>4, 5, 6, 8 &amp; 9 Perceived role versus actual role</td>
</tr>
<tr>
<td>5. I love doing this sort of stuff [non-essential care activities/emotional care] because it makes such a huge impact on them (younger residents).</td>
<td>5. Being important. Quality of life. Fulfilment. Meaningful work. Emotional care</td>
<td>6, 8 &amp; 9 Emotional responses to both perceived and actual role</td>
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<td>6. It brightens their day and makes them feel better, which makes me feel like I’ve done something good, and I feel good.</td>
<td>6. Fulfilment. Do good work.</td>
<td>6, 8 &amp; 9 Emotional responses to both perceived and actual role</td>
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<tr>
<td>7. It’s just a pity there’s not enough time to do more of that stuff though.</td>
<td>7. Pressure. Priorities Negotiations. No time Obstacles</td>
<td>6, 8 &amp; 9 Emotional responses to both perceived and actual role</td>
<td>1, 2 &amp; 3 Degree of mastery over environment</td>
</tr>
</tbody>
</table>
8. Even worse is that there is a huge gulf that I and probably nobody else can or will ever close. What I know needs to be done, what is really needed to make that real difference [to the lives of a younger resident] but can’t be because of the where and why and the here and the now of this place.

9. I live in the face of what isn’t, in the face of what is lacking, rather than feeling any pride of what is, and what has been given or done [in reference to meeting caregiving needs].
