A Palliative Approach for People with Declining Health
Living in Hostel Accommodation:
The State of Play

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Doctor of Philosophy

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DECLARATION

I hereby certify that this thesis does not contain, without the appropriate acknowledgement, any material previously submitted for a degree in any university. I also certify that this thesis does not contain, without the appropriate acknowledgement, any material previously published or written by another person.

…………………………
Peta K. McVey

19/8/11
Date
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In undertaking this research I am eternally indebted to the participants for sharing their experiences, reflections and precious time.

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ABSTRACT

In Australia, residential aged care facilities are increasingly becoming the place of care and site of death for older people with complex chronic illnesses. Consequently, it is becoming ever more relevant for these facilities to provide appropriate ongoing care as well as end of life care for this growing group of people. Since most related research to date has focused on end-of-life care in high-level care nursing home settings, little is currently known about the use of a palliative approach in caring for older people with complex needs living in hostel settings in Australia.

This study aimed to: (i) map high-level care residents in residential low-level care settings (hostels) in relation to demographic information, medical illnesses, co-morbidities, physical function and individual symptoms, (ii) explore resident perceptions of their situation and how they would like their care to be managed into the future, (iii) explore aged care staff understandings of what constitutes a palliative approach, and their perspectives on how this approach is being incorporated into the care of their high-level residents in hostel settings, and (iv) review related organisational and managerial data such as policies, procedures and staffing.

A concurrent mixed methods design incorporating both quantitative and qualitative approaches to data collection was conducted in two residential aged care facilities in NSW. Data collection was conducted over a eight month period. Descriptive statistics were used to summarise the characteristics of the 93 high-level care residents participating or participating by proxy (that is through the involvement of a person responsible acting on behalf of the resident), the prevalence of symptoms and the number of symptoms per resident, associations between symptoms and diagnosis, and the functional status and psychosocial well-being of participating residents. Three validated tools were used to describe the residents’ health status, wellbeing, and functional ability and assess current symptoms. A medical record audit tool was developed to collect demographic data, and organizational and managerial data tools were developed to collect information about polices, education and staffing levels. Of the 412 residents in the eight hostel facilities,
58% were categorised as requiring ‘high-level’ care. In addition, unstructured interviews were conducted with 72 high-level care residents and 21 persons responsible and semi-structured interviews were conducted with 30 aged care staff.

The findings show that, although hostel staff are familiar with the concept of a palliative approach, the discourse of this approach to care is not widely adopted or operationalised within hostel settings. The study also demonstrates that staff, high-level care residents and their families all struggle with the difficulties and complexities of the transition towards the end of life within hostels, and particularly with the constraints that, in most cases, preclude the possibility of ‘dying in place’. This thesis presents a new way of conceptualising care for those people in hostels who are transitioning towards end of life: a community of care, in which a palliative approach is one of several elements of the care provided. Implementing communities of care within hostel settings is not, however, without challenges. Recommendations are made in this thesis about how some of these issues might be addressed.
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Aged Care Funding Instrument: is the funding model that superseded the Residential Classification System in March 2008. This model allows for three levels of Australian government care subsidy based on the resident’s daily living activities, behaviour and complex health care needs. Assessment has ratings (A, B, C and D). The rating is based on the answers to 12 questions about each domain. Each of these domains has three funded levels – low, medium and high (Australian Institute of Health and Welfare (AIHW, 2009).

Ageing-in-Place: an Australian aged care policy, introduced with the Aged Care Act in 1997, focuses on enabling residents of an aged care facility to remain in the same environment when their care needs increase.

Alternating pressure mattresses: these types of mattresses alternate the pressure beneath the person, reducing the need to move the person frequently, and are available in a wide variety of makes and models.

Endorsed Enrolled Nurse: is an enrolled nurse (see below) who has undergone an additional regulatory authority approved medication administration education program. Therefore, they can undertake more complex tasks including, medication administration (Access Economics, 2009).

Enrolled Nurse: a person registered with Australian Health Practitioner Regulation Agency. The minimum educational requirement for an enrolled nurse is a one-year diploma qualification from a Vocational Education and Training (VET) provider, or equivalent from a recognised hospital-based program. Enrolled nurses usually work with registered nurses to provide patients with basic nursing care, undertaking less complex procedures than RNs (Access Economics, 2009).
**End of Life:** within the Australian context refers to generally, the last weeks, days or hours of life (Dy, Shugarman, Lorenz, Mularski & Lynn, 2008). Within the United Kingdom context, end of life refers to the last six to 12 months of life (The National Gold Standards Framework Centre, 2008).

**Frailty:** a combination of loss of weight and strength, altered balance, poor endurance, inactivity and fatigue, and the likelihood that the individual will deteriorate further (Lo & Woo, 2006).

**High-level Care Resident:** a resident who requires assistance with most activities of daily living, close monitoring and/or complex care. In this study the Residential Classification System (RCS) (see definition below) has been used to identify such residents. Categories 1-4 on the RCS indicate high-level care requirements.

**Hostel:** a facility that has historically provided low-level care to the aged care residents, but now provides a combination of high- and low-level care.

**Low-level Care Resident:** a resident who requires minimal assistance with activities of daily living. Categories 5-8 on the RCS indicate low-level care requirements.

**Nursing Home:** a facility that provides high-level care to aged care residents.

**Residential Aged Care Facility:** an organisation that provides a combination of self-care units, hostel and nursing home accommodation for the aged.

**Nursing Home:** a facility that provides high-level care to aged care residents.

**Older Person:** people 65 years and over.

**Palliative Approach:** an approach to care linked to the principles and philosophy of palliative care to be used by primary care services and practitioners (Palliative Care Australia, 2005b).
**Palliative Care:** care that aims to improve 'the quality of life of individuals and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial or spiritual' (WHO, 2002, p. 84).

**Personal Care Assistant:** an unregulated worker in an aged care facility who is supervised by nurses (Registered Nurses, Endorsed Enrolled Nurses or Enrolled Nurses) and who provides the majority of personal care to residents (Access Economics, 2009). A Personal Care Assistant is also referred to as Assistant in Nursing, Nursing Assistant, Carer, Personal Care Worker, Care Service Employee, Care Aide, or Nurse’s Aide, depending on the place of work.

**Person Responsible:** is a statutory concept defined in Section 4 of the Guardianship and Administration Act 1995. A person responsible is a delegated person who is responsible for making decisions for individuals who have a disability or are incapable of consenting to treatment. The person responsible is not necessarily the patient's next of kin (New South Wales (NSW) Government, Office of the Public Trustee, (no date [n.d]).

**Residential Classification System:** a classification model used in residential aged care facilities prior to March 2008 to determine the level of Australian government subsidisation of a resident’s care. The RCS is an eight-category classification system, which assigns each resident to one of eight RCS categories that are designed to reflect care needs with an associated funding of a 'daily basic subsidy' tied to each classification. The RCS assessment comprises of 20 questions, which are given variable response weightings (A – D) and can total a score of 100. Categories one to four represent high-care status and categories five to eight represent low-care status (Australian Department of Health & Ageing (DoHA), 2003).

**Registered Nurse:** a person registered with Australian Health Practitioner Regulation Agency. The minimum educational requirement for a registered nurse (RN) today is a three-year degree from a higher education institution or equivalent from a...
recognised hospital-based program. RNs manage teams of care staff and may delegate tasks to other workers and are required to provide direct or indirect supervision to these workers (Access Economics, 2009).
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<table>
<thead>
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<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<td>ACFI</td>
<td>Aged Care Funding Instrument</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>APRAC</td>
<td>Australian Palliative Residential Aged Care</td>
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<tr>
<td>DoHA</td>
<td>Department of Health and Ageing</td>
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<td>EEN</td>
<td>Endorsed Enrolled Nurse</td>
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<td>EN</td>
<td>Enrolled Nurse</td>
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<td>HLC</td>
<td>High-Level Care</td>
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<td>PCA</td>
<td>Personal Care Assistant</td>
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<td>RACF</td>
<td>Residential Aged Care Facility</td>
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<td>RCS</td>
<td>Residential Classification System</td>
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<td>RN</td>
<td>Registered Nurse</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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CHAPTER ONE:

Introduction

In response to a growing call from Aged Care providers in Australia, the Commonwealth DoHA supported the development of evidence-based guidelines for the provision of palliative care in residential aged care settings (Australian DoHA, 2004a). The Australian Palliative Residential Aged Care (APRAC) guidelines were launched in 2004, to provide increased support and guidance to optimise palliative care for older Australians in residential care settings (ibid). A key element of the guidelines was the introduction of a ‘palliative approach’, with the emphasis on not waiting till the last few weeks of an individual’s life to implement evidence based approaches to improve symptom control. These guidelines specifically targeted residential care settings, where the proportion of high care need residents is high and therefore the need perceived to be great. As the number of aged Australians grows, and increasing numbers of high care residents with complex chronic conditions are being cared for in community and hostel settings, there is increased demand for support for aged care staff. To date, though, it is not known which residents, if any, may benefit from the introduction of a palliative approach, or the extent to which the new guidelines have been operationalised in aged care settings.

This study sought to address this gap in knowledge by exploring aged care staff perspectives on the incorporation of a palliative approach into the care of their high-level hostel-based residents. Specifically, the research aimed to explore the extent to which a palliative approach is being used in the organisation and provision of care for older people with complex needs living in hostel settings. It was also considered important to explore the experiences of such older people and their families, including their perceptions of how appropriately their needs are being met by the available services. This study sought to describe hostel-based residents identified as requiring high-level care in relation to their demographics, medical diagnoses, co-morbidities,
physical functioning and individual symptoms. It was anticipated that the knowledge generated from this inquiry would (i) contribute to the development of future models of care that will assist people with complex needs to remain in their hostel setting if that is their wish, and (ii) further inform future policy directions.

This chapter provides an overview of ageing and palliative care in Australia, the broader context in which the study has been conducted. This is followed by the researcher’s statement of interest, a statement of the problem, and an outline of the purpose of this research. The methodological approach, rationale and significance of this study are also introduced. The chapter concludes with the specific research objectives.

1.1 Background and Context of the Study

1.1.1 Ageing in Australia

The proportion of older people in Australia living with chronic illnesses is increasing, particularly in the 85 years and over age bracket. Many are suffering from conditions which can impede their physical, psychological and social functioning (Waters, Allsopp, Davidson & Dennis, 2001; Abbey, Froggatt, Parker & Abbey, 2006). This situation has significant implications for aged care policy and service provision, as these individuals are increasingly likely to require assistance and care from others.

The Australian Institute of Health and Welfare reports that 13.3% of the Australian population is now above the age of 65 years (AIHW, 2010a). In 2007, there were 2.4 million people aged 65-84 years (ABS, 2009) of which 6% were living in residential aged care facilities (AIHW, 2007a). Over the next 30 years, the number of people aged 65 years and over is expected to more than double, from 2.7 million to 6.3 million, accounting for 24% of the total population (AIHW, 2007b). Given the estimated growth in the ‘very old’ population (those aged 85 years and over), there will be a significant increase in government spending on aged care services in the future (ibid).
As the Australian older population increases, more people are likely to experience disabilities and ill health and require significant assistance. Figures for those aged 65 years and older illustrate that this population significantly contributes to the total proportion of ill health in Australia, inevitably influencing the need for health services to meet the chronic and complex needs of this group. People aged 75 years and over experienced 25% of the total burden of disease in Australia in 2003 (Begg, Vos, Barker, Stevenson, Stanley & Lopez, 2007). Adults aged 65–74 years made up 7% of the total population and experienced 16% of the total burden of disease and injury in Australia in 2003 (ibid).

The presence of multiple health conditions tends to be associated with more severe disability (ABS, 2003). In line with this trend, it is expected that over the next thirty years there will be a 70% increase in the number of older persons with profound disabilities (Giles, Cameron & Crotty, 2003). In 2003, the average number of health conditions in people aged 65 years and over was 2.84 conditions, but this figure rises significantly for the 85 years and older group with an average of 4.85 health conditions (ABS, 2003). Older age groups (85 years and older) had higher average numbers of health conditions across all categories of disability status (AIHW, 2007b).

For older Australians, the most prominent health conditions resulting in hospitalisation and death are cancer (particularly lung, prostate and colorectal cancers) and cardiovascular disease. However, neurological health conditions such as dementia is the most common cause of death among older people (85 years and over), affecting some 25% of older females and 17% of older males (AIHW, 2010a), with figures projected to increase by 150% over the next 20 years (AIHW, 2008). Although not always the primary cause of death, dementia is the most prominent health condition among people aged 65 years and over and most likely to be associated with a severe or profound core activity limitation (ABS, 2003).

Since dementia is such a disabbling health condition of older Australians, those who are moderately or severely affected usually require full-time care (AIHW, 2008). Indeed, serious chronic illness associated with cognitive as well as physical impairment frequently leads to placement in residential aged care (Greene & Ondich, 1990;
This situation has affected the pattern of where people die in Australia. According to Foreman, Hunt, Luke and Roder (2006), today people are most likely to die in a hospital or other institutional setting. And, increasingly, older people who die as a consequence of the end stages of advanced chronic illness are less likely to have family or community supports available to them. Therefore, as the Australian population ages, it is anticipated that more people will require residential aged care, and many will die in residential care with little or no family support.

These population and health projections highlight the fact that the Australian older population is rapidly growing and that this group is increasingly likely to have profound disabilities and complex medical conditions, requiring complex management and care. Therefore, it is important to focus on this older group, particularly given that as they deteriorate they are more likely to require 24-hour assistance, possibly within a residential aged care facility if they have limited social support.

A considerable body of international evidence shows that older people with chronic illnesses may suffer unnecessarily owing to widespread under-assessment and undertreatment of their clinical problems, and that their quality of life is reduced as a result (English & Mastrean, 1995; Kristjanson, Toye & Dawson, 2003; WHO, 2004; Hudson, Toye & Kristjanson, 2006; Spence, Hasson, Waldron, Kernohan, McLaughlin, Cochrane & Watson, 2008; O’Leary, Murphy, O’Loughlin, Tiernan & McDonald, 2009). These factors have prompted the need for changes to aged care services in Australia, including the need to ensure that access to specialist palliative care services is extended to residential aged care facilities (RACFs).

1.1.2 Residential Aged Care in Australia

RACFs have become the key area of focus for examining ways to improve access to palliative care in the older person with chronic illnesses, as these facilities are the main formal providers of care for this population (AIHW, 2010b). It is within the
RACF that aged care staff focus on reducing the impact of chronic illness and disability associated with aging on the individual’s quality of life. Until 1997, residential care in Australia had two distinct tiers: hostels and nursing homes. Traditionally, residents in hostel accommodation required low-level care which includes the provision of suitable accommodation and related services such as laundry, meals and cleaning, and personal care services such as assistance with the activities of daily living. Residents in nursing homes required high-level care which includes all low-level care provisions plus nursing care and availability of special equipment. If their care needs changed, hostel residents were required to move to a nursing home. According to Gray (2001b), up until the late 20th century the public view of hostels was as an ‘accommodation’ option for ‘social’ reasons, whereas nursing homes were about ‘care’. Flicker (2000) argued that older people took up this option because of chronic medical conditions resulting in permanent disability which could no longer be sustained at home.

The introduction of the Aged Care Act 1997 saw the amalgamation of hostels and nursing homes into a single entity termed ‘residential care facilities’ and the introduction of a single funding system, the Residential Classification Scale (RCS). This coincided with the implementation of the Australian Government’s Ageing in Place policy (Howe, 2000). The aim of the ageing-in-place policy is to enable facilities to adjust their service provision and level of care to meet residents’ changing needs so that they may remain in the same facility instead of transferring to a nursing home. Residential aged care organisations can choose to implement an ageing–in-place policy within their facilities, an approach which is likely to attract a high level of funding. Today most Australian residential aged care facilities (hostel/nursing homes) now accommodate a combination of low-level and high-level care residents, ostensibly offering the full continuum of care (Australian DoHA, 2008).

Despite this amalgamation and the use of a single umbrella term, primarily for funding purposes, clinicians continue to differentiate between hostel and nursing home settings. A key reason for the distinction lies in the significantly different staffing levels and skill mix which impact on the level of care able to be provided (De Bellis & Parker, 1998). Hostels frequently employ small numbers of registered nurses who also
act as managers of the facility and supervise the higher proportion of personal care assistants providing hands-on care to residents (Phillips, Davidson, Ollerton, Jackson & Kristjanson, 2007; Access Economics, 2009; Australian Nursing Federation, 2009). Nursing homes have a higher proportion of registered and enrolled nurses delivering all aspects of care (Australian Nursing Federation, 2009).

Over the past decade, both the dependency level and length of stay of residents in aged care facilities has significantly increased (AIHW, 2010b). The average completed length of stay for permanent residents between 2008 and 2009 was 147 weeks, compared with 131.3 weeks in 1998 and 1999 (AIHW, 2010b). The new aged-care funding model (Aged Care Funding Instrument, ‘ACFI’) introduced in 2008 attests to the increasing dependency of residents. Between 1998 and 2008, the proportion of residents classified as high-level care increased from 58% to 75%, while the proportion of those requiring low-care fell from 42% to 25% (AIHW, 2010b). These dependency figures include both nursing home and hostel figures but, the numbers of high-level care residents currently residing in hostels is unknown. However, as Coburn and colleagues (1998) have noted:

*The staff who care for Australia’s nursing home and hostel residents have an increasingly complex and challenging role. Over the past 20 years, Federal Government policies of enhancing community care provision, preadmission client assessment, and the linking of funding to the level of client dependency have ensured that only the most dependent people now access residential care.*

(p. 20)

The proportion of people dying in residential aged care facilities in Australia has significantly increased over the past two decades. The number of resident deaths reported between 2008 and 2009 was 88%, compared with 61% in 2007 and 2009 (AIHW, 2010b). By 2020, half of all deaths in Australia are expected to occur in RACFs (ibid). RAFCs are increasingly becoming the place of care and site of death, highlighting the potential need for ensuring this group of people have access to optimal aged care and also end of life care.
As noted above, in Australia it is not clear how many high-level care residents are now living in hostels. However, research from South Australia suggests that hostel residents are more likely to die in the acute care setting than in their hostel home (Grbich, Maddocks, Parker, Brown, Willis & Hofmeyer, 2005). Grbich and colleagues (2005) identified that the main reason for transfer from the hostel facility to an acute care facility was related to the rapid deterioration of the resident, care needs beyond the facility’s capabilities, or request for transfer by the general practitioner or family (Grbich, Maddocks, Parker, Brown, Willis & Hofmeyer, 2005).

Clearly, the need for palliative care services is increasing in both hostels and nursing homes because the Australian aged population is living longer with increasing disabilities and complex medical conditions. More is known in Australia, though, about the experiences of palliative care in nursing home settings than in hostels.

1.1.3. Developments in Palliative Care for the Residential Aged Care Sector in Australia

Palliative care is widely recognised as having the potential to improve the quality of life of individuals with incurable life-limiting illnesses (Chochinov, Hack, McClement, Kristjansen & Harlos, 2002; Pemberton, Storey & Howard, 2003; Ahmedzai, Costa, Blengini, Bosch, Sanz-Ortiz, Ventafridda & Verhagen, 2004). The concept of palliative care has emerged with deeper professional understandings of the emotional and physical suffering experienced by people who are dying. The WHO, 2002) defines palliative care:

\[
\textit{as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (p. 84).}
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Health professionals working in palliative care argue that they approach the management of patients in their care from a different philosophical perspective to that
of their colleagues in other speciality areas. Principally this difference lies in a philosophy of ‘care’ as opposed to ‘cure’, whereby the goal of palliative care is to achieve quality of life and a dignified death, preferably in a place of the patient’s and their family’s choosing (Pemberton et al., 2003).

Palliative care developed through the hospice movement which focused on the needs of individuals with advanced cancer and on their families (Field & Addington-Hall, 1999; Higginson, 2005). Increasingly, research has identified patients with other life-threatening diagnoses, such as Parkinson’s disease, heart failure, renal failure, chronic obstructive pulmonary disease and dementia, as having similar palliative care needs (English & Mastrean, 1995; Stewart, MacIntyre, Hole, Capewell & McMurray, 2001; Hall, Schroder & Weaver, 2002; Kristjanson et al., 2003; Brandt, Deliens, van der Steen, Ooms, Ribbe & van der Wal, 2005; Brandt, Ooms, Deliens, van der Wal & Ribbe, 2006; Hudson et al., 2006; Aminoff & Adunsky, 2006; Bausewein, Booth, Gylsels, Kuhnbach, Haberland & Higginson, 2010). The potential benefits of implementing palliative care for those with non-malignant, life threatening conditions, has been increasingly recognised.

Within the last decade in Australia, there has been a further shift in the provision of palliative care in light of widespread recognition that the benefits of palliative care are not limited to the final days or weeks before dying. As a result, a distinction has been drawn in policy development between a ‘palliative approach’ - a set of skills expected of every health professional who provides care for someone with a life-threatening illness - and specialised palliative care services provided by health professionals whose substantive training and work is in palliative care (Finlay & Jones, 1995). Thus, the term ‘palliative approach’ has become synonymous with the provision of palliative care by non-palliative care specialist providers.

The aged care sector in Australia has recognised the need to improve access to palliative care for residents in RACFs. In response to calls from the Aged Care Sector, the Australian DoHA, under the National Palliative Care Program and the National Health and Medical Research Council (NHMRC), commissioned a review of the evidence for palliative care in the aged care sector. This review led to the
development, and subsequent NHMRC endorsement, of the world’s first evidence-based *Guidelines for a Palliative Approach in Residential Aged Care* (Australian DoHA, 2004a). These guidelines reinforce the recommendation that, for aged care residents with chronic, non-malignant illnesses with uncertain disease trajectories, a palliative approach can be initiated well before the terminal stages of illness, thereby facilitating the identification of the wishes of patients and their families regarding care throughout a period of declining health as well as in the final end-of-life stage. A palliative approach aims to broaden and improve the quality and effectiveness of all palliative care service delivery across Australia. In support of the guidelines, a national education program was implemented to educate aged care staff from residential aged care facilities in the delivery of a palliative approach. This may be an appropriate way to implement a palliative approach in residential aged care settings (Panke, 2002; Kristjanson et al., 2003; Murtagh, Preston & Higginson, 2004), but there has been little research into the extent to which the approach is helpful and effective in the care of older people in residential aged care facilities. Although the number of high care residents in hostels is rapidly increasing, the applicability and feasibility of providing a palliative approach to this group remains unknown.

### 1.2 Researcher’s Statement of Interest

My professional role is as a clinical nurse consultant (CNC) in palliative care. I have worked in this specialty for more than 20 years. During this time, education has been a key aspect of my role, including within the aged care sector. I have also been a trainer in the national ‘Train the Trainer’ workshops for the implementation of the *Guidelines for a Palliative Approach for Residential Aged Care Facilities* (McVey & White, workshop - 25 August 2005).

My interest in the research topic arose out of clinical issues identified in the field while providing palliative consultations within aged care facilities. During my visits, I observed that some hostel staff experienced difficulties organising and managing the care of high-level care residents with complex chronic conditions with the limited
staff resources available. For example, to ensure the administration of medications such as regular subcutaneous drugs and the use of as required ‘break-through medications, in some instances, staff felt compelled to return to the facility during their rostered time off to administer these medications. Others struggled with the competing demands of maintaining frequent assessments and delivery of complex care required for those residents with higher-level care needs than other residents within the facility. This prompted me to question how aged care staff in hostel settings understood a palliative approach and the extent to which they were able to implement such an approach, given the significant difference in staffing levels and skill mix compared to that in nursing home settings. I also wondered how residents living in these settings felt about the care provided and their future care needs.

These initial questions were the starting point for my literature review, which revealed that most research had focused on the nursing home setting rather than the hostel setting, thus highlighting the need for research into the latter. The literature review made it clear that little is known about the demographic differences between hostel and nursing home residents in Australia and also that the extent to which a palliative approach is being implemented in hostels is unclear.

1.3 Statement of Problem

Most research concerned with the use of a palliative approach in Australian RACFs has been focused on nursing home settings and has concentrated on age care staff education needs, the interface between specialist palliative care services and RACFs, perceptions of what constitutes a palliative approach and end-of-life care. Little research has focused on the use of a palliative approach in the care of older people with complex care needs living in hostel settings in Australia. Given the growing numbers of older people in Australia with increasingly complex chronic care needs and longer disease trajectories who live in such facilities, the need to ensure services can provide optimal care is critical.
1.4 Statement of Purpose

The purpose of this study is to explore aged care staff understandings and use of a palliative approach in the care of high-level care residents, and to explore these same residents’ perceptions of the care provided and their future care needs. In addition, this research describes the demographics of high-level care hostel residents. It is anticipated that, through a better understanding of these demographics and aged care staff and resident perceptions about care, any gaps, issues and challenges to service provision will be identified, thereby allowing for more informed decisions in future strategic planning.

1.5 Research Method

To understand the complexities surrounding the use of a palliative approach in the care of high-level care residents living in hostels setting, a descriptive and explorative approach was considered essential. This study employs a mixed method design combining quantitative and qualitative approaches. The aim of using different approaches to investigate different aspects of the research problem (Creswell & Plano Clark, 2007) is to enable a more complete and comprehensive account of a palliative approach in hostel settings to emerge.

Approval from the University’s Human Research Ethics Committee (Appendix 1) was granted to conduct the study and approval from both residential aged care facilities.

1.6 Rationale and Significance of Study

The Australian Palliative Residential Aged Care Project (Australian DoHA, 2004a) highlighted a need for the development of links between aged and palliative care services, and education support for aged care staff. The need for access to palliative care continues to exist with evidence that the needs of people living with chronic diseases, of those with multiple complex health and social problems, and of older,
increasingly frail, people were not being met (Australian National Health and Hospitals Reform Commission (NHHRC) report 2009). The NHHRC report (2009) highlighted the need for residential care facilities to improve the capacity and competence of their primary health care services to provide generalist palliative care support for their terminally ill patients. It also identified the need for greater educational support and improved collaboration and networking with specialist palliative care service providers.

This study set out to identify current practices in aged care relating to the management of older people with declining health and increasingly complex care needs living in hostels. The study explored the experiences of such older people and their families, including their perceptions of how appropriately their needs were being met by the available services. The examination of the extent to which a palliative approach was being incorporated in hostels was intended to assist with the identification of knowledge gaps, barriers and unmet needs. This information will be beneficial in planning for future strategies and will enhance the quality of care for our ageing population and the staff who provide their care.

The results of this study will assist in developing collaborative strategies for current and future practices and appropriate servicing. The significance of this project lies in its potential to inform future policy directions that will address the rapidly growing need for effective management of people with chronic illnesses living in hostel settings. It is also anticipated that this study will contribute to the development of future models of care that will enable people with complex needs to remain in their hostel setting, if that is their wish.
1.7 Research Objectives

The objectives of this study are:

1. to describe high-level care residents living in hostels in relation to demographic information (e.g., age, gender, marital status and family support), medical illnesses, co-morbidities, physical functioning, and individual symptoms and/or cluster symptoms;

2. to explore health issues for this group of residents, as well as their perceptions of the care they are receiving and how they would like that care to be managed into the future;

3. to explore aged care staff understandings of what constitutes a palliative approach, and to examine their perspectives on how a palliative approach is incorporated into the care of their high-level hostel-based residents; and

4. to examine organisational and managerial factors that support a palliative approach within hostels.

1.8 Conclusion

The impact of ageing and the associated changing patterns of disease have prompted changes to the provision of aged care services in Australia, in particular, the need for a palliative approach to be implemented in RACFs. While most Australian research on a palliative approach has focused on nursing home settings, it is clear that the dependency levels and complex chronic care needs of residents in hostels are increasing. Research focusing the on an approach to palliative care in the hostel setting is needed to identify and address any unmet needs and to improve resident outcomes.
The following chapter gives context to palliative care in residential aged care facilities by reviewing the historical developments and developing trends of palliative care. It also highlights the impact of palliative care and aged care policy on the aged care sector. In addition, several national strategies and initiatives regarding a palliative approach are reviewed and challenges in the provision of this approach identified.
CHAPTER TWO:

Background and Literature Review

This chapter reviews the background and literature relevant to the use of a palliative approach in residential aged care facilities. The review includes consideration of the developing trends in palliative care and the political impact of Australian national aged care and palliative care policies influencing service delivery. It reviews literature on challenges to implementing a palliative approach in RACFs, education strategies in Australia for a palliative approach and the use of link nurses as a strategy for guiding and developing the palliative approach in RACFs.

The literature review included searching of databases Ageline, Medline, CINAHL, Ovid, EMBASE and PsychINFO for the period from 1990 to 2010. It was anticipated this timeframe would capture recent research related to the multiple changes within the age care and palliative care arena. The search terms used were: palliative care, palliative approach, end-of-life care, terminal care, dying, end of life, nursing homes, residential care, hostel, low-level care, high-level care, assisted living facilities, care assistants, personal care assistants, assistants in nursing, aged care, aging in place and chronic illness. Where reference was made to any other relevant studies, these were sourced. Relevant grey literature was searched using CareSearch, an online palliative care knowledge network. CareSearch (2011) consolidates evidence-based and quality information for various groups within the palliative care community and is funded by the Australian Government Department of Health and Ageing as part of the National Palliative Care Program.

The search confirmed that most research concerned with palliation or a palliative approach in Australia has been conducted in nursing home settings, with the focus on end-of-life care, specialist palliative care interface, the educational needs of aged care staff, and their perceptions of what constitutes a palliative approach in the care of...
high-level care residents. Very little research has focused specifically on the use of a palliative approach in the care of people in hostel settings.

2.1 Developing Trends of Palliative Care

Several trends have occurred in the development of palliative care in Australia, influencing both practice and service delivery. These include changes in the definition of palliative care, the increasing prevalence of chronic illness, the recognition of palliative care needs among this population, and changes in workforce resources which have resulted in the review of palliative care service delivery models. All of these trends have had a significant impact on the provision of palliative care, particularly within RACFs.

2.1.1 Redefining Palliative Care

Traditionally, palliative care has primarily been offered to people suffering from terminal cancer (WHO, 1990; Field & Addington-Hall, 1999; Murtagh et al., 2004; Mitchell, Johnston, Thomas & Murray, 2010). This is partly because the course of this illness is relatively predictable and it is thus easier to recognise and plan for the needs of patients and their families as they face end of life. However, one of the consequences of this focus has been the misperception by acute care centres, many health professionals and the general public, that palliative care is relevant only in the ‘terminal’ phase, the final phase of a person’s life where death may occur within days or weeks (Jerant, Azari, Nesbitt, Edwards-Goodbee & Meyers, 2006; Hartley, 2008). Even the earlier WHO’s (1990) definition of palliative care as being for those ‘whose disease is not responsive to curative treatment’ (p. 11) could be interpreted as relegating palliative care to the last stages of life (Sepulveda, Marlin, Yoshida & Ullrich, 2002). The more recent and revised WHO definition (2002) embraces a wider concept of palliative care, extending it to any patients and their families facing problems associated with life-threatening illness, and specifies that patients (and families) should receive palliative care earlier in the disease trajectory.
In Australia, in keeping with international trends, palliative care and end-of-life care is now provided in other settings, including RACFs, and to a broader patient population. Regardless of diagnosis, the focus of palliative care is now on managing a range of physical symptoms and psychological domains in order to maintain quality of life (Fisher, 2006). Within this new paradigm, palliative care becomes a necessary part of the treatment plan, irrespective of the disease trajectory or setting (Mahon & Sorrell, 2008).

Consequently, definitions of the scope and tasks of palliative care have evolved. However, there remains a lack of agreement on the definition of palliative care, and many health professionals, including palliative care experts, are confused as to what palliative care and a palliative approach entail (Pastrana, Junger, Ostgathe, Elsner & Radbruch, 2008). Finlay and Jones (1995) describe three distinct but interconnected aspects of palliative care to help clarify the boundaries and relationships between different types of care and modes of delivery, these being: a palliative approach, an approach to treatment by all clinicians that recognises the importance of meeting the psychological, spiritual and physical needs of a person with a life-threatening illness; palliative interventions, interventions that are often carried out by medical specialists (for example, radiotherapy, surgery or chemotherapy) with the aim of controlling symptoms and improving quality of life; and specialist palliative care, care delivered by specialist clinicians within a dedicated multidisciplinary team.

2.1.2 Palliative Care within Residential Aged Care Facilities

Numerous research studies have identified obstacles to the provision of palliative care in aged care facilities. These include: inadequate staffing levels; a regulatory focus on rehabilitation; a lack of familiarity with the protocols of palliative care; failure to recognise the futility of treatment; lack of communication between decision makers, residents and families; no agreement on a course for end-of-life care; failure to implement a timely end-of-life care plan and lack of recognition that appropriate palliative care education and training is required to make this approach to their care of older people with chronic conditions effective (Avis, Greening Jackson, Cox & Miskella, 1999; Komaromy, Sidell & Katz, 2000; Kayser-Jones 2002, Froggatt &
The interpretation of palliative care and when it should commence differs between aged care staff. In a survey conducted by Froggatt and Payne (2006), 81 care managers of nursing homes across the United Kingdom (UK) were asked to define end-of-life care. It should be noted that within the UK, end of life commonly refers to the last six to 12 months of life (The National Gold Standards Framework Centre, 2008). Interestingly, the majority of managers in Froggatt and Payne’s study, focused their definition on death and the immediate period leading up to death with terms such as ‘the last days’, the ‘final stages’, ‘when the end is near’. Palliative care was mentioned by only one respondent. Whittaker and colleagues (2007) explored the level of knowledge about palliative care among 508 care assistants in nursing homes in one region in the UK (Whittaker, Kernohan, Hasson, Howard & McLaughlin, 2007). Most care assistants believed the term focused on the care of the dying, especially those diagnosed with cancer, while others provided a description of the need for pain control, spiritual and family support. When asked at what stage in a resident’s illness they felt palliative care would be of most benefit, the majority stated that this was within the last hours or days of life. A minority felt that palliative care should begin earlier.

Clearly, there is a lack of clarity regarding the understanding and implementation of palliative care. It appears aged care staff interpret palliative care as a form of care that is really only necessary at the end of life, thus highlighting a gap in knowledge. The idea that a palliative approach could be used in Australian RACFs evolved in 2004 (Australian DoHA, 2004a). As stated previously, the principles and philosophy of palliative care underpin a palliative approach; therefore an understanding of these is necessary. However, for aged care staff caring for older residents with increasingly chronic and complex conditions, one of the challenges is to be able to identify when to introduce a palliative approach.
2.1.3 Applying a Palliative Approach in RACFs

A palliative approach acknowledges the likelihood of gradual transition to palliative care by emphasising quality-of-life considerations, including during the active treatment phase. It recognises that treatment goals will change from seeking a cure to controlling the disease and associated complications, maintaining physical functioning and quality of life, and ultimately to controlling actual symptoms (Meyers, Linder, Beckett, Christensen, Blair & Gandara, 2004). However, the concept of dying with dignity moves a palliative approach far beyond mere symptom control to the consideration of psychological, social, spiritual and existential aspects of end-of-life care (Chochinov, 2002).

According to Finlay and Jones, (1995), a practitioner providing a palliative approach should be able to assess patients’ primary palliative care needs; meet those needs within the limits of their knowledge, skills and competence; and know when to seek advice from or refer to specialist palliative care services. In addition to providing such active comfort measures to address the individual’s symptoms and distress, discussions with the person and family about their future treatment choices and wishes should take place (Kristjanson et al., 2003). Early identification of the wishes of patients and their families about care throughout the foreseeable period of declining health gives the person more autonomy and reduces their sense of powerlessness in the face of death (Murtagh et al., 2004). A palliative approach within the context of residential aged care facilities can reduce potential distress to the resident and family caused by transfer to an acute hospital and allows the resident to stay in familiar surroundings and among staff who have known the resident and family for a long period (Avis et al., 1999; Panke, 2002).

As noted in Chapter One, the patterns of disease in the last years of life are changing such that people are increasingly dying from serious chronic diseases rather than from acute illnesses (Palliative Care Australia, 2010b). A number of research studies have documented people with chronic illnesses experiencing similar issues to those with cancer. It is suggested that a palliative approach, particularly for older people with chronic illnesses such as heart (English & Mastrean, 1995; Stewart et al., 2001) and
respiratory diseases (Gore, Brophy & Greenstone, 2000), dementia (Morrison & Siu, 2000; Mitchell, Kiely & Hamel, 2004; McCarron, Gill, McCallion & Begley, 2005) and frailty (Lunney, Lynn, Foley, Lipson & Guralnik, 2003), can be extremely beneficial in improving the delivery of quality care and optimising end-of-life care.

Unlike cancer, which has a relatively predictable course with the patient able to perform activities of daily living until late in the illness (Lynn, 2001), the trajectory of end-stage organ failure is unpredictable and there is a lack of clear prognostic indicators to approaching end of life. This is the most commonly cited barrier to providing palliative care for these patients (Hanrahan, Raymond, McCowan & Luchins, 1999; Grbich, Maddocks, Parker, Brown, Piller & Hofmeyer, 2005; Lorenz, Schugarman & Lynn, 2006). As end-stage organ failure has a trajectory that is episodic and characterised by acute flare-ups and periods of remission, physicians will hesitate to terminate active treatment while there is still hope that the patient will recover (Lynn, 2001). However, this may result in a delayed recognition of a terminal event and the need to implement end-of-life care (O’Leary et al., 2009).

The challenge for health professionals remains as how a palliative approach to care might best be offered to individuals with non-malignant disease, particularly to those who may not wish to identify themselves as having a terminal illness and for whom the illness trajectory may be long and uncertain (Hudson et al., 2006).

As identified earlier, in Australia, people are most likely to die in a hospital or other institutional setting as a consequence of the end stages of advanced chronic illness, often with limited family or community supports (Foreman et al., 2006). Therefore, as the Australian population ages, it can be expected that more people will require residential aged care, and that many people will die in this care setting. In fact, Abbey and colleagues (2006) postulate that long-term care facilities will become the hospices of the future, caring for increasingly older people with chronic conditions and longer trajectories to death, dementia being the most common condition. Knowledge of this trend has raised awareness of the need to incorporate a palliative approach into the care of residents in RACFs who are likely to die in these settings (Giles et al, 2003; O’Connor & Pearson, 2004).
2.1.3.1 The Guidelines for a Palliative Approach in Residential Aged Care

In recognition of many of these obstacles and growing concerns regarding the provision of end of life care in residential aged care settings, the Australian Commonwealth Department of Health and Ageing supported the development of The Guidelines for a Palliative Approach in Residential Aged Care in 2004. The evidence based guidelines were developed based on a detailed systematic review of the literature, and the result of a broad consultation process involving both palliative care and aged care sectors. The guidelines were endorsed by the Australian National Health and Medical Research Council, as they were the first to provide an evidence-based approach.

In 2005, Palliative Care Australia was given funding by the Department of Health and Ageing to undertake the introduction and Train the Training approach of aged care staff in the use of these Guidelines. Over a six-month period, Palliative Care Australia conducted 236 workshops across Australia (Palliative Care Australia, 2006). To ensure that all RACFs had equitable access to a workshop, 69 workshops took place in regional, 33 in rural and seven in remote areas around the country. Approximately two-thirds of all RACFs sent one or more staff members to a workshop, amounting to a total of 3,361 aged care staff who attended (ibid). In addition to these workshops, the DoHA funded Palliative Care Australia to develop and produce teaching resources for competencies regarding a palliative approach for Certificate III and Certificate IV qualifications. Continued support for the Guidelines and the use of a palliative approach in RACFS is delivered through Palliative Care Australia’s Residential Aged Care Palliative Approach Network newsletter and through website training resources which can be used as a self-directed learning package or utilised by trainers providing education for staff in their facility (Palliative Care Australia, 2009a).

The focus of the guidelines and subsequent implementation was primarily for nursing homes not hostels, as nursing homes were presumed to have a higher need as these facilities cared for a higher proportion of high-level care residents. Therefore, it is important to investigate any flow on effect to hostel settings who are increasingly caring for more high-level care residents with chronic and complex conditions.
2.1.3.2 Understanding the Needs of Residents

A review of the literature highlights that two differing goals exist regarding the purpose of RACFs. Traditionally, the primary aim of health care for residents in RACFs has been restorative care (Hodgson & Lehning, 2008). Abbey and colleagues (2006) suggest this traditional ‘caring’ goal may promote perseverance with previous practices, such as getting people out of bed even when they are too weak to do so, or continuing with assisted feeding when food is unable to be tolerated. While the primary aim of rehabilitation is restoration of function (Nocon & Baldwin, 1998), modifying such practices and gaining an understanding of the value and appropriateness of a palliative approach where the focus is on relief of suffering and comfort, requires educational and cultural change.

Edward and colleagues (2003) observed interactions between aged care staff and high-level care residents in a 78-bed residential aged care facility in Brisbane, Australia, and found communication between staff and residents in aged care facilities to be infrequent, of short duration and oriented to physical care (Edward, Gaskill, Sanders, Forster, Morrison, Fleming, McClure & Chapman, 2003). While this study was small, only twenty residents and/or their next of kin and 68 aged care staff participated, the authors concluded that residential aged care practice continues to be focused on technology and tasks. The low level of interaction between aged care staff and residents raises serious questions, not only about the effectiveness of the processes of care, but also about the quality of the care and the level of resident participation in future care planning.

Murtagh and colleagues (2004) suggest that with any advancing disease, the focus of care requires a gradual change in perspective from disease-centred to person-centred, focusing on quality of life. A discourse analysis of aged care and palliative care policy documents by O’Connor and Pearson (2004) revealed competing discourses about care of the dying in residential aged care. They also argue for the need to shift the focus of care away from maintenance of independence to palliation and management of accompanying symptoms in the final stages of life, and suggest that the term ‘dying in place’ (p. 35) be appended to the Australian Government’s Ageing in Place policy.
The different focus of care between the dying resident and other residents involves a shift from the promotion of independence and a rehabilitation framework to promoting quality and comfort in the life remaining. Implementing a palliative approach in RACFs requires aged care staff not only to readjust the focus of care but may also require skills and knowledge in order to address specific end-of-life issues.

2.1.3.3 Recognising the Transition to End of Life

One of the challenges to providing a palliative approach and optimising end-of-life care is not only identifying when to introduce a palliative approach, but the degree to which all those involved recognise that a transition is occurring. Failure to recognise that transition phase in RACFs can cause conflict between the resident, care team, and/or family when the resident is expected to improve but continues to decline. When dying is not recognised, care planning remains focused on the maintenance of physical and cognitive function (Gillick, Bern-Klug & Gessert, 1999).

Much of the research that has investigated the ability of aged care staff to recognise the transitioning towards the final stages of life has been conduced outside Australia. For example, a qualitative study by Porock and Parker Oliver (2007) described the cues used by five certified nursing assistants, four licensed practice nurses and five registered nurses to recognise the dying process in two long-term care facilities in the USA. The authors describe five major themes described by participants as ‘ambiguous cues’, ‘decision codes’, ‘ready-to-go codes’, ‘withdrawal and saying goodbye’ and having ‘the look about them’. The ‘ambiguous cues’ related to an increasing awareness by staff that the resident’s condition was deteriorating when an event occurred (either physical [a fall] or psychological [family event]) that caused the resident to question the continuation of treatments or procedures. The ‘decision codes’ referred to a definite decision made by the resident where there was a marked change from the resident questioning to actual preparation for dying, such as refusing fluids, refusing medications. The third group of cues called ‘ready to go’ reflected the growing awareness in staff that the resident is making preparations for death such as verbalizing that they are ready to die. The fourth group of cues indicated a higher level
of awareness of recognition that death was coming as the resident ‘withdraws and says goodbye’ to family and staff around them. The final group of cues, ‘the look about them’, is where staff noted signs of imminent death, such as becoming pale, cyanosed, and breathing changes.

Interestingly, the authors observed that despite recognising the cues of dying early in the process, this group of aged care staff tended not to act on them because of a taboo about talking about death (Porock & Parker Oliver, 2007). However, as the cues became more obvious, the strength of the taboo was gradually weakened and when the resident finally had ‘the look about them’, the cues for dying could no longer be ignored and the taboo was broken. Staff then actively sought to talk about the impending death among themselves and other residents. Only once the taboo was broken, then the staff actions surrounding the comfort and dignity of the resident occurred. In the final stage of the dying process, only a few participants thought to mention hospice involvement. This finding confirms the perception that hospice care is connected with imminent dying rather than palliative care and preparation for death. This study highlights the risk that the benefits of palliative care are overlooked and that referral occurs later than would be beneficial.

Wadensten, Conden, Wahlund and Murray (2007) conducted a qualitative study among 25 nursing staff in five nursing homes in Sweden to explore how staff dealt with residents who talked about death. The findings illustrate the variation in how nursing staff respond in this situation. Some staff facilitated talk about death by listening to the resident, making comments and asking more questions with the intention of helping the resident verbalise their thoughts regarding death. Other staff tried to avoid talking about death with the resident by changing the topic or trying to cheer the resident up in the belief that their actions of avoidance would prevent depression among residents. These authors suggest that the variation in the ability of nursing staff to facilitate talk about death may be related to the nurse’s maturity, experience and knowledge. The most common reason why staff in Wadensten and colleagues’ this study responded the way they did was because they were unsure of, or did not know how to, commence discussions about death.
The provision of a palliative approach involves staff members being available to discuss issues with the individual and family members, providing information in a proactive way, and a sense of partnership with people and their families (Cooper & Glaetzer, 2004). While these studies focused on the ability of aged care staff to recognise residents who may be transitioning towards the final stages of life in residential facilities, clearly, staff had difficulty or lack of confidence to engage in discussions about death. This raises the question as to how personal care assistants in hostel settings would address this situation.

2.1.3.4 Providing an Appropriate Environment for Residents Requiring Palliative Care until End of Life Care

Environmental factors and aged care policies have influenced the differing foci of care in aged care facilities. In accordance with long-standing Australian Government policy, aged care facilities are required to present an ambience that emphasises the ‘home-like’ environment, rather than a clinical one (O’Connor & Pearson, 2004). This means that ‘although the provision of high quality nursing care is essential, a nursing home is not a hospital…’ (Australian Commonwealth Working Party on Nursing Home Standards, 1987, quoted in O’Connor & Pearson, 2004, p. 34). However, this emphasis on providing a sense of homeliness implies that the requirement for nursing and medical care is minimal. Residents who live in these settings are often dependent and frail, and the majority require high-level care (75% in 2010) (AIHW, 2010b). As early as 1998, authors argued that the change in name of a nursing home to a ‘residential aged care facility’ under the Aged Care Act 1997 (Commonwealth of Australia, 1997) implies that people are not sick and downgrades levels of dependency to suggest that perhaps nursing care is not required (Mannix, 1998). Wilson and Daley (1998) describe the social context of nursing homes compared to the acute health sector, where in the former there is ‘limited physician involvement, more deaths from chronic and prolonged illnesses, limited family involvement, and, often, less opportunity for the resident to communicate their needs and preferences’ (p. 22).

A study by Kayser-Jones, Schell, Lyons, Kris, Chan and Beard (2003) investigating the physical environment and organisational factors that influenced the care of
terminally ill residents in three nursing homes in the USA by observing and interviewing residents, families, nursing staff and physicians found that the physical environment was not conducive to optimal end-of-life care. These authors point out the rooms were small and crowded with multiple beds and little privacy.

While accommodating residents in multi-bed rooms in nursing home facilities has been common practice in Australia, this situation is changing. In 1998 the Australian Aged Care Standard required facilities to work towards single-room accommodation for all residents, a requirement that is still evolving (Australian Commonwealth Department of Health and Aged Care, 1998) as it requires structured change at the same time as meeting the increasing needs for places. However, Komarony (2000) argues that while privacy for the dying person and their family is needed, the routine of removing a dying person to a single room contributes to a culture of denial of dying.

While age care policy has focused on providing a ‘home-like’ environment within RACFs, it is important to investigate how this foci impacts on aged care staffs’ provision of care, particularly when high numbers of residents die within these facilities.

2.2 Background to Australian Aged Care Policies

2.2.1 Aged Care Act 1997

Prior to the 1970’s, aged care in Australia was mainly unregulated, with few controls and little planning. In 1975, the report by the Australian Government Social Welfare Commission on Care of the Aged found that Australia’s aged care system was unsuccessful in meeting people’s needs and financially inefficient (Australian Government Social Welfare Commission, 1975). In response to this report and in recognition of the ageing of the population and the need to provide adequate funding
and services for older people entering the 21st century, a process of reform was initiated through the development of the 1997 Aged Care Act. The major changes resulting from this reform included the introduction of fees for residents, better integration of the nursing home and hostel sectors, an accreditation framework focusing on continuous quality improvement and linked to the provision of funding, and improved access to respite care services (Gray, 2001b).

The aim of these reforms was to shift the balance of care from institutional to community-based care, to improve the quality of aged care, to enhance access to the appropriate level of care, and to promote sustainable economic management of the industry (Gibson & Means, 2000, Howe, 2000). Consequently, these structural reforms saw the introduction of the Ageing in Place policy.

### 2.2.2 Ageing-in-Place Policy

The Ageing in Place policy is aimed at allowing low-level care residents to remain in the same facility as their dependency needs increase, thus avoiding the need to negotiate a move to a new service and having to adjust to this new service, new staff and new co-residents (Howe, 2000; Gray & Heinsch, 2009). Ageing-in-Place has advantages for service providers as they can claim a higher Government reimbursement for residents with high-care needs. The initial funding model developed to coincide with the Ageing-in-Place policy was the Residential Classification System (RCS) whereby residents receive funding regardless of where they are (nursing home or hostel). Consequently, although the staffing levels and skill mix differ significantly between these facilities, it is no longer technically necessary for residents who are in hostel care to move to a nursing home when they become more dependent (De Bellis & Parker, 1999). The capacity of individual facilities to accommodate ageing in place is variable and depends largely on the physical environment and their staffing capability (Australian DoHA, 2004b). The challenges for service providers include; changing staffing mix and night staff requirements that incur consequential cost increases; certification costs and possible building
upgrades/redevelopment costs; and fluctuating subsidies and accommodation fees due to changing resident profiles (ibid).

Anecdotally, not all ‘hostels’ have implemented the ageing-in-place policy and many still transfer residents to a ‘nursing home’ when they require higher-level care needs. Gray and Heinsch’s (2009) review of aged care policy in Australia highlights the variability across RACFs in relation to whether or not the ageing-in-place policy is implemented.

2.2.3 Impact of the Ageing-in-Place Policy

As previously mentioned, there has been a significant increase in the proportion of RACF residents classified as requiring high-level care and a drop in the number of those requiring low-level care (AIHW, 2010b). This decline in low-level care requirements in aged care facilities is a direct result of the Ageing-in-Place policy being extended to the community setting with the emphasis on providing services to support older Australians in their preferred place of care (home), and reducing the potential or inappropriate need for admission to residential care (Gray & Heinsch, 2009). It is also more economically viable for governments to have people live in their own homes rather than in RACFs (Bruen, 2005). Currently several government-funded programs provide assistance to older people at home who would be eligible for residential care, such as the Extended Aged Care at Home (EACH) and the Extended Aged Care at Home Dementia (EACH D) programmes, designed to provide high-level care to people with behavioural problems associated with dementia (Gray & Heinsch, 2009). Clearly, receiving care at home rather than moving to residential care is preferable, and these care packages are not inexpensive, with costs averaging $85 per day (Kendig & Duckett, 2001). However, the success of these programs is dependent on informal family carers’ willingness and capacity to also provide care. Many informal family carers are often themselves older and not be able to manage the complex care needs of another person. Globally, families in general have also become smaller, more dispersed and varied and affected by increased migration, divorce and external pressures (WHO, 2004).
Family members who are potentially carers and are in reasonable health frequently remain in the workforce longer than in the past due to financial constraints. This may result in the frail older person requiring residential aged care placement (Kristjanson et al., 2003, ABS, 2009). In 2008, the Australian DoHA reported that about one in 13 people over the age of 70 years left their home to seek care in a residential care facility. Thus, one of the outcomes of ‘ageing in place’ in the community setting has been an increase in numbers of older people requiring higher-level care on entry to a residential care facility (AIHW, 2009).

The Australian Government has recognised that some degree of funded support for informal carers is necessary to help retain these people in their caring roles (DoHA, 1997). Subsequently, a range of care support measures has been introduced including financial support, subsidised respite care, help lines, counselling services and increased support for state and national carer associations (Bruen, 2005). For example, the National Respite for Carers Program provides carer information, education and support through varies respite programs (Australian DoHA, 2010). This enables carers of older people to take a break to look after their own health and wellbeing, with the comfort of knowing that their dependants are well looked after. The program also includes the National Carer Counselling Program which can provide the carer with specialised professional counselling. The Commonwealth Carer Respite Centres can organise either short-term or emergency respite services so carers can take a break. This can take place in the home or in a facility.

In theory, the Ageing in Place policy allows residents in RACFs to remain in the same facility as their needs increase or as they transition towards the end of their life. Given the elective nature of this policy, it is important to investigate whether this occurs in hostel settings where skill mix differs significantly to that in nursing homes, and, if not, to identify any constraints that may impede this.
2.2.4 The Aged Care Funding Model

The Age Care Act 1997 introduced major changes to the funding system within hostels and nursing homes in Australia. Formerly two separate instruments were used for assessing resident dependency, the Resident Classification Instrument used in nursing homes and the Personal Care Assessment Instrument used in hostels. In 1997, a single RCS was introduced for all aged care needs assessment. The main rationale for a single RCS was to address the discrepancy in funding for residents with similar dependencies in the two settings (Andrews-Hall, Howe & Robinson, 2007).

The RCS is an eight-category classification system that relies on assessing resident needs according to 20 areas (RCS questions) and resident needs are rated for each of these areas (from A to D). The 20 assessment questions includes items such as; the residents behaviour, social needs, technical and complex nursing issues, abilities in communication and activities of daily living (i.e. grooming, mobility, personal hygiene, toileting) (Australian DoHA, 2003). The level of Australian Government care subsidy is based on the level of care need indicated by each RCS category. There are four high-level categories (one to four), category one being the highest rating where a resident would score 81/100 or higher, and four low-level categories (five to eight) (Australian DoHA, 2003). No basic subsidy is paid for residents in RCS category eight (the lowest level category).

Entry into a residential facility requires assessment by the Aged Care Assessment Team (ACAT) (ibid). Once admitted to a residential aged care facility, an assessment of the resident is undertaken to assess care needs and this assessment is the basis for submitting an RCS claim for Commonwealth subsidy. Once subsidies are approved, a series of administrative and operational requirements must be met by the facility. RCS classification is reviewed by the Commonwealth both generally through monitoring of the distribution of RCS categories across all facilities and through random and targeted reviews of individual RCS claims (ibid).

In March 2008, the RCS funding system was superseded by the Aged Care Funding Instrument (ACFI). The ACFI is different from the previous RCS tool in that it
focuses on assessed care needs related to the resident’s day-to-day care requirements rather than the overall care provided. It attempts to separate and measure only those care elements that significantly contribute to the cost of care (AIHW, 2009) within three categories or ‘domains’: activities of daily living; behaviour supplement and complex health care supplement. Funding is allocated according to the assessment of 12 domains, in which there are four sub-questions per category, rated A, B, C or D. Each of the domains has three funded levels - low, medium and high. A high score in any one of the three domains will categorise the resident as requiring high-level. While palliative care, pain management and medication needs fall under the domain of complex health care, they do not necessarily elevate the level of care for the resident. To elevate a resident requiring palliative care to high-level care, two domains with medium scores (such as complex care and activities of daily living) are required. There are also two diagnostic questions, one mental and behavioural and one medical. These aim to assess for various cancers and chronic illnesses.

Not only does the Australian Government fund aged care facilities in the form of subsidies paid to the providers but individuals requiring such care are charged fees in the form of daily care fees and accommodation payments (Australian DoHA, 2010). The amount of fees charged is dependent on the person’s income and assets, and their required level of care. All residents are charged a daily fee. In addition, residents entering a RACF requiring high-level care may be required to pay an accommodation charge if the person’s assets exceed the amount set out by the Australian Government. Low-level care residents are required to pay an accommodation bond. Some RACFs offer ‘extra services’ in the form of a higher standard of accommodation and a wider selection of food and services. Low-level care residents accessing these services pay an additional daily fee and accommodation bond (ibid).

Accommodation bonds or payments were set up to provide aged care facilities with a funding stream to upgrade and maintain building standards and improve aged care services provided (Australian DoHA, 2000). While there is evidence that there has been a substantial increase in the number of employees in hostels between 1996 to 2001, primarily this has been personal care assistant’s (Australian DoHA, 2004). This has resulted in a reduced staff skill mix that impacts on the ability to meet the complex
care needs of residents (O’Connor & Pearson, 2004). Predominately, personal care assistants, who are supervised by a small number of nurses (registered, endorsed enrolled nurses and/or enrolled nurses) and who receive lower remuneration, provide the majority of personal care to hostel residents (Access Economic, 2009; Australian Nursing Federation, 2009). Interestingly, the Aged Care Act 1997 removed the legislative and regulatory requirement for residential facilities to provide 24-hour care by registered nurses (RNs), an obligation previously upheld by the National Health Act 1953 (Cooper & Mitchell, 2006).

Whilst these age care reforms seek to appropriately distribute resources within nursing homes and hostels and provide more choice to residents, the reality is that a higher proportion of older people with complex needs now reside in hostel facilities (Gray, 2001a; Richardson & Bartlett, 2009). Ageing-in-place, according to Gray (1999, p. 5), is ‘...changing the character of them [hostels] to that akin to nursing homes...’, because of the increasing need to provide higher level care to residents in these settings. A key concern for residents who ‘age in place’ and remain in a hostel for end-of-life care is the quality of care they can hope to receive given the related workforce issues (Gray, 2001b; Pfefferle & Weinberg, 2008; Access Economics, 2009).

Changes to the aged care funding model, which began in 1997, and has continued, to address the discrepancies of resident dependency levels between hostels and nursing homes. However, what is not clear is the number of high-level care residents now residing in hostel settings.

2.2.5 Aged Care Accreditation Standards

As part of the Aged Care Act 1997, an accreditation system was introduced that linked aged care funding and the renewal of RACF operating licenses to the achievements of certain standards. The standards set benchmarks which, when met, purport to demonstrate the provision of quality care and services for residents. The system of accreditation relies on each facility demonstrating that care has been delivered in accordance with a comprehensive set of outcome standards, and that the facility has the capacity to improve their care delivery. If these standards are not met, then the
facility’s license can be revoked and they may lose their funding (Aged Care Accreditation Standards Agency, 2009b). There are four standards measured according to 44 outcomes. The standards cover such things as management systems, staffing and organisational development, health and personal care, lifestyle, quality and safety issues. Within Standard Two, ‘Health and Personal Care’, there are 17 expected outcomes that need to be met; in particular, there are two standards that relate to the needs of residents who require palliative care (Aged Care Accreditation Standards Agency, 2009a). These include A ‘Pain Management’ standard (Outcome 2.8) such that all residents are as free as possible from pain, and A ‘Palliative Care’ standard (Outcome 2.9), whereby the comfort and dignity of terminally ill residents is maintained (ibid).

The aged care accreditation standards set out to improve the quality of care and services for residents in RACFs. As reported earlier, there are increasing numbers of residents who die in RACFs (88%, AIHW, 2010b) therefore requiring end of life care, however, there are only two related palliative care outcomes that are measured. While these outcomes are very broad and the outcome evaluations are unclear, exploring the residents’ perceptions of their care and measuring any symptoms they may have will highlight any deficits.

2.3 Background to Australian Palliative Care Policies

The aim of national policy for palliative care in Australia is to improve the access to, and quality of, palliative care for all Australians. The framework for this policy was developed by the peak national body, Palliative Care Australia, which incorporates palliative care associations from the eight states and territories and the Australian and New Zealand Society of Palliative Medicine, and provides advice and direction to the Government. The framework is set out in three major policy documents: i) Standards for Providing Quality Palliative Care for All Australians - 4th Edition (Palliative Care Australia, 2005a) which represents a whole-of-sector approach to ensuring high quality, needs-based care at the end of life and outlines the relationship between
primary care providers and specialist palliative care services; ii) *Palliative Care Service Provision in Australia: A Planning Guide - 2nd Edition* (Palliative Care Australia, 2003) which provides guidance on palliative care service delivery with the aim of improving patient and carer outcomes; and iii) *The Guide to Palliative Care Service Development: A Population-based Approach* (Palliative Care Australia, 2005b) which provides the context within which the Standards and the Service Provision Guide can be interpreted and applied, and which proposes a needs-based approach to palliative care to be used by primary health care services.

In addition, the National Palliative Care Program has four broad areas to help achieve the aims of the national policy. These areas include financial support – offered to patients, families and carers in the community; increased access to palliative care medicines in the community; education, training and support for the workforce; and research and quality improvement for palliative care services.

Initiatives within the education and training workforce program that relate to assisting aged care providers include: the *Program of Experience in the Palliative Approach* (PEPA) (discussed in detailed in section 2.4.3 of this chapter) and the *Guidelines for a Palliative Approach in Residential Care* (DoHA, 2004a).

In addition, the Palliative Care Curriculum for Undergraduates (PCC4U) Project (n.d) aims to promote inclusion of palliative care content as an integral part of all medical, nursing and allied health undergraduate educational training. Initiatives within the research and quality improvement for palliative care services program that relate to assisting aged care providers include CareSearch, a palliative care knowledge network which provides access to evidence-based information, and practical resources available on the Internet (CareSearch, last updated 2011).

Policy changes within Australian sub-acute, in-patient, palliative care units have affected the aged care sector (Aranda, O’Connor & Milne, 1998). In targeting shorter length of stay as a clinical indicator of performance, sub-acute, in-patient services have tightened the entry criteria for symptom management and end-of-life care (ibid). The consequence of shortening stays in these care units has been a flow-on effect to RACFs, because older people with vague or lengthy prognoses are being increasingly
transferred to aged care facilities (Enes, Lucas, Aberdein & Lucioni, 2004; O’Connor & Pearson, 2004).

In the acute hospital setting, there has also been increased pressure to discharge older patients from such expensive care to the more economical alternative in RACFs (Cooper & Glaetzer, 2004). However, the increasing number of patients diagnosed with chronic illnesses with slower dying trajectories has impacted on the availability of aged care beds, frequently preventing acute hospitals from transferring stabilised patients to RACFs (Travers, McDonnell, Broe, Anderson, Karmel & Gray, 2008). The aged care funding changes and Government emphasis on following the Ageing-in-Place Policy within residential aged care facilities allow for residents to return to or be admitted to, a hostel should they require high-level care, although variations exist within facilities (Gray & Heinsch, 2009). Travers and colleagues (2008) suggest that for residents of hostels where high level-care cannot be provided, who now require a nursing home bed, hospitals have effectively become the safety net to accommodate them while they are waiting for a bed to become available. In Australia, a specified national target ratio is used to determine the geographic distribution and types of aged care places to be made available. The Australian Institute of Health and Welfare 2010 report, reveals that the current Commonwealth Government’s 2011 target is 88 operational residential aged care places for every 1,000 people aged 70 years or older (AIHW, 2010b), compared to 87.7 operational residential aged care places in 2008 (AIHW, 2009). This small increase in the availability of places in RACFs may be set too low to keep pace with the increase in need.

While it is evident that national palliative care policies and initiatives have supported the extension of palliative care within RACFs, changes to policies within the acute and sub-acute hospital sector have negatively impacted on residents who are likely to be returned to or enter RACFs with unstable conditions, needing close monitoring. Therefore, it is important to explore how aged care staff manage high-level care residents with complex medical conditions in the hostel setting.
2.4    **Improving Standards of Palliative Care**

It is well recognised both in Australia and internationally that there is a need to improve standards of palliative care to promote better equity and choice with respect to end-of-life care in a range of settings including residential aged care facilities (Higginson, 2005; Krisjantson, Watson & Toye, 2005; Palliative Care Australia, 2010a). There have been a number of initiatives to address this. Within this literature review, four areas were the focus of analysis due to likely impact on RACFs. These were: i) advance care planning, ii) tools to assist in identifying individuals who may benefit from palliative care input, iii) capacity building opportunities such as the Australian National Program of Experience in the Palliative Approach (PEPA), and iv) establishing clinical champions such as the link nurse.

2.4.1    **Advance Care Plans**

There is a growing agreement that patients should have greater opportunity to plan their future care, through a process known as advance care planning (New South Wales Department of Health (NSW DoH), 2004; Thompson & Parker Oliver, 2008; Froggatt, Vaughan, Bernard & Wild, 2009). Advance care planning is an on-going process, giving patients the opportunity to consider, discuss and plan end-of-life care; it often includes documentation called ‘advance care directives’ (NSW DoH, 2004). These directives, alternatively termed ‘advance directives’, ‘advance health directives’ or ‘living wills’, may be defined as a set of documents containing instructions that consent to, or refuse, specified medical treatments, and which articulate care and lifestyle preferences in anticipating future events or scenarios. Providing the individual with the opportunity to discuss their wishes and choices for future care is an integral part of a palliative approach, and stipulation of the patient’s preferred conditions for care provides a mechanism for limiting unnecessary and/or unwanted hospitalisations, care or interventions.

Most states in Australia have some form of advance directive legislation to record an individual’s wishes regarding end-of-life care and to appoint an agent to make decisions on their behalf if the resident is no longer competent to do so. However,
there is a lack of consistency in the legislation across Australian states. In 2004, the New South Wales Department of Health formed a working party to develop a guide for *Using Advance Care Directives* (NSW DoH, 2004). The guide aims to assist health professionals in discussing advance care planning with patients in all clinical settings, and to clarify how to use an advance care directive as part of that process (ibid).

A number of research studies have identified that advance care plans in a variety of settings are currently poorly understood by the general public, and that implementation can be ad hoc and adherence is not guaranteed (Barnes, Jones, Tookman & King, 2007; Bergman-Evans, Kuhnel, McNitt & Myers, 2008; Tung & North, 2009; Clements, 2009). The Aged Care Accreditation Standard 2.9 ‘Palliative Care’ states that ‘...the comfort and dignity of terminally ill residents is maintained’ (Aged Care Accreditation Standards Agency, 2009a). However, it is not specified how an aged care provider would meet this standard. The impact of this lack of clarity in RACFs is unknown as no one has investigated this to date.

Nair, Kerridgey, Dobson, McPhee and Saul (2000) examined the formal or informal process of advance care planning and the prevalence of advance directives in 88 RACFs in New South Wales. Their findings revealed low levels of formal advance directives with only 1.1% of residents recording ‘no-cardio-pulmonary-resuscitation’ orders in the medical record. In addition, only 5.6% of residents had appointed a formal guardian, and 2.8% had an enduring guardian. Informal processes of advance planning were much more prevalent. Sixty-five per cent of residents had a ‘person responsible’ recorded to make decisions for them if they were unable to make their own decisions, while in 13% of cases, there was ‘staff consensus’ as to the optimal care for the resident. This ambiguous situation has led to the development of the NSW Advance Care Directive guide noted above.

Brown and colleagues (2005) examined the provision of palliative care for residents with a non-cancer diagnosis, including the use of advance directives and advance care planning as part of palliative care policies, in residential aged care facilities (both nursing homes and hostels) in South Australia (Brown, Grbich, Maddocks, Parker,
Almost three-quarters of the aged care facilities surveyed had a policy on palliative care, but there was little consistency in the process of advance care planning or advance care directives. Although most facilities had developed a form to record residents’ wishes, there was no consistency in the content, the terminology, or the information provided.

The Respecting Patient Choices (RPC) Program is one of the Australian Education, Training and Support for the Workforce initiatives funded by the Australian DoHA. The Program is based on the Respecting Choices® program developed by the Gundersen Lutheran Medical Foundation (GLMF) in Wisconsin, USA. There are five aims of RPC: (i) to initiate conversations with adults regarding views about future medical care, (ii) to assist individuals with advance care planning, (iii) to make sure plans are clear, (iv) to ensure plans are available, and (v) to appropriately follow plans. A modified version of the American Respecting Choices Program, Respecting Patient Choices (RPC) Program was introduced as pilot program in 2002 at the Austin Hospital, Melbourne (Respecting Patient Choices Program, last updated 2010). The Australian DoHA has since purchased the rights of RPC. The program has been extended to a number of health services and communities in Victoria and New South Wales and has also been implemented at one lead hospital in each state and territory (ibid). The expansion been funded by the Australian Government DoHA, and the Victorian Government Department of Human Service (ibid).

Adams, Kirsner and Silvester (2007) assessed the impact of the RPC program in 17 RACFs (including both nursing homes and hostels) in northeast Melbourne. Aged care staff were trained to facilitate discussions with regard to patients’ goals and values and their wishes regarding future care, and were provided with education on how to complete documentation of Advance Care Plans. The delivery of ‘good’ end-of-life care for the 1108 residents exposed to RPC in these 17 RACFs was significantly increased. For those not exposed to advance care planning there was a higher likelihood of being transferred to hospital to die. The findings showed that, for many residents and families, advance care planning resulted in peace of mind and fewer decisions being made under stressful situations. It also improved the facility staff perceptions of delivery of quality care.
An Australian randomised control trial conducted by Detering, Hancock and Silvester (2010) investigated the impact of using the RPC program among hospitalised older people (80 years or more) in Melbourne, Australia. The results showed that advance care planning carried out properly by trained non-medical staff improves end of life care by enabling patients’ wishes to be understood, documented, and respected at end of life, and in 92% of cases where wishes were known, these were respected.

In the US, there is legislative support for advance directives, yet studies show the majority of competent and incompetent residents lack a clear process for decision-making (Forbes, Bern-Klug & Gessert, 2000; Evers, Purohit, Perl, Khan & Martin, 2002). A quantitative semi-structured audit conducted in the US by Evers and colleagues (2002) examined the frequency of palliative and aggressive treatments delivered during the previous six months of patients’ lives, including those living with and without dementia. They found that the use of systemic antibiotics was prevalent in treatment of chest infections for patients with end-stage dementia (53%). The authors suggest that this high prevalence of systemic antibiotic treatment is due in part to the lack of advance directives, to the inadequate training of physicians in discussing end-of-life decisions, and to prognostic uncertainty about the trajectory of the disease.

Similar findings have been identified in other international studies. Canadian research conducted on the last 48 hours of life of residents in long-term care facilities found that advance directives had not been recorded in 67% of residents’ progress notes (Hall et al., 2002). A survey conducted by Froggatt and Payne (2006) examining end-of-life care in 78 UK care homes found that, out of a total of 2624 residents, only 2.3% (61) were known by the manager to hold an advance directive.

While several studies have demonstrated the effectiveness of advance care planning (Winzelberg, Hanson & Tulsky, 2005; Levy, Morris & Kramer, 2008; Detering, Hancock & Silvester, 2010) broader application and implementation is required to improve awareness and knowledge among treating practitioners to support the development of advance care plans. It has been argued that better coordination across and among service providers to support the effective implementation of advance care
plans and enhanced community understanding of advance care plans are also needed (Palliative Care Australia, 2010a). As recommended in the Australian National Health and Hospitals Reform Commission (NHHRC) report (2009), advance care planning needs to be funded and implemented nationally, commencing with all residential aged care services.

Care pathways for the dying have been developed as a model to improve the end-of-life care of all patients. These pathways relate to the final stages of life, typically one – five days. One of the most renowned, the Liverpool Care Pathway (LCP) developed by Ellershaw and Wilkinson (2003), is currently used in a variety of settings in the UK and, Australia. It aims to bring together all predictable aspects of end of life care and to provide supporting documentation on assessment, symptom control, ongoing care and care after death (Mellor, Foley, Connolly, Mercier, & Spanswick, 2004). The introduction of these pathways in the Australian health system and aged care facilities has been erratic and irregular. This pathway has also been the subject of recent critique in the UK (Treloar, 2008), but despite this criticism, the pathway remains in widespread use in the UK and, to a lesser extent in Australia.

2.4.2 Identifying Individuals Who May Benefit from Palliative Care

Palliative care has relied in part on prognosis- or diagnosis-based models to guide health professionals regarding the appropriate timing of when to implement palliative care, and there are a number of tools that have been developed to assist in this process. The Gold Standards Framework (GSF), originally developed by Thomas in 2000, is one of several documents that have been developed to assist health professionals to identify patients who might benefit from palliative care (King, Thomas, Martin, Bell & Farrell, 2005).

The aim of the GSF is to improve the organisation and quality of care in the community for patients in the last year of life. The GSF seeks to facilitate consistent, high-quality palliative care through a set of guidelines, mechanisms and assessment tools. Although the initial intention was for the framework to be used with patients identified with a diagnosis of cancer, it is now used for patients with any life-
threatening condition. The GSF has been developed and expanded over the last nine years to meet the challenges of end-of-life care in a variety of settings. In 2006, the Prognostic Indicator Guidance paper was developed to be used in conjunction with GSF to help support and assist primary health care teams to identify appropriate patients (particularly patients with non-cancer diagnosis) in need of palliative care by way of useful prompts or triggers (The National Gold Standards Framework Centre, 2008). Despite the growing acceptance of the GSF and endorsement by the UK National Health System End of Life Care Strategy, there is limited evidence of the implementation of the GFS in the Australian health system.

The American National Hospice Organization (NHO, 1996) published guidelines for determining prognosis in selected non-cancer diseases to provide clinicians and policy makers with a framework for assessing which patients could be eligible for hospice services. A study by Grbich and colleagues (2005) adapted criteria from these NHO guidelines and other assessment tools in an attempt to identify criteria suitable for measuring the eligibility of patients with end-stage non-cancer diseases for palliative care services in Australian residential aged care facilities (Grbich, Maddocks, Parker, Brown, Willis, Piller, & Hofmeyer, 2005). The study, conducted on a sample of 23 rural and urban aged care facilities in South Australia, found the adapted NHO guidelines were a useful prognostic framework to assist in identifying patients with end-stage chronic conditions that would benefit from palliative care services.

However, the need to provide palliative care in a more accessible and equitable manner has led to Palliative Care Australia recommending a model of care that is based on the individual’s needs (Palliative Care Australia, 2005b). In 2006, the Palliative Care Needs Assessment Guidelines (Girgis, Johnson, Currow, Waller, Kristjanson, Mitchell, Yates, Neil, Kelly, Tattersall & Bowman, 2006) were developed in an attempt to fill a gap nationally and internationally. The Palliative Care Assessment Guidelines provide advice to those caring for people with cancer and their families, to ensure that they are offered the most appropriate care to meet their specific needs. To support the recommendations in the Guidelines, the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C) was developed by the same authors for use in both generalist and specialist settings to provide support in
matching the types and levels of need experienced by people with advanced cancer. In generalist settings (general practice), the NAT: PD-C can be used to determine which needs may be met in that setting and which needs are more complex and may be better managed by specialists (Waller, Girgis, Currow, Lecathelinais, 2008). In specialist settings (specialist palliative care services), the NAT: PD-C can assist in determining when complex needs have been met and act as a discharge planning tool; or identify the need for ongoing support (ibid).

The NAT: PD-C was originally developed for use among individuals with cancer. The same researchers have recently developed a version of this tool for use among individuals suffering from a range of other progressive diseases, such as heart failure and chronic obstructive pulmonary disease.

One of the challenges of providing a palliative approach in residential aged care settings is the variation of chronic diseases. While this tool has not been tested in RACFs there is the potential for this needs based assessment tool to be used in this setting.

2.4.3 Australian National Program of Experience in the Palliative Approach (PEPA)

The Australian Program of Experience in the Palliative Approach (PEPA) was established in 2004 to provide health practitioners with an opportunity to develop knowledge and skills in the palliative approach. The overall aim of the PEPA is to improve the quality, availability and access to palliative care for all people who are dying and their families. Funded by the Australian Government DoHA under the National Palliative Care Program, PEPA enables availability of supervised clinical placements to a wide range of health professionals including general practitioners, Aboriginal and Torres Strait Islander health workers, dieticians, registered and enrolled (Division 2) nurses, occupational therapist, physiotherapists, residential aged care workers and assistants in nursing, social workers, pharmacists, speech pathologists and specialist palliative care professionals.
The PEPA program is a learning experience and participants are placed with a host facility that can meet their individual learning needs. On-site education at the clinical placement may include seminars that focus on discipline specific issues and multidisciplinary aspects of care. Post placement there is a support program to enable health professionals who have undertaken supervised clinical placements to assimilate new palliative care skills and knowledge into work practices, and to develop support networks for future collaboration. While the PEPA does not lead to a formal qualification or recognition as a ‘specialist’ in palliative care, participating organisations such as the Royal Australian College of General Practitioners and the Australian College of Rural and Remote Medicine will award credit points towards continuing professional development (PEPA, Information and Application Kit, 2007). Through the National Palliative Care Program, the Department of Health and Ageing (DoHA) can reimburse some of the costs associated with backfilling staff and contribute towards travel and accommodation for rural site visits.

At the completion of the clinical placement, participants are required to submit a short report detailing their experience of participating in the supervised clinical placement and the impact it has had on their practice; to implement an activity relevant to their workplace/practice, within three months of completing the supervised clinical placement; and participate in post-placement support networks and/or activities. Details on any of these evaluations could not be found.

PEPA is seen as a prime opportunity for aged care staff to enhance their knowledge and skills and gain experience in a palliative care at supervised clinical placements. The 2007-2010 phase of the PEPA program has funding to support 1030 planned placements nationally. Since this phase of PEPA was initiated, a total of 450 placements have been completed and a further 2895 participants have attended 111 workshops (Palliative Care Australia, 2009b). The majority of placements have been taken up by nurses, but the data does not specify whether these were from the aged care sector. However, in 2011, PEPA placements have given priority to aged care workers to further support the increasing need in this sector.
2.4.4 Link Nurses as a Strategy for Guiding and Developing the Palliative Approach

Given the demographic trends of the aged care population for the foreseeable future, the need to provide aged care staff in residential care facilities with ongoing education and support in regard to palliative care is undeniable. Several researchers have documented the general and specific needs of such palliative care education (De Bellis & Parker, 1998; Raudonis, Kyba & Kinsey, 2002; Cartwright & Kayser-Jones, 2003; Won, Lapane, Vallow, Schein, Morris & Lipsitz, 2004; Stillman, Strumpf, Capezuti & Tuch, 2005; Hirakawa, Masuda, Kuzuya, Iguchi & Uemura, 2007; Phillips et al., 2007; Whittaker et al., 2007; Liao & Ackerman, 2008; Ronaldson, Hayes, Carey & Aggar, 2008). However, Eresk and Wilson (2003) suggest that while education initiatives are valuable, they may not be sufficient to change practice as ad hoc or infrequent training may not result in consistent improvement in care.

It has been suggested that the ‘link nurse’ model could provide a way to develop palliative care practices in nursing homes, but it is acknowledged that this approach requires further exploration (Maddocks & Parker, 2001). The term ‘link nurse’ is used by Froggatt and Hoult (2002) to identify a named individual in the aged care environment who is supported by other practitioners (for example, a clinical nurse specialist) and who can act as a local resource to disseminate information and learning within the setting. The value and effectiveness of link nurses has been recognised in many clinical specialties, such as infection control (Roberts & Casey, 2004), diabetes (Lake, 2003) and colorectal cancer (Perry-Woodford & Whayman, 2005). The aims of this role appear to be similar across all fields and include: improving clinical practice and facilitating change; dissemination of current and evidence-based knowledge; and networking and enabling improved communication between specialties (Jack, Gambles, Saltmarsh, Murphy, Hutchinson & Ellershaw, 2004; Heals, 2008).

The palliative care link nurse role in RACFs has been demonstrated to be successful in the UK. Heals (2008) reported on the development of a link-nurse program for registered nurses working in nursing homes in the South West of England. Two self-selected registered nurses from each of the 26 participating nursing homes attended
three study days held at a hospice. In addition to study days, the link nurses were provided with clinical placements in the hospice to bridge the theory-practice gap. They also received ongoing visits from hospice community nurse specialists who provided advice and support through informal teaching sessions. Evaluation of the program after 12 months suggested that link nurses found the program valuable; that link nurses’ increased their palliative care knowledge and skills, which gave them greater confidence in talking to general practitioners, families and residents; changes in documentation and care planning occurred; and networking with the hospice through CNS visits and use of the 24-hour advice line was considered an integral part of the program.

Hasson and colleagues (2008) explored 14 link nurses’ views and experiences regarding the development of the palliative care link nurse role in nursing homes in the UK (Hasson, Kernohan, Waldron, Whittaker and McLaughlin, 2008). While there was a consensus that the link nurse system can improve care for residents within nursing homes, several barriers were identified. These include a lack of managerial support for the initiative, and lack of understanding of link nurse’s role, such as the need to free such staff from the clinical setting, which impacts directly on the effectiveness of the link system itself. Further barriers identified included: that the link nurses experienced difficulties implementing education programs and acting as facilitators as they had limited skills in disseminating information, and teaching and lacked experience in supporting colleagues in the clinical setting. Confusion existed over role boundaries between registered nurses and care staff, particularly when teaching overseas staff, and in aged care there is a transient workforce. The link nurses in this UK study were registered nurses who volunteered to assume this role in addition to their normal allocated duties. Their performance of this role was thus based on goodwill.

There is limited evidence of the link nurse role in Australia. The only Australian research to examine the role of a link nurse was conducted in South Australia (Maddocks & Parker, 2001), where identified aged care ‘link nurses’ attended a 30-day training course which addressed issues relating to palliative care. The project evaluation demonstrated that link nurses valued their improved knowledge, skills, and
confidence in providing palliative care, however, no service impact evaluation was included in this study.

More commonly in Australia, formal ties are forged with established specialist palliative care services to oversee delivery of palliative care. One of the issues surrounding the development of linkages between RACFs and specialist palliative care services is staffing and funding. Aged care is funded through the Commonwealth while palliative care services are made available through state funding; there is no provision for ‘cross sharing’ of care in either budgets (O’Connor & Pearson, 2004). Currently within specialist palliative care services in Australia, staffing numbers are struggling to meet the demand of service provision (Grbic, Maddocks, Parker, Brown, Willis & Hofmeyer, 2005) and consequently, these services do not have the resources to take on residential aged care. It is working within this model that has led the researcher to undertake this doctoral study. Therefore, due to these funding issues, linkages and collaboration between aged care facilities and specialist palliative care services vary considerably.

It has been identified from the literature that while link nurses can be internal professionals with training in a particular care environment such as aged care, or external nurses from a specialist service such as palliative care, no sustainable Australian model for link nurses in palliative care in RACFs has been established; instead this remains a challenge for the future (Maddocks & Parker, 2001).

2. 5 Challenges to Implementing a Palliative Approach in RACFs

Prior to the development of the concept of a palliative approach in Australia, it was already clear there were challenges to the provision of palliative care within RACFs (Palliative Care Australia, 1999). In a discussion paper regarding the provision of palliative care in aged care facilities, Palliative Care Australia (1999) identified issues in relation to staffing skill mix, the burden of staff stress, the facility’s budget, the limited availability of expertise in low-care settings, the lack of resident choice of a
general practitioner and education of staff. More recent studies have found a lack of staff education and training, lack of skilled staff, lack of adequate time, work pressures, lack of support from medical colleagues and managers and failure to implement a timely end-of-life plan to be common challenges to providing a palliative approach in RACFs (Komaromy et al., 2000; Froggatt & Houl, 2002; Hanson et al., 2002; Clarke & Ross, 2006; Phillips, Davidson, Jackson, Kristjanson, Daly & Curran, 2006). These issues are discussed in more detail below. However, in reviewing the literature it became clear that there was little distinction made between palliative care and a palliative approach even though clear definitions exist and the Australian guidelines exist.

2.5.1 Educational Needs of Aged Care Staff

Numerous studies have highlighted the palliative care educational needs (the basis for providing a palliative approach) of aged care staff in RACFs to include: communication skills, pain and symptom management, psychosocial issues, and information about the philosophy and principles of palliative care, which underpin a palliative approach (De Bellis & Parker, 1998, Raudonis et al., 2002; Cartwright & Kayser-Jones, 2003; Won et al., 2004; Stillman et al., 2005; Phillips, Davidson, Jackson, Kristjanson, Bennett & Daly, 2006; Phillips et al., 2007; Whittaker et al., 2007; Hirakawa et al., 2007; Liao & Ackerman, 2008; Ronaldson et al., 2008). As noted earlier, there is varying skill mix between hostels and nursing home settings, however, much of the research fails to separate and differentiate between nursing homes and hostels.

A study conducted by Phillips and colleagues (2007) surveyed nine RACFs in regional Australia involving the varying skill mix of aged care staff (registered nurses, enrolled nurses and personal care assistants) to assess their views and attitudes towards palliative care and to identify their learning needs. Personal care assistants who had less educational preparation indicated greater uncertainty in understanding complex clinical-decision making (such as the use of artificial hydration), the rights of families to refuse treatment and as to what constitutes the best care for a resident who is dying.
In hostel settings, personal care assistants (PCAs) have the most contact with residents and are often the first to notice changes or a decline in a resident’s health condition. Since PCAs play a critical role at the bedside of seriously ill or dying residents, and can help make the difference between a good or poor dying experience for the resident and family, it is vital that this group be given education to ensure quality care at the end of life for older residents. However, education strategies need to be provided at an appropriate level, and will differ from the education offered to registered nurses or enrolled nurses (Raudonis et al., 2002; Partington, 2006; Phillips et al., 2007).

Ronaldson and colleagues (2008) investigated the palliative care knowledge among 36 RNs and 61 Assistants in Nursing (AINs) in five Australian nursing homes using the Palliative Care Quiz for Nursing (PCQN) tool. The PCQN questionnaire is divided into three conceptual categories, which include philosophy and principles of palliative care, psychosocial and spiritual care, and pain and symptom management (Ross, McDonald & McGuinnes, 2006). The total score possible for the questionnaire is 20. The mean score for RNs was 11.7 (SD 3.1) while for AINs it was 5.8 (SD 3.3). The authors attributed the significant difference between the mean score results for RNs and AINs (P = 0.000) to differences in palliative care education and differences in caring roles and levels of responsibilities. For both RNs and AINs, the greatest misconceptions were found in regard to the philosophy and principles of palliative care, followed by pain and symptom management, therefore identifying the need for future targeted education programs.

Until now, few education programs have targeted PCAs (Hurd, Joslin, Nakhnikan & Wilner, 2002; Raudonis et al., 2002). In the US, Braun and Zir (2005) developed the Appropriate Care of Residents in Nursing Homes (ACORN) project, an eight-hour, active learning curriculum structured to involve the care nurse assistants (CNAs) in discussion by using case studies and a facilitator who is listening. Findings indicated that among the 100 participants, of which 86% were paraprofessionals (82 CNAs and four activity aides), a significant improvement was achieved in relation to their knowledge of death and dying, their knowledge of grieving, their comfort providing at end of life, their perception of the facility’s management of pain, and their perception of the facility’s management of dying and death. The authors concluded that the use of
this active-learning, in-service curriculum represented an effective means of providing end-of-life care training to paraprofessional nursing home staff.

Pain is a well documented problem in older people (American Geriatrics Society, 2000). Several studies have identified the difficulty of assessing pain among older people in residential care facilities, particularly those with dementia (Zanocchi, Maero, Nicola, Martinelli, Luppino, Gonella, Gargiglio, Fissore, Bardelli, Obialero & Molaschi, 2008; Torvik, Kaasa, Kirkevold & Rustoen, 2009; van Herk, Boerlage, van Dijk, Baar, Tibboel & de Wit, 2009). Australian studies highlighting the issue of appropriate pain assessment and management have estimated that between 26% (McLean & Higginbotham, 2002) and 86% (Madjar & Higgins, 1997) of older residents living in RACFs experience unrelieved pain on a regular basis. However, Holloway and McConigley’s (2009) descriptive qualitative study noted that when there is continuity of staff and the ability to develop an understanding of the resident’s usual behaviours, residents are likely to receive appropriate pain management.

In response to the identified problem of pain for residents in RACFs, the Australian Pain Society (APS) developed a set of pain management strategies published as Pain in Residential Aged Care Facilities – Management Strategies to assist in providing care for residents (Australian Pain Society, 2005). These clinical practice guidelines were developed on the basis of an extensive literature review and expert opinion. The strategies address pain identification and assessment methods, pain management strategies using pharmacological and non-pharmacological treatments, and relevant health management strategies intended to guide clinical practice within the Australian residential aged care system (ibid). However, clinical practitioners often face difficulties when trying to translate guidelines into practice.

McConigley and colleagues attempted to translate the strategies into more clearly applicable practice guidelines, to identify barriers to guideline implementation and to develop a toolkit to enhance guideline uptake in Australian RACFs (McConigley, Toye, Goucke & Kristjanson, 2008). The most commonly stated concern in regard to implementing the guidelines was the heavy workload of RACF staff. As care assistants make up the bulk of the frontline workers, the identification of residents in pain is dependent on these workers noticing behaviour that suggest pain and reporting
these concerns to nursing staff. The most pressing need associated with the implementation of the pain guidelines was the need for more education about pain management for all carers in the aged care setting. In particular, participants suggested that face-to-face education sessions accompanying the roll-out of pain management strategies would be useful. While there was a time delay for the publication of McConigley and colleagues study, these findings contributed to the development of a resource ‘toolkit’, the Pain Management Guidelines (PMG) Kit for Aged Care in 2007 to accompany the pain management guidelines (Commonwealth of Australia, 2007).

Pain assessment and management appears to be a major issue in aged care facilities elsewhere too. Teno, Weitzen, Wetle and Mor (2001) identified significant rates of persistent severe pain among all 2.2 million residents in US nursing homes. A study by van Herk and colleagues (2009) explored several aspects of pain, pain intensity and pain treatment among 232 residents in Dutch nursing homes and reported 66% of residents experienced pain, 41% had intolerable pain, and approximately one-quarter of residents did not receive any pain medication. These studies indicate that pain assessment and management remains a huge issue in nursing homes. This is a major challenge as much of the work reported has been conducted in RACFs as a homogenous group or nursing homes and rarely is there a focus on hostel settings.

2.5.2 Staffing / Skill Mix

When providing a palliative approach and end-of-life care within the context of RACFs, it is important to examine the staffing numbers and skill mix of this workforce. Within Australian RACFs, nursing care is provided by RNs, EENs, ENs, AIN, PCAs and care service employees (CSEs) (a brief description can be found in the glossary section). The ‘skill mix’ of these staff delivering care to residents varies between nursing homes and hostels, which operate under different awards and staffing structures.

The nursing home sector utilizes a Nursing State Award and nursing structure which involves the employment of directors of nursing (DONs), RNs, ENs and AINs. The
cost associated with employing registered nursing staff represents a large proportion of the overall expenditure in nursing homes.

The hostel sector operates within the Charitable Sector Aged and Disability Care Service Award and has structures including managers, supervisors and PCAs or CSEs (Chandler, Madison & Han, 2005). An important distinction between AINs, PCAs and CSEs is that, unlike AINs, the latter two groups are permitted to assist with administering medications under the Charitable Sector Award (Commonwealth Department of Health and Aged Care, 2000). This dispenses with the need to employ the more expensive RNs to perform this task.

Data from the Australian National Institute of Labour Studies (2008) compared the RACF workforce between 2003 and 2007 and found a total workforce growth from 76,006 to 78,849 full-time equivalents (FTEs) (Martin & King, 2008). PCAs increased the most, from 57% to 64% of FTE; RNs fell from 21% to 17%; ENs fell from 14% to 12.5%; and the remainder (allied health workers) fell from 7.6% to 6.6%.

Unlike within acute hospitals, in several Australian states, there are no fixed registered nurses-to-patient staffing ratios that apply in Australian RACFs (Angus & Nay, 2003). In these facilities, management alone determines the staffing levels for the provision of nursing care for residents, based on the principle of a duty of care (Nursing and Midwifery Council of Australia, 2002) and on the demonstrated competencies of the nurses (Nursing and Midwifery Council of Australia, 2003).

Staffing in long-term aged care is a complex issue influenced by many factors. These include an international shortage of nurses, the perceived low status of aged care, lower levels of remuneration compared to the nurses working in the public/private health system and demanding work conditions (Gray, 2001b; Pfefferle & Weinberg, 2008; Access Economics, 2009). Chandler’s (2007) demographic review of managers of low-level care facilities in New South Wales found significant differences in earnings and qualifications between nurse managers and non-nurse managers. In the non-nurse manager group, the title of ‘chief executive officer’ or ‘administrator’ equated with a wage of above $50,000 per annum, while the title of ‘supervisor’ reflected the poorest earning potential with a wage of below $40,000. In contrast,
general managers, care managers, supervisors and directors of nursing in the nurse manager group all earned in the top wage bracket of $71,000 per annum or more. The qualifications held by the nurse manager and non-nurse manager groups differed. The maximum qualification held by the non-nurse group was a Certificate III or IV, most participants stating that they had no desire to study, whereas the nurse manager group possessed university qualifications of a bachelor’s or master’s degree (Chandler, 2007).

In March 2009, the Australian Nurses Federation launched the national aged care campaign, Because We Care. The campaign aims to boost recognition of highly skilled and dedicated nursing and care staff by ensuring they have the resources necessary to deliver the best possible care to older Australians (Campaign for Equality and Quality in Aged Care, 2009). The then Federal Minister for Ageing, Justine Elliott, stated:

*We desperately need nursing staff with the right mix of nursing skills and increased Federal Government funding, with greater accountability for that funding. The fact is, nurses working in aged care are paid significantly less than their counterparts in other sectors, on average $300 a week less, which is one of the reasons we’re having difficulty recruiting nursing staff to the industry (Elliott, 2009 quoted in Campaign for the Equality and Quality in Aged Care, p. 12)*.

Although the aged care workforce in Australia is characterised by considerable diversity in educational preparation and responsibilities (Phillips et al., 2007), it is generally care assistants supervised by a small number of nurses (registered, endorsed enrolled nurses and enrolled nurses) who provide the majority of personal care to residents (Australian Nursing Federation, 2009). It would appear that the political and structural reforms to aged care in Australia have shown little consideration of the effect this skill mix is having on the practice of nursing and retention of nursing staff in residential aged care.

Inadequate staffing levels and skill mix in aged care have also been reported in the international literature. A study in the US by Kayser-Jones and colleagues (2003)
investigating factors which influence the process of providing care to the terminally ill nursing home residents found that, in two facilities with a total of 312 beds, inadequate staffing and lack of supervision of certified nurse assistants were the most significant factors influencing care. Staffing within RACFs in the UK is similar to Australian facilities in that there is a small numbers of registered nurses and a higher proportion of support workers (Partington, 2006).

Partington (2006) raises concern over whether the large proportion of support workers, who have not undergone formal palliative care education and yet are expected to use care pathways and assess and document symptoms, can influence the care provided when there is no real understanding of the underlying theory or philosophy of care. Although there is limited Australian literature on the role of support workers within RACFs, several international studies have focused on support workers and how they interpret their role. Katz, Komaromy and Sidell (1999) found that support workers in care homes tended to see palliative care as wholly linked to symptom control and that viewing it as a technical activity could thus lead to a lack of emotional and spiritual input from the staff who provide the majority of care. A study by Cartwright and Kayser-Jones (2003) examining end-of-life care in assisted living facilities in the US identified that caregivers did not see doing assessments and documentation as part of their role, but clearly that of the registered nurses. Consequently, pain-rating scales were not used and documentation of changes to a resident’s functional status or other symptoms was infrequently completed by caregivers.

Increasing workloads among staff in age care facilities, leading to stress and feeling undervalued, has been identified in the literature, and this may affect retention of staff. Bowers and Becker (1992) explored the work of 30 nurse assistants in three nursing homes in the US. The study reported on the challenges faced by care assistants, highlighting the stress they experienced in performing the multiple tasks required in their role and the lack of supervision. Venturato, Kellett and Windsor (2007) explored 14 RNs experiences in nursing homes and hostel settings in Queensland, Australia, finding that increasing requirements of documentation for funding and accreditation purposes limited the RNs clinical involvement in resident care and led to the
delegation of clinical nursing tasks in order to be able fulfil managerial tasks. This ‘paper-based’ nursing made RNs feel devalued and caused them to question the value of professional nursing care for older people.

Interestingly, Pfefferle and Weinberg’s (2008) research in the US found that while certified nursing assistants (CNAs) in nursing homes felt devalued and perceived a lack of respect from management, and experienced emotional consequences from the physical and emotional demands of low-status work, they nevertheless found satisfaction with their work. This satisfaction was derived from the sense of self-worth afforded by caring for others, something they often expressed in spiritual terms such as ‘doing God’s work’, and that performing the repetitive daily tasks, such as bathing, dressing, toileting and feeding, fostered relationships that provided an important source of gratification.

2.5.3 Provision of Palliative Medication in RACFs

The provision of appropriate PRN (as required) Schedule Eight (drugs of addiction including restricted opioid medications) medication for residents who require palliative approach or end-of-life care in hostels has also been identified as an issue. Rohr, Schneider, Good and Sattler (2003) surveyed 39 hostels in the Hunter area of New South Wales, Australia, to investigate the availability of Schedule Eight medications required for pain management on a PRN basis for residents requiring palliative care. For residents capable of managing self-medication, many of the hostels reported storing Schedule Eight medications for breakthrough pain in the resident’s room. Where a resident was unable to self-administer oral breakthrough medication, RNs did this in 66% of hostels; alternatively this task was attended to by AINs (33%) or PCAs (48%). If an injection was required for breakthrough pain after hours, 60% of hostels indicated the availability of a registered nurse, 22% could source a general practitioner, 48% had access to the palliative care outreach service, and 12% had access to community nurses. Three hostels (9%) could not make injectable breakthrough medications available to their residents. This study highlights how residents requiring a palliative approach may be disadvantaged when it comes to the availability of Schedule Eight medications as needed. Of particular concern is the
reliance on AINs and/or PCAs to provide the greater volume of after-hours palliative care. Although registered nurses were ‘on call’ after hours and on weekends, for 50% of the hostels surveyed, this situation placed limitations on the availability of timely and adequate PRN analgesia for palliative care residents.

Registered nurses and enrolled nurses in Australia are regulated and accountable to the community for providing quality care through safe, ethical and effective practice. Thus, according to the Nursing and Midwifery Council of Australia (2006), if a RN is to delegate care, the RN must first determine the level of skill and knowledge required by the person charged with performing the task, to ensure the safety, comfort, and security of the client. It is also the registered nurses responsibility to provide direct or indirect supervision according to the nature of the delegated tasks. Support workers or care assistants in residential aged care facilities are not professionally regulated, so they are not bound by standards set by a licensing authority or professional registration. Support workers are individually accountable for their own actions and accountable to the registered nurse or midwife and their employer for delegated actions (Nursing & Midwifery Council of Australia, 2006).

According to the NSW Department of Health’s Medication Handling in Community-Based Health Services/Residential Facilities in NSW - Guidelines (2005), a health care employee who is not a registered nurse, medical practitioner, dentist or pharmacist may provide whatever assistance is necessary (other than giving an injection or filling a ‘box’ medication compliance aid), including administration direct from the client’s labelled container, to enable a client to take their medication in a community setting. However, ‘prescription-only’ stock medication must not be administered by any person other than a registered nurse, a medical practitioner, a dentist or a pharmacist; and injections may only be administered by a medical practitioner or a registered nurse.

The aim of a palliative approach is to relieve suffering by means of early identification, assessment and treatment of the physical, psychological and spiritual difficulties patients and families encounter (WHO, 2004). Part of this approach involves assessment of the resident in regard to pain and troubling symptoms. While it is acknowledged in the literature that there is a variation in the skill mix among
RACFs, the provision of highly competent care by skilled nurses is clearly essential to maintaining quality care for residents requiring a palliative approach in RACFs. Thus for ‘ageing in place’ to be available for residents requiring a palliative approach, registered nurses need to either be on duty on site or be available to provide support to PCAs from an attached facility. Efficient management of pain requires appropriate medication including Schedule Eight medications being available for the resident 24 hours a day.

2.5.4 Physician Support in RACFs

When a palliative approach is initiated for a resident with complex needs, it is vital that their medical condition is regularly reviewed and that communication regarding their wishes and on-going care planning occurs. Medical care in RACFs is provided by primary health care providers - general practitioners. A 1996 survey of general practitioners in Sydney (Draper, 1999) over a one year period found that 54% of general practitioners (GPs) visited at least one nursing home, and averaged two to three patients per facility - with a median of just over one nursing home visit per week. In recognition of possible unmet medical care needs of residents with chronic and complex illnesses, several Medicare rebate incentives were introduced (Australian Society of Geriatric Medicine, 2001).

In 2001, Medicare rebates for GP visits to residential care facilities were brought into line with community home visits, and the Enhance Primary Care (EPC) program was introduced to remunerate GP involved in care planning, multidisciplinary case conferences, and comprehensive annual health assessments for people over 75 (Commonwealth of Australia, 2001). An Enhanced Primary Care (EPC) case conference is a meeting of health and care providers to plan for the health and care needs of an individual patient with at least one chronic medical condition and complex multidisciplinary care needs requiring care from a GP and at least two other health or care providers.

In 2004, two Aged Care Initiatives were introduced: Aged Care GP Panels (from 2004 to 2008) and Comprehensive Medical Assessment (CMA). The rationale behind these initiatives was, firstly, that it is difficult for aged care homes to maintain GP services
for regular consultations with residents; secondly, that current services are being provided by a small and decreasing proportion of GPs; and, finally, the number of aged care residents with high-care needs and complex conditions is increasing (Campbell, 2004).

The Comprehensive Medical Assessment (CMA) was an adjunct to normal medical care rather than a substitute. The aim of a CMA is to improve the quality of, and access to, primary medical care for residents of aged care facilities. It is a Medical Benefit Scheme (MBS) item for new and existing residents and is particularly important for those requiring a palliative approach (Campbell, 2004).

The aim of the Aged Care GP Panels Initiative was to ensure better access to primary medical care for residents of aged care facilities. It aimed to enable GPs and allied health service providers to work with RACFs on quality improvement strategies for the care of all residents, and to assist GPs and Divisions to work more effectively with aged care facilities to improve the provision of end-of-life care. An aged care GP panel consisted of a number of GPs who have agreed to work collaboratively with aged care homes. There was no Commonwealth funding to support the participation with aged care facilities, so participation is voluntary.

In mid 2008, GP Aged Care Panels were replaced with a new program called the Aged Care Access Initiative (Australian DoHA, 2009). Within this initiative there are two components: the GP incentive component and the allied health services component. The GP incentive payment administered through Medicare Australia aims to encourage GPs to provide increased and continuing services in RACFs. The allied health services component is a payment for clinical care provided by Allied Health Professionals (AHPs) in RACFs, where these services are not currently covered by Medicare or other government funding arrangements. This component is supplied by organisations, based in each State and Territory, which may purchase allied health services directly or through contractual arrangements with Divisions of General Practice.

These physician-supported initiatives are important developments which should enhance the quality of care for residents requiring a palliative approach and improve the
delivery of such an approach to a wider population. Importantly, initiatives are consistent with Goal Two of the National Palliative Care Strategy, namely, to support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia.

2.6 Conclusion

Although people with advanced cancer are typically the group referred to palliative care, people with non-cancer diagnoses have similar issues in regard to end-of-life care. Over the past two decades, policy and funding changes have been introduced to broaden the scope and service delivery models of palliative care to meet the changing needs of the Australian population. This has brought about the distinction between a palliative approach (an approach to care by all clinicians that recognises the importance of meeting a dying patient’s psychological, spiritual and physical needs) and specialist palliative care (care delivered by specialist clinicians within a dedicated multidisciplinary team).

Several Australian national policies, strategies and initiatives have been introduced to support a palliative approach within residential aged care facilities, including the world first evidenced based guidelines of a palliative approach in residential aged care facilities (Australian DoHA, 2004). The literature reveals that, of the many challenges to providing a palliative approach in RACFs, staffing and skill mix are the most prominent issues. Although the interface between the RACFs care sector and specialist palliative care services has strengthened, there is still evidence of variability of services as a result of the separate ‘no cross-sharing’ funding by the Commonwealth and the States.

This literature review has focused on palliative care within residential aged care facilities, and it has identified that most of this research has been conducted in nursing homes rather than in hostel settings and that there is little distinction made here between palliative care and a palliative approach. In addition, much of the literature focuses on RACFs as a whole and does not differentiate between nursing homes and
hostels. This means that little is known specifically about the use of a palliative approach and other forms of end of life care in hostel settings.

Within the context of Australian residential aged care sector, there is now a singular term ‘residential aged care facilities’ that describes residents in either a nursing home or hostel. However, a distinction continues to exist, mainly because of the significant variations in skill mix and staffing levels between these two settings. It has been identified that generally among RACFs there are increasing number of high-level dependent residents, and with the emphasis of ‘ageing-in-place’, it is vital that research is conducted into the needs of high-level care residents in hostel settings and how palliative care is provided in this setting.

Therefore from this review of the literature, the following five research questions were posed:

1. What are the demographics, medical illnesses, co-morbidities and functional status of high-level care residents in hostel settings?

2. What are the symptoms experienced by high-level care residents in hostel settings?

3. How do high-level care resident perceive their health and the care provided, and how do they see this care being managed in the future?

4. What are age care staff understandings of a palliative approach and what are their perspectives on how a palliative approach is being incorporated into the care of their high-level care residents in hostel settings?

5. What organisational and managerial systems are in place to support a palliative approach in hostel settings?

The following chapter describes the methodological approach taken to answer these questions.
CHAPTER THREE:

Methodology

This chapter describes the research design, data collection and analysis for this study. It includes details about the setting, the characteristics of the participants involved in this research project, and discusses the strategies employed to strengthen the validity and reliability of the findings and to ensure ethical practice throughout the study.

To answer the five identified research questions, it was decided that a mixed-method design would be required. The chapter begins by explaining the rational for this decision.

3.1 Rationale behind Mixed Method Approach

3.1.1 Introduction

Because of the exploratory and descriptive nature of the research, it was clear to the researcher that it would be necessary to collect both qualitative and quantitative data in order to address all of the research questions. In addition, it would be necessary to integrate the findings from each data set to achieve a full understanding of the experiences of both staff and residents as well as a comprehensive description of the setting. With this in mind, it was decided to employ a mixed-method approach.

Mixed-method research uses both quantitative and qualitative data collection and analysis techniques in parallel or sequential phases (Teddlie & Tashakkori, 2003) to yield findings of greater insight and validity than would be possible through either approach alone (Johnston & Onwuegbuzie, 2004; Creswell, 2009). Drawing on the
strengths of both quantitative and qualitative approaches (Johnson & Onwuegbuzie, 2004) allows a more complete picture of the phenomena being studied to be obtained.

### 3.1.2 Research Paradigms

Mixed-method research is associated with pragmatism, which, according to Onwuegbuzie and Leech (2005), is a paradigm that helps bridge the schism between quantitative and qualitative research. The emphasis is on the research problem and the use of all approaches available to understand the problem (Rossman & Wilson, 1985). According to Creswell (2009), ‘...pragmatism is not committed to any one system of philosophy and reality...’ (p. 10); instead the pragmatic investigator draws on both qualitative and quantitative assumptions to engage in their research (Morgan, 2007). There is no absolute truth but a truth of what works at the time (Creswell, 2009). The investigator using a pragmatic approach is not exclusively driven by theory or data but engages in a process of abduction enabling the researcher to move back and forth between induction and deduction during the process of inquiry (Morgan, 2007).

The philosophical framework for this research is based on a pragmatist worldview. This research project developed from clinical issues identified in my clinical area, where differences were noted in the care of older residents in hostel settings. In the local hostel facilities where I provide clinical consultations, some aged care staff confided to me that they did not feel they were managing the situation, while others appeared to be managing well. Therefore, I wanted to explore current practices of aged care staff in the management of older people whose care needs are becoming increasingly more complex and not necessarily amenable to cure.

### 3.1.3 Rationale for Using Mixed Methods

The literature review for this study revealed that little was known about the use of a palliative approach in hostel settings. To understand the complexities surrounding a palliative approach in hostels setting, a research approach was needed that allowed for a full exploration of this contemporary approach to care within this context. A quantitative approach using descriptive statistics would yield a clear, detailed picture
of the demographics and symptoms of the high-level care residents, and facilitate the review of organisational and managerial data. A qualitative approach involving semi-structured and unstructured interviews would enable the researcher to: (i) explore these residents’ perceptions of the health care provided and their perceived future care needs, and, (ii) to explore aged care staffs’ understandings of a palliative approach and its use within hostel settings.

Each research approach was used to address different aspects of the research problem and the findings were used side by side to reinforce each other (Creswell and Plano Clark, 2007). Therefore, this complex research design enabled a more complete and comprehensive account of the use and understandings of a palliative approach in hostel settings. According to Greene, Caracelli and Graham (1989), this kind of approach can be defined as an expansion which ‘...seeks to extend the breadth and range of inquiry by using different methods for different inquiry components’ (p. 259).

### 3.1.4 Types of Mixed Method Designs

Over the past several years, a plethora of mixed-method research designs have been developed. Tashakkori and Teddlie (2003) present 35 mixed methods research designs in their *Handbook of Mixed Methods in Social & Behavioral Research* (2003). Leech and Onwuegbuzie (2009) describe a matrix of eight types of mixed method research designs whereby their three-dimensional matrix is dependent on whether the research is partially mixed or fully mixed, concurrent or sequential and whether the qualitative or quantitative approach has equal status versus dominant status. Creswell (2009) describes six types of mixed method strategies which either use a sequential or concurrent strategy.

While there are multiple typologies, the way in which a mixed method design is conducted revolves around the investigator making decisions based on four criteria. These are: the sequence of methods, the priority among methods, the point of the integration of data and the investigator’s theoretical lens (Creswell, Plano Clark, Gutmann & Hanson, 2003). The sequence of methods refers to whether the
quantitative and qualitative phases of the research study occur at approximately the
same time (concurrently) or whether these two components occur one after the other
(sequentially) (Creswell, 2009). Priority refers to whether both qualitative and
quantitative phases of the study have approximately equal emphasis with respect to
addressing the research question(s), or whether one component is given significantly
higher priority than another (Leech & Onwuegbuzie, 2009). The point of integration
refers to when data from both approaches are combined, i.e. during data collection,
data analysis or interpretation. Leech and Onwuegbuzie (2009) argue that despite the
fact that these designs lie on a continuum, they can still be classified as either partially
mixed or fully mixed methods.

Decisions in regard to the four criteria as discussed above, therefore, propose the
approach taken for the research. For example, according to Creswell (2009), a
sequential explanatory strategy is characterised by the collection and analysis of
quantitative data in the first phase of research followed by collection and analysis of
qualitative data. The priority is usually given to the quantitative data, and integration
of data occurs in the interpretation phase (Creswell, 2009). The purpose of this
strategy is to use the qualitative results to assist in explaining and interpreting
quantitative findings (Creswell et al., 2003). Creswell’s (2009) sequential exploratory
strategy is characterised by the collection of qualitative data initially, followed by
quantitative data collection and analysis that builds on the results of the first
qualitative phase. Priority is generally placed on the qualitative data, and the
integration of data occurs in the interpretation phase (Creswell, 2009). Creswell’s
(2009) concurrent triangulation strategy involves collecting quantitative and
qualitative data at the same time with priority rarely given to either method. The
purpose of this strategy is to confirm, cross-validate or corroborate findings within a
single study (Creswell et al., 2003).

In this doctoral study, one of Leech and Onwuegbuzie’s (2009) three-dimensional
mixed-method designs – a partially mixed, concurrent, equal status design – has been
applied. This means that:
1. Data is collected concurrently, but analysis occurs separately drawing on techniques that are usually applied for qualitative and quantitative data respectively, therefore, each component stands alone and is subject to the usual scrutiny of its own methodological standards for validity and reliability (Carter & Henderson, 2006).

2. Both approaches are considered approximately equal in priority and requisite to addressing the different research questions posed.

3. The integration of data occurs side by side in the discussion of the findings.

3.1.5 **Strengths / Limitations of Mixed Method Designs**

The strength of mixed method research designs is that they incorporate techniques from both the qualitative and quantitative research traditions yet combine them in unique ways to answer the research questions that are not able to be answered by quantitative or qualitative methodologies alone (Creswell & Plano Clark, 2007). Therefore, this research design has the ability to develop a very broad and also deep understanding of the research problem, in which one approach supports and builds on the findings from the other approach (Creswell, 2009). A concurrent mixed methods design allows investigators to integrate the results from the quantitative and qualitative components of their research, thereby allowing them to ‘confirm, cross-validate, or corroborate findings within a single study’ (Creswell et al., 2003, p. 229).

It is recognised that all research methods have limitations and the use of multiple methods can neutralise some of the disadvantages of certain methods (Creswell, 2009). Mixed method research requires extensive data collection and is often time-intensive. This approach was considered appropriate for this doctoral study as both qualitative and quantitative data were required to answer the research questions. It is also acknowledged that a concurrent approach is considered a more time ‘efficient’ way of collecting both types of data than sequential approaches (Creswell, 2009). Given the travel required to collect data in the rural site for this study, it was clearly going to be more efficient to utilise a concurrent approach.
3.2 Study Context

3.2.1 Research Sites

This study was conducted in two residential aged care organisations in New South Wales, Australia, each of which provided residential (self-care units, hostel and nursing home accommodation) and community aged care services. There were a total of nine hostels between the two organisations, and eight of these incorporated both low-level and high-level care. Since the focus of this research was to explore the use of a palliative approach with high-level care residents in the hostel settings, the one hostel that only provided low-level care was excluded from the study. The eight hostels included in the study had a total of 412 beds.

The two residential aged care organisations were purposefully selected because of their size and location, one being rural, the other metropolitan. The rural site employed a clinical nurse specialist in palliative care who was responsible for palliative care education, designated palliative care projects and palliative care consultations to residents. The metropolitan site had access to a visiting specialist palliative care service, which also provided on-going palliative care education.

The rural site is situated in north-western New South Wales. It is an independent charitable organization, registered as a benevolent public institution and registered training organisation. Although the rural site has a total of four hostels, one of these only accommodated low-level care residents. Thus only three of the hostels (78 beds) from the rural site were included in this study.

The metropolitan site is situated in suburban Sydney. It is run by a charitable organisation formed in 1911. The organisation is large, with 4,000 residents in different facilities across ten locations. The metropolitan site has five hostels, with 334 hostel beds, all of which were included in the study.

At both sites, accommodation includes a single room with an en-suite bathroom. Residents are encouraged to bring some of their own furniture, which, depending on
size, may include a wardrobe, dressing table, armchair, small fridge, television, and a coffee table. The services provided at both facilities include all meals served in a central dining room, washing, cleaning, personal care assistance activities, and supervised outings.

3.2.2 Gaining Access

I initially approached the facilities through an email and telephone call to their respective Chief Executive Officers (CEO), followed by written correspondence. Written communication included a summary of the research project and a request for a letter of support to conduct this project once approved by relevant medical councils in their institutions. Both medical councils at each institution were willing to accept ratified approval from the University of Sydney’s Human Research Ethics approval. On receiving letters of support from both institutions, the research proposal was submitted to the University of Sydney’s Human Research Ethics Committee. On receiving approval from this body in March 2008 (see Appendix 1), the two CEO’s were requested to identify a contact person from their respective facility to assist in the facilitation of informative meetings with relevant managers and aged care staff.

3.2.2.1 Rural Site

The contact person at the rural site was the clinical nurse specialist in palliative care. Through email communication, a date and time were arranged for me to meet on-site with the CEO and hostel managers/supervisors. This meeting was held in addition to ‘routine’ meetings and all managers/supervisors were requested by the CEO to attend to discuss the research project and to seek clarification where required. The CEO, Director of Care, palliative care nurse specialist, three hostel managers/supervisors and three team leaders attended. The meeting duration was approximately 90 minutes, during which I outlined the study and details of care managers’ involvement in the study. Staff expressed interest for the project.
During our discussions, the staffing structure was noted to be different from my expectations. It was identified that not all managers/supervisors were registered nurses and that many of the personal care assistants acted as team leaders as well as being allocated a resident load.

At the end of the meeting each manager/supervisor was provided with an easily identifiable bright green folder which held copies of the information statements to be given to potential aged care staff, residents and persons responsible (refer to glossary) interested in participating. The folder also contained inclusion and exclusion criteria and a general summary of the research project (see Appendix 2). Posters were distributed to the care managers to display around their facility to remind staff of the project (see Appendix 3). After this meeting, I was given a tour of the facility and the opportunity to informally speak to aged care staff about the study. Aged care staff were made aware of the folder which was to remain in each hostel nurses’ stations.

### 3.2.2.2 Metropolitan Site

The contact person at the metropolitan site was the Deputy CEO. Email and telephone contact was used to arrange an initial meeting with hostel managers. A presentation outlining the research project was scheduled to take place at the beginning of the managers’ routine monthly meeting. The General Manager, Clinical Manager, Manager of New Residents – Assisted Living and five hostel managers/supervisors attended. The time allocated to provide the details of the study was constrained by other items on the meeting agenda. There were varying levels of support for the project at this initial meeting, and it was later revealed that lack of time available for discussion impacted on the support for the project within the organisation.

The Manager of New Residents – Assisted Living requested that the facility be referred to as a ‘home’ rather than an institution in my oral presentation. Correct terminologies of the staffing structure were also discussed. This included the term ‘personal care assistant’ which was not used in this facility; instead unqualified care staff were referred to as ‘care assistants’. This RACF also employed recreational
officers who assisted with activities and were incorporated into team discussions about residents.

As in the rural facility, the managers/supervisors in this facility were provided with bright green folders containing the research information and participation documents. Posters to remind staff of the project were supplied to care managers of this facility. Due to the time constraints of the meeting, a tour of the facility was not possible. It was agreed that I would contact each manager individually to arrange a time to provide aged care staff at the individual hostels with details of the study.

3.3 Study Population

Three participant groups were sought for inclusion into the study. These included: high-level care residents or their persons responsible (for residents with cognition issues) and aged care staff.

3.3.1 Resident /Person Responsible Inclusion Criteria

Due to the anticipated high number of residents with dementia, I decided to also include the persons responsible for residents with dementia. The inclusion criteria for resident/person responsible participants were as follows:

1. being classified as needing ‘high-level’ care according to the residential classification scale;
2. where deemed by the institution to be cognitively impaired, having a person responsible willing to participate on their behalf;
3. speaking and reading English;
4. being deemed (by the manager) to be well enough on the day of data collection to participate in the research; and
5. being over 18 years of age.
3.3.2 Aged Care Staff Inclusion Criteria

The criteria for participation by aged care staff were as follows:

1. being employed at one of the participating facilities;
2. having cared for at least one high-level care resident within the last six months; and
3. speaking and reading English.

3.4 Participant Populations

3.4.1 Resident / Person Responsible

One of the purposes of this study was to describe high-level care residents living in hostels in relation to demographic information (for example, age, gender, marital status and family support), medical illnesses, co-morbidities, physical functioning and individual symptoms. As noted earlier, the total number of hostel beds was 412. Since the exact number of high-level care residents residing in these facilities was unknown prior to commencing data collection, I relied on information from the Australian Department of Health and Ageing (DoHA) in developing the research plan. According to the Australian DoHA (2006), 31% of newly admitted residents to hostel accommodation were classified as high level. Although this figure does not account for residents already in the hostel, it was estimated that there would be a minimum of 102 high-level care residents residing in the participating facilities. However, it was anticipated that some of these high-level, older participants might be deemed ‘too ill’ to participate on the day of data collection while others might decline to participate.

Once I had gained access to the sites, it was determined that the number of high-level care residents across the eight hostels was much higher than anticipated. There were 58% (237) high-level care residents in total across both sites (facilities). Of these, 30.4% (n=72) of residents and 9% (n=21) of persons responsible were recruited.
Therefore, the sample used to describe the characteristics of the high-level care residents in this study was over one third (39.2%, n=93) of the total population.

Convenience sampling was used to recruit the residents and persons responsible who participated in this study. Convenience sampling refers to the most conveniently available people meeting the inclusion criteria at the time of data collection. Thus all willing high-level care residents or their willing person responsible from the eight participating hostels were included. This form of non-probability sampling does not allow results to be generalised for a larger population. However, this approach was chosen because the exact number of high-level care residents living in these hostels was unknown. Burns and Grove (2007) state that, although multiple biases may exist in convenience sampling, extraneous variables can be overcome by developing and adhering to strict entrance criteria.

Although it is usual for qualitative data collection to be limited to a smaller group of participants, the emphasis being on quality detail rather than quantity, in this instance the sampling method used prevented that. All participants who had been involved in the collection of the quantitative data were keen to proceed with an interview and to have their experiences and opinions included in the study.

In mixed method designs, where databases are considered equal and quantitative and qualitative data are collected to answer different research questions, Creswell and Plano Clark (2007) suggest increasing the number of qualitative participants. However, they warn that in doing so, some of the detail elicited from individuals may need to be sacrificed. They also warn that with concurrent data collection it is possible that one form of data might introduce biases that confound the results from the other. In a study by Victor, Ross and Axford (2004), quantitative data were collected among the intervention and control groups and a qualitative arm was used in which the intervention group maintained diaries during the trial period. To prevent data bias, the investigators collected and reviewed the diaries after the intervention period. Creswell and Plano Clark (2007) suggest that bias could equally have been reduced by collecting qualitative data across all treatment and control groups, or by the
researchers postponing qualitative data collection until after the intervention, thus employing a sequential data collection design.

In the current study, qualitative data were collected from all resident and person responsible participants who completed the quantitative questionnaires (n=93). Analysis of quantitative and qualitative data occurred separately after the completion of all data collection. As argued by Morse (1991), with simultaneous (concurrent) methodological triangulation, as used in this study, limited interaction occurs between the two sources of data during the data collection stage, but the findings complement one another at the data interpretation stage.

### 3.4.2 Aged Care Staff

Purposive sampling was used to recruit aged care staff from the eight hostels for the qualitative part of the study. This sampling method is aimed at gaining insight into the phenomenon rather than achieving empirical generalisation (Teddlie & Yu, 2007). Purposive sampling involves selecting certain units or cases ‘based on a specific purpose rather than randomly’ (Tashakkori & Teddlie, 2003, p. 713) in order to represent a broader group of cases as closely as possible (Teddlie & Yu, 2007). Purposive sampling was selected as it offers information-rich participants (Patton, 2002) and illuminates useful manifestations of the phenomenon of interest. In this instance, managers, RNs, EENs, ENs and PCAs working at the RACFs were recruited for their ability to inform the researcher about their personal experiences in providing care to high-level care residents. Among the seven managers (one managed two hostels), four were RNs, one was an EEN and one was a PCA Certificate IV. While some hostels employed part-time ENs and RNs, they were not available on the day of data collection.
3.5 Recruitment

Seventy-two high-level care residents, 21 persons responsible and 30 aged care staff from the participating facilities were recruited for this study over an eight-month period from May to December 2008. Out of a potential 237 high-level care residents candidates, 144 high-level care residents who did not enter the study, 10 declined participation, strongly stating that they believed they were ‘not intelligent enough’, expressed that they had ‘nothing to offer’ or that they did not have the energy. Fourteen residents were in an acute hospital at the time of data collection, while a further six residents were not available on the days of data collection. Sixteen of the residents were deemed by the manager as ‘too ill’ or not appropriate to participate. The remaining 98 residents who did not enter the study had some degree of cognition impairment requiring guardian consent. Multiple attempts to contact these persons responsible were made. However, due to the time constraints of the study, further attempts to contact these persons responsible were abandoned. Participants were invited to participate according to the inclusion/exclusion criteria detailed below.

One issue that arose during resident recruitment was that some residents who initially agreed to participate, changed their mind stating they felt they were ‘not intelligent enough’, so I decided to change the wording when introducing the study. Instead of introducing the project as ‘a research study’, the term ‘research’ was dropped. Despite the fact that the term ‘research study’ was used in the Information Statement provided to participants, this simple change of wording appeared to allay their concerns about participating in the study.

3.5.1 Residents / Persons Responsible

Hostel managers were asked to identify residents according to the inclusion/exclusion criteria. The RCS was used to determine the ‘high-level care’ residents. Although the RCS had been superseded by the Aged Care Funding Instrument (ACFI) in March 2008, not all residents had been reassessed or reclassified using the new funding instrument. For the few residents who had been classified according to the new system, managers/co-coordinators were consulted as to whether the resident would
meet the RCS ‘high-level care’ classification, and, if so, they were then included in the study.

The aged care staff were asked to invite the qualifying high-level residents to participate in the study and to distribute the Information Statement to them (see Appendix 4). Residents expressing an interest in participating were visited by the researcher who explained the project in more detail and answered any questions they or their family had about the project. Residents who agreed to participate were asked to sign the Consent Form (see Appendix 5). Where residents who were deemed by the manager to be cognitively impaired, the hostel manager approached the resident’s person responsible to participate on their behalf; if they agreed, the manager provided them with an Information Statement (see Appendix 4). Persons responsible expressing an interest in participating were then visited by the researcher who explained the project in more detail and answered any questions they had about the project. Participant consent to enter the study was sought at that time.

There were 72 residents and 21 persons responsible from across both sites that participated over an eight-month period. The persons responsible who agreed to participate were either a spouse or daughter of the resident. Sons or other family members were difficult to contact or not available.

### 3.5.2 Aged Care Staff

The care managers made a list of aged care staff who met the inclusion / exclusion criteria and who were willing to participate in an interview on the day of data collection. Prior to conducting interviews at each hostel, the care manager sought out the willing participants and designated an area to conduct the interviews. Seven hostel managers and 23 PCAs were recruited into the study. Permission was granted to interview them in the workplace during work time. Participating managers were interviewed individually using semi-structured interviews. Initially, it was thought that personal care assistants with limited training might lack the confidence to participate in a one-on-one interview and focus groups would be a more appropriate avenue to explore their experience of a palliative approach for the high-level care residents. In
research such as this, focus groups can be used to allow organised discussion to explore a specific set of issues (Carter & Henderson, 2006). Unfortunately, due to the staffing numbers (two to three per shift) and short shifts of PCAs, it was not possible to conduct focus groups. Instead, group, semi-structured interviews were conducted with either two or three care assistants, and managers were interviewed individually.

3.6 Data Collection

Quantitative and qualitative data were collected concurrently over a eight-month period. As there were two aged care facilities with multiple hostels, I decided to focus one site at time. Data collection commenced at the rural site in May 2008 and was completed after only three months, during which I visited the facility three times for a stay of 2–3 days. Collecting the data from the rural site during such a short timeframe was aided by the exceptional organisational skills of the managers/supervisors in setting up participant interviews. Data collection at the metropolitan site was a slower process, commencing in July 2008 and completed December 2008. Rather than managers/supervisors setting up participant interviews, I was provided with a list of appropriate residents in the hostel and given contact details of persons responsible who had indicated they wanted to participate in the research. All data collection was undertaken by the researcher. An overview of the data collection process is detailed in Figure 3.1.
3.6.1 Quantitative Data Collection

The quantitative data collected on high-level care residents included demographic details as well as assessment of their symptoms, using the Edmonton Symptom Assessment System (ESAS) (Appendix 7) and the Patient Outcome Score (POS,v2) (Appendix 8), and their functional abilities, using the Barthel Index (Appendix 6). Each of the individual data tools will be described in detail and then discussion of the reliability and validity of these tools will follow. Data was also collected on the policy and procedural organisation of the facility in relation to a palliative approach, and on managerial aspects (such as staffing levels, use of agency staff, education) to assess staffing levels.
3.6.1.1 Resident Demographic Data

Demographic data were collected using a data extraction tool developed for this project (see Appendix 6). Information on participating residents’ age, gender, marital status, country of birth, cultural background, living status prior to hostel admission, carer support prior to entry, previous accommodation before hostel, and length of time categorised as ‘high-level’ care was recorded on this tool. These socio-demographic characteristics were based on similar residential aged care statistics collected yearly by the AIHW (2010b), and enabled the researcher to use this data as a comparison for analysis. The data extraction tool was piloted on the first few participants and no changes to the tool were required.

Medical information, including current major health problems and co-morbidities, was collected from residents’ medical records. Permission to access these records had been granted by each participating resident or their person responsible via the consent form. Medical record auditing is frequently used in health care research and is a valuable technique for obtaining demographic and medical information (Gordon, Hiatt & Lampert, 1993).

The decision regarding which current and concurrent health conditions to include in the audit was based on a review of recent data from the ABS. According to the ABS Causes of Death report (2008), the four leading causes of death were: heart and circulatory disease, cancer (particularly lung, prostate, and colorectal cancers), end-stage organ failure (end stage of chronic renal, respiratory disease or diabetes) and dementia. Therefore each of these conditions was included on the demographic extraction tool. In 2003, the ABS reported that the average number of health conditions for people aged 65 years and over was 2.84 conditions, but that older people (85 years plus) had an average of 4.85 health conditions. Therefore, an additional ‘other’ category was included to capture any co-morbidities not listed.
3.6.1.2 Edmonton Symptom Assessment System (ESAS)

The Edmonton Symptom Assessment Scale (ESAS) (see Appendix 7) was used to identify symptoms experienced by the high-level care residents with chronic life-limiting illnesses or cancer diagnosis. The ESAS tool was developed by Bruera, Kuehn, Miller, Selmser and Macmillan (1991) to provide a brief and clinically useful bedside tool for palliative care in-patients with advanced cancer to self-report symptom intensity.

The ESAS tool includes nine common symptoms of advanced cancer (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath), with the option of adding a further patient-specific symptom.

While symptom prevalence in patients with chronic illness varies considerably, pain, shortness of breath and fatigue have been found to be common symptoms experienced by people with heart disease, chronic obstructive respiratory disease, and renal disease (Solano, Gomes & Higginson, 2006). A pilot study conducted by Brechtl, Murshed, Homel and Bookbinder (2006), using the ESAS instrument to monitor symptoms among 108 patients with end-stage chronic illnesses living in a residential aged care facility, revealed pain, tiredness, decreased sense of well-being and poor appetite as the four most frequently experienced symptoms.

There are two methods for reporting and interpreting responses in the ESAS. The first uses a continuous scale (either 0 – 100 for the visual analogue scale or 0 – 10 for the numerical rating scale) to describe symptom intensity. The second collapses the continuous variables into categorical groupings (Philip, Smith, Craft & Lickiss, 1998; Nekolaichuk, Watanbe & Beaumont, 2008). A numerical rating scale was used in this study as most residents had reduced visual acuity that might limit their ability to mark the appropriate spot on an analogue line. Some studies have used a total symptom distress score for the ESAS as a measure of overall symptom burden (Davison, Jhangri & Johnson, 2006b), while others have focused on each symptom independently (Bruera, Kuehn, Miller, Selmser & McMillan, 1991; Chow, Wong, Connolly, Hruby, Franssen, Fung, Vachon, Lourdes Andersson, Pope, Holden,
Szumacher, Schueller, Stefaniuk, Finkelstein, Hayter & Danjoux, 2001; Pautex, Berger, Chatelin, Herrman & Zulian, 2003; Modonesi, Scarpi, Maltoni, Derni, Fabbri, Martini, Sansoni & Amadori, 2005; Brechtl, Murshed, Homel & Bookbinder, 2006. And some studies have used both individual items and total ESAS symptom distress scores (Dudgeon, Harlos & Clinch, 1999; Chang, Hwang & Feuerman, 2000). In this study, the total ESAS score was used to examine whether a specific diagnostic group could be identified as having a higher symptom burden, while the reports of individual symptoms were also considered independently using a numerical rating scale (0= nil, 10= worst possible).

The ESAS assessment was conducted on a single occasion, the day of data collection, with the assistance of the researcher. Participants were asked if they were currently experiencing any of the nine symptoms specified on the ESAS tool and to rate the symptom severity from zero to ten using a numerical rating scale. The assessment itself takes approximately 5 -10 minutes to complete. This tool is publically available and no permission from the developers is required to use this tool beyond appropriate acknowledgement.

3.6.1.3 Patient Outcomes Score Version 2 (POS v2)

The Patient Outcomes Score Version 2 (POS, v2) was chosen because of its ability to measure health outcomes and to assist in identifying palliative care needs. Hearn and Higginson (1999) developed the original Palliative Care Outcomes Score (Version 1) to be used in specialist palliative care services following a systematic review of palliative care outcome measures. The POS (v2) was developed to measure palliative care outcomes in other non-specialist palliative care settings and included a number of changes recommended after implementation of the original version 1 in a pilot study. These included a change of title (from ‘Palliative Care Outcome Score’ to ‘Patient Outcome Score’) and Question Seven being amended from ‘Have you felt that life was worthwhile?’ to ‘Have you been feeling depressed?’. Since its development, the POS (v2) has been demonstrated to be an effective outcomes measure for use with people with palliative care needs who are diagnosed with a chronic or progressive
disease such as dementia, cardiac, motor neurone disease and respiratory disease (Hughes, Aspinal, Higginson, Addington-Hall, Dunckley, Faull & Sinha, 2004; Brandt et al., 2005).

The POS (v2) incorporates ten items concerning physical, psychological, practical, and spiritual domains of life (see Appendix 8). In addition, there is an open-ended item which allows for listing of the main problems in the previous seven days. The POS-items one to eight include questions regarding: pain, any other symptoms (for example constipation, nausea), anxiety or family anxiety, depression, self worth and whether sufficient information related to the person’s condition had been provided to the individual or family members. It is scored on a 5-point Likert scale, ranging from 0 (no problem) to 4 (overwhelming problem) (Horton, 2002). Item nine (the amount of time wasted on waiting for appointments) and item ten (whether they had experienced any practical matters resulting from their illness) of the POS are scored on a 3-point scale (0-2-4) ranging from 0 (good) to bad (4).

The POS (V2) is comprised of two similarly constructed questionnaires, one for patients and one for staff. However, since the purpose of employing this tool in the current study was to assess symptoms as rated by participants only, the staff questionnaire was not required. The POS questionnaire was completed with the researcher asking the questions of the resident or person responsible, and took approximately ten minutes to be completed.

According to Aspinal, Hughes, Higginson, Chidgey, Drescher & Thompson (2002), individual item scores can help identify individual patient needs and inform clinical decisions. Repeated individual scores can also be analysed to monitor patients’ clinical change over time for each item. A summary score generated by totalling scores from each patient can provide insight into the patient’s overall condition, whereby the maximum overall score of 40 indicates the least favourable patient outcome. Permission to use the POS (v2) in this project was obtained by completing the user information and registration form from the King’s College London Weston Education Centre (see Appendix 9).
3.6.1.4 Barthel Index (BI)

The Barthel Index (BI) was used to assess the functional abilities of high-level care residents (see Appendix 6). The BI was developed by Mahoney and Barthel (1965) and is an objective clinical tool that measures a person’s daily functioning ability, specifically the activities of daily living. It is commonly used in aged care populations (van der Putten, Hobart, Freeman & Thompson, 1999). The BI consists of ten items that measure abilities in regard to feeding, moving from wheelchair to bed and return, grooming, transferring to and from a toilet, bathing, walking on a level surface, going up and down stairs, dressing, and continence of bowels and bladder. The items are weighted according to the time and amount of actual physical assistance required if a patient is unable to perform the activity. Two items are rated on a two-point scale of 0 and 5 (bathing and grooming), six items are rated on a three-point scale of 0, 5, and 10 (feeding, dressing, bowels, bladder, toilet use and stairs), and two items are rated on a four-point scale of 0, 5, 10, and 15 (transfers and mobility).

The individual item scores are tallied to obtain a total score, with a possible range of 0 – 100. A higher total score indicates more independence and functional ability while lower scores indicate loss of function and increasing dependence. In this study, both the total and individual scores were assessed to determine a general functional ability score and to identify specific functional needs respectively. As PCAs provide the majority of hands-on care to residents in hostels, they were considered to be the best source to accurately assess each resident’s functional ability. Each resident’s functional ability was thus established by the researcher asking the personal care assistant assigned to them to respond to the questions related to their activities of daily living on the days of data collection. With appropriate acknowledgement, no permission is required to use this tool.

3.6.1.5 Comparative Data to Determine Symptom Clusters

Multiple studies have shown variations in symptom burdens between older individuals with non-malignant and those with malignant diagnoses (Grbich, Maddocks, Parker, Brown, Willis, Piller, & Hofmeyer, 2005; Burt, Shipman, Richardson, Ream &
Addington-Hall, 2010). In particular, it has been identified that older individuals with non-malignant diagnoses are unlikely to receive effective symptom management and their symptoms are often under-estimated (Zanocchi et al., 2008). In addition, studies reveal that particular symptoms, such as pain, correlate with functional interference (Li, Fung, Sinclair, Danjoux, Barnes, Tsao & Chow, 2005, Harris, Li, Flynn & Chow, 2007).

The term symptom cluster was first coined by Dodd, Miaskowski and Paul (2001) to describe the manifestation of at least two or three interrelated symptoms which may reveal specific underlying dimensions or mechanisms. Several symptom clusters have been identified in end-stage non-malignant and malignant diseases. Jurgens, Moser, Armola, Carlson, Sethares, Riegel and the Heart Failure Quality of Life Trialist Collaborators (2009) identified acute volume overload clusters (shortness of breath, fatigue, sleep problems) and emotional clusters (depression, memory problems and worry) among patients with congestive cardiac failure. End-stage renal disease has been associated by Curtin, Bultman, Thomas-Hawkins, Walters and Scatell (2002) with a cluster of symptoms around mobility issues (numbness, tingling, or burning of feet/hands, muscle soreness, muscle weakness, and bone or joint pains) and fatigue/sleep issues (lack of energy or feeling washed out, trouble staying awake during the day, trouble falling asleep, and waking during the night/trouble falling back to asleep). Symptom clusters have also been associated with specific cancers. For example, Esper and Heidrich (2005) found ‘confusion-constipation-pain’, ‘agitation-delirium’, ‘anorexia-dehydration-nausea’, and ‘breathlessness-cough-fatigue’ in advanced cancer patients.

A comparison of the means, standard deviations and 95% confidence intervals of the total POS score, total BI and total ESAS score for each primary diagnosis was conducted to explore symptom clusters between specific diagnostic groups.
3.6.1.6  Reliability and Validity of Quantitative Instruments

Within the context of quantitative research approaches, the reliability and validity of the instrument is crucial to the research (Bryman, 2008). Reliability of an instrument refers to its stability and consistency within a given period, whereas validity of an instrument refers to the extent to which measures used in the data collection achieve what they set out to do (Bowling, 2006). Measures of reliability include test-retest reliability (or stability, a method for determining reliability of test using repeated applications on the same person), inter-rater reliability (consistency among different users), internal consistency (the degree to which parts of a test or scale measure the same variable), and Cronbach’s alphas, which estimate the reliability based on all possible correlations between all the items within a scale (Bowling, 2006). The Cronbach’s alpha coefficient ranges from 0 to 1, with higher values indicating greater reliability. According to Bowling (2006), there are variations among the minimum acceptable standards for scale reliability, whereby some regard values ≥ 0.7 as acceptable for internal consistency reliability (Nunnally, 1978) while others accept > 0.50 as an indicator of good internal consistency (Cronbach, 1951; Helms, 1964).

Important measures of validity include the content validity (how well the tool is measuring a particular characteristic to be assessed) and criterion-related validity (the establishment of a relationship between the instrument and the characteristic). Construct validity is also an important measure of validity. It determines whether the instrument actually measures the theoretical construct it purports to measure, that is, the extent to which a participant actually possess the characteristics under study (Wilkin et al., 1994; Bowling, 2006).

3.6.1.6.1  Reliability and Validity of ESAS

Several studies have evaluated the reliability of the ESAS instrument, primarily in regard to assessing palliative care cancer patients in in-patient and/or out-patient settings (Nekolaichuk et al., 2000). Only four studies could be found in non-cancer settings (Brandt, Ooms, Deliens, van der Wal & Ribbe, 2006; Brecht & al., 2006; Davison, Jhangri & Johnson, 2006a; Davison et al, 2006b).
In a pilot study, Brechtl and colleagues (2006) used the ESAS instrument to monitor symptoms of aged care facility residents with chronic illnesses such as late-stage AIDS, cirrhosis, dementia and cerebral vascular disease but no reliability of the instrument was reported. Another study by Brandt and colleagues (2006) evaluated the presence of burdensome symptoms of nursing home patients in the last two days of life, but again no reliability of the instrument was reported.

The overall Cronbach alpha for the ESAS instrument has been reported as 0.79 to 0.93 among medical oncology patients, be they outpatients and inpatients or palliative care patients in a hospice unit (Tierney, Horton, Hannan & Tierney, 1998; Chang, Hwang & Feuerman, 2000). While several studies have demonstrated high correlation for test re-test reliability studies ranging between one day and one week, the purpose of using the ESAS in this study was for a one off assessment (Chang et al., 2000; Davison et al., 2006a & b).

The construct validity of the ESAS instrument has been tested against other measurements. Tierney and colleagues (1998) validated the ESAS instrument against the McGill quality of life tool, which comprises of five subscales: physical symptoms, overall physical wellbeing, psychiatric or affective symptoms, existential quality of life and social support. The overall ESAS and McGill scores were highly correlated (r=0.64, p <0.0001), the highest correlations occurring under physical wellbeing and psychological symptoms.

Vignaroli, Pace, Wiley, Palmer, Zhang and Bruera (2006) compared the screening performance of the ESAS instrument for depression and anxiety against the Hospital Anxiety and Depression Scale (HADS) to demonstrate a sensitivity of 77% and a specificity of 55% for depression, and a sensitivity of 83% and specificity of 47% for anxiety; however, they used low cut-off scores for both the ESAS (2/10 for depression and 3/10 for anxiety) and the HADS (>6 depression and > 7 for anxiety). It should be noted that a higher cut-off point decreases sensitivity and increases specificity, a lower cut-off increases sensitivity and decreases specificity (Lynch, 1995; Herrmann, 1997). A cross-sectional study by Davison and colleagues (2006a) reported the validation of a modified version of the ESAS against the Kidney Quality of Life-Short Form.
(KDQOL-SF). Their results demonstrated that the ESAS pain item was highly correlated with the physical health component of the KDQOL – SF ($r = -0.56$, $p< 0.01$), the ESAS depression item correlated with the mental health component ($r= -0.52$, $p< 0.01$), and the overall ESAS system distress score correlated with the KDQOL-SF subscales symptom/problem list ($r = -0.69$, $p< 0.01$).

### 3.6.1.6.2 Reliability and Validity of POS (v2)

The POS was developed as an assessment and outcome measure for palliative care patients with cancer and was designed to cover more than physical symptoms and quality of life related questions (Hearn & Higginson, 1999). The POS comprises two complementary questionnaires, one for the patient and one for staff, of a similar structure. This instrument has been shown to have good internal consistency, Hearn and Higginson’s (1999) validation study among palliative care inpatients and outpatients reported a Cronbach alpha of 0.65 ($n=128$) for the patient rated scale and 0.70 ($n=308$) for the staff rated scale. Eisenchlas, Harding, Daud, Perez, De Simone, and Higginson (2008) reported similar Cronbach alpha’s (0.68 - 0.69 for patients and 0.66 - 0.73 for staff) in their cross-cultural validation of the POS among 48 patients and 11 staff.

The POS allows comparison of the assessments by patients and staff, which may highlight issues for staff to follow up on with patients or identify areas for practice development. While Hearn and Higginson’s (1999) validation study demonstrated high correlation for test re-test reliability studies (0.74 to 1), ranging between three days and one week, as stated earlier the focus of the present study was to identify patients unmet needs on a single occasion.

The construct validity of the POS has been tested against other measurements, such as the European Organization for Research and Treatment of Cancer Quality of Life C-30 tool (EORTC QLQ-30), and the Support Team Assessment Schedule (STAS). Hearn and Higginson (1999) compared the EORTC QLQ-30, the STAS and the POS for criterion validity. Among the 29 patients who completed both the POS and
EORTC QLQ-30, correlations ranged between 0.43 for quality of life to 0.51 for physical symptoms. Among the 43 staff who completed both the STAS and POS, correlations ranged between 0.51 for quality of life to 0.80 for physical symptoms. In Eisenchlas and colleagues’ (2008) study comparing the construct validity of the EORTC QLQ-30 and the POS among 48 palliative patients and 11 staff, found that the pain item for both to be strongly correlated (r = 0.91), as were the POS items ‘worry/anxiety’ and ‘self-worth’ with the EQRTC item for ‘depression’ (r= 0.68 in both instances).

3.6.1.6.3 Reliability and Validity of Barthel Index

Several studies have evaluated the reliability of the Barthel Index (BI) (Collin, Wade & Davis, 1988; van der Putten et al., 1999). The BI can be self-administered or conducted by a member of staff. van der Putten and colleagues (1999) reported a Cronbach alpha coefficient of 0.65 for patients and 0.70 for staff for the Barthel Index.

The construct validity of the BI has been tested against other measurement tools such as the Functional Independence Measure (FIM), the Plutchik Scale and the Katz index (KI) of activities of daily living (ADL) (Houlden, Edwards, McNeil & Greenwood, 2006; van der Patten et al., 1999). van der Putten and colleagues’ (1999) study compared the appropriateness and responsiveness of the BI and the FIM among patients with multiple sclerosis and those who had a stroke. The FIM is an 18 item instrument that can generate a total score and / or a motor score (13 items) and/or a cognitive score (5 items). The responsiveness of all three measures, the ability to detect clinically significant change, was found to be similar in both disease groups.

3.6.1.6.4 Reliability of Proxy Assessment by Persons Responsible

A person responsible is a delegated person who is responsible for making decisions for individuals who have a disability or are incapable of consenting to treatment. The person responsible is not necessarily the patient's next of kin (New South Wales Government, Office of the Public Guardian, no date (n.d). Since persons responsible
were asked to participate on behalf of residents with dementia in this doctoral study, it is pertinent to examine the reliability of proxy assessment.

The literature reports varying reliability of proxy reports. Several studies have reported that proxy assessments made by significant others are reasonably accurate concerning health status, measures of functioning, activities of daily living and some symptoms (for example, fatigue, dyspnoea and vomiting) (Neuman, Araki & Gutterman, 2000, McPherson & Addington-Hall, 2003, Brandt et al., 2005). Equally, however, the literature suggests that for subjective items such as psychological and spiritual issues, proxies may overestimate symptoms (Neuman et al., 2000, McPherson & Addington-Hall, 2003; Brandt et al., 2005). It would seem that in either instance the relationship between the patient and proxy influences responses. Findings from health research and epidemiological surveys suggest that the person closest to the patient, in many cases the spouse, is considered the most able to report on the patient’s experiences (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Bassett, Magaziner & Hebel, 1990).

The way in which clinicians/researchers prompt proxy caregivers can influence their response. Pickard and Knight (2005) describe numerous theoretical approaches that clinicians can take when they are prompting proxy caregivers. In the current study, Pichard and Knight’s (2005) ‘proxy-patient perspective’ was used. The proxy-patient perspective entails prompting proxy caregivers ‘...to take a substituted judgement, where the caregiver is prompted to assess the patient as one thinks the patient would rate his or her experience’ (Lobchuk, McClement, Daeninck, Shay & Elands, 2007, p. 132). In a randomised control trial by Lobchuk and colleagues (2007), investigating the inter-rater gap between patient self-assessment and caregiver assessments using the Memorial Symptom Assessment Scale, it was found that the proxy-patient perspective reduced caregiver discrepancies. However, when interviewing person responsible in this doctoral study, inevitably sometimes the interviews went off in a different direction and became their story as opposed to strictly sticking to answering on behalf of their loved one.
3.6.1.7 Organisational and Managerial Data

An organisational and managerial data form was developed specifically for this project to assist in understanding the organisational supports for a palliative approach and to develop a profile of the aged care staff in the hostels (Appendix 10). In addition, a general hostel information and resident dependency profile form was developed to assess the overall dependency levels of all residents within the two sites (see Appendix 11).

Procedure guidelines can ensure compliance with regulatory and accreditation requirements and enable staff to follow the same practice and standards of care. Twenty-six policies and 12 procedural guidelines were considered relevant to providing a palliative approach to residents within the hostel environment. Many of the specific policies/guidelines as listed on Appendix 10 were based on the evidence-based Guidelines for a Palliative Approach in Residential Aged Care (Australian DoHA, 2004a) and additional policies were added according to my views as a Clinical Nurse Consultant in palliative care with experience in developing policies and guidelines. For example, if the resident’s poor fluid intake is of concern, yet there is a preference for the resident and family to remain in the hostel setting, the use of subcutaneous fluids may be an alternative to transferral to hospital for intravenous fluids. Some examples of policies and guidelines I have developed include; guidelines for using a Grasbey syringe driver and specialist community palliative care admission and discharge policy.

Information regarding the number of resident separations (death/permanent discharge) was collected from each hostel manager. Information regarding the number of residents requiring a hospital admission or visit to an emergency department and the diagnoses or reason for admission or visit was also collected over a six-month period. As the diagnoses could be different from their primary health problem, categories of diagnoses were developed from an Australian population-based retrospective study by Ingarfield and colleagues (2009), who investigated differences between emergency department presentations of older people (over 65 years) who do and do not live in RACFs over a three year period. Among the 6,167 residents who presented to an
emergency department over this time period, pneumonia/influenza, urinary tract infections and injuries (predominantly hip fractures) were the most common emergency department diagnoses for these residents from RACFs (Ingarfield, Finn, Jacobs, Gibson, DÁrcy, Holman, Jelinek & Flicker, 2009). A study by Brandt and colleagues (2005) among nursing home residents with dementia found pneumonia, cachexia, and dehydration to frequently be the direct cause of death. Consequently these issues were included in the data tool.

Managerial data pertained to staffing numbers, staff/resident ratios, use of agency and casual staff were collected (see Appendix 10). As noted earlier, there are no mandated staffing ratios of RNs / PCAs-to-residents in Australian RACFs. Management staff determine the staffing levels for the provision of nursing care for residents of RACFs, based on the principle of a duty of care (Nursing and Midwifery Council of Australia, 2002) and on the demonstrated competencies of the nurses (Nursing and Midwifery Council of Australia, 2003). In addition to staffing resources, data on education activities and educational literature were elicited.

3.6.1.8 Issues Arising During Quantitative Data Collection

One of the issues that arose in relation to the quantitative data collection was a logistical one. During data collection, one of the hostels included in the study transferred a resident’s progress record to their computer system, to which I did not have direct access. Thus, in order to complete the resident’s BI functional assessment scale, I was required to approach one of the PCAs looking after that resident. Due to low staffing levels, a member of staff was not easily available to answer these questions. Nevertheless, I was able to collect all of the required data for each participant. The resident’s progress records were often updated by staff at lunchtime so, I waited at the nurses’ station and was able to complete several outstanding BI assessments at one time. Thus, despite this challenge, there was no missing data.
3.6.2 Qualitative Data Collection

Qualitative data was collected through unstructured and semi-structured interviews with residents, persons responsible and aged care staff. Interviews with residents were used to obtain their perspective of their health status, and of the care provided, and their future care wishes. The interviews with aged care staff were incorporated to elicit their understandings and perceptions of a palliative approach in the hostel setting. All interviews were audio recorded and fully transcribed.

3.6.2.1 Interviews with Residents / Persons Responsible

3.6.2.1.1 Setting

The interviews with residents or their person responsible were conducted immediately upon completion of the quantitative data collection as agreed by all participants. Interviews with all residents occurred in the privacy of their own rooms. Due to the lack of available office or meeting-room space, interviews with persons responsible took place in a variety of other settings within the hostel, including garden areas, the hostel manager’s office or the staff meeting room, or a quiet alcove within the facility. Two interviews were conducted in the corner of a hallway, and one interview took place at the person responsible private residence as this was the most convenient for them.

These settings were not always ideal and sometimes led to interruptions from other residents or family members. While the interruptions did not deter from the flow of the interview, they did require me to delete unnecessary data from the interview transcripts.

3.6.2.1.2 Interview Format

The interviews with participating residents or their person responsible were conducted without any predefined structure and began with a single open-ended question. Since the focus was to explore how they perceived their own or their loved one’s health and
future care needs, they were asked: ‘Is there anything you would like to tell me about your health or how you would like your care to be managed in the future?’

The purpose of posing open-ended questions is to avoid pre-empting issues and instead allow the participant to set the agenda. While allowing participants to speak freely and at length should provide data with greater depth and detail (Morse and Field, 1995), this was not always achieved by posing the above question. Some residents asked for clarification of the question. Since this open-ended question was difficult for the resident participants to answer, the researcher split the question into two parts: ‘How do you see your health at the moment?’ and ‘How do you see your care being managed in the future?’ Occasionally participants would need a little prompting and the researcher would say something such as, ‘tell me more about …’ or the researcher would need to re-direct participants to the topic with prompts such as ‘you mentioned before…’.

Interviews with residents and persons responsible ranged between 5 and 32 minutes, but most interviews averaged 20 minutes. There were two reasons why a few interviews were short. Firstly, many of the residents were very frail and secondly, some participants found it difficult to elaborate in more detail about their health and their care stating that both their care and health was ‘good’.

3.6.2.2 Interviews with Aged Care Staff

3.6.2.2.1 Setting

Interviews with aged care staff were conducted in a variety of areas within the hostel including the handover room, the staff tearoom, the nurses’ station, the hostel manager’s office, and an outside staff rest area. The nurses’ station was not ideal for conducting the interview as other staff would occasionally interrupt the interview to collect notes or to attempt to access the central computer. At one site, the manager interrupted the interview on two occasions to ask the participating staff member to do something. This was despite having agreed on the day we met that this would be a convenient time to conduct the interview. While these interruptions did not pose a
significant problem, it did require me to re-phrase the question in order for the staff member to re-focus and find the thread. Overall, interviews were conducted during the quieter periods of the hostel schedule. Within the rural site, mid-afternoons following handover were more convenient; at the metropolitan site mid-mornings after handover were preferred.

3.6.2.2.2 Interview Format

Semi-structured interviews were used to address the questions related to aged care staff’s understandings and perceptions of a palliative approach, to identify any issues or gaps in this approach to care, and to explore how age care staff recognise and respond to residents’ needs. The length of individual interviews for managers/supervisors ranged between 10 to 60 minutes; for the one-on-one interviews conducted with five PCAs, the duration ranged between 14 and 44 minutes while the group interviews with the remaining PCAs took between 16 and 31 minutes. Overall, aged care staff interviews averaged 30 minutes, only a few were shorter due to the available time they could spare from their busy workload.

Semi-structured interviews involve a mix of ‘open’ and ‘closed’ questions (Carter & Henderson, 2006) whereby the questions are planned but flexible. The advantage of conducting semi-structured interviews is that they allow participants the opportunity to elaborate on areas they feel are important. The investigator may also probe for more detail or return to the same topic for clarification as the interview progresses. Carter and Henderson (2006) explain that semi-structured interviews allow the respondent to develop their own narrative while the investigator maintains overall control of the interview via a structured topic guide which covers the areas considered important to the research questions. The topic guide used with managers of the RACFs in this study can be viewed in Appendix 12.

PCAs participated in a semi-structured, one-on-one or group interview. As stated earlier, the preferred approach of conducting focus groups with PCAs was not possible due to staffing numbers and shift allocations. Instead, five PCAs were
interviewed individually, while 19 others participated in six groups of two, one group of three and one group of four.

It has been suggested that group interviewing be ‘limited to those situations where the assembled group is small enough to permit genuine discussion among all its members’ (Stewart & Shamdasani, 1990, p. 10). The key difference between group interviews and focus groups is group interaction (Carter & Henderson, 2006). While focus groups require the researcher to facilitate the discussion of set topics so that similarities and differences within the group can be explored (Carter & Henderson, 2006), group interviews, such as the ones conducted in this study, rely on the researcher posing questions to which the participants respond in turn.

3.7 Data Analysis

3.7.1 Quantitative Data Analysis

For analysis of the quantitative data, the software program SPSS Version 17 was used. Since the purpose of the study was to describe high-level care residents’ demographics as well as any unmet physical, psychological or spiritual needs – rather than carry out statistical testing to explore differences – descriptive statistics have been used to summarise the characteristics of the 93 participating high-level care residents. The data, a mixture of continuous and categorical variables, are represented through frequency distributions, bar charts, and frequencies and percentages. Means, standard deviations (median if skewed) and 95% confidence intervals (CI) were used with POS, ESAS and BI assessments. For data that were skewed, the 95% CI of the median was calculated using a formula provided by Sheskin (2007, p. 234). In keeping with not performing classical statistical testing in this study, 95% CIs were used to identify differences/similarities in scores between residents and guardians. Confidence intervals provide a range that captures the ‘true’ value of the population mean with 95% probability (Kuzma, 1992). Intervals that completely or mostly overlap can be considered similar, and intervals that have a small or nonexistent overlap can be considered different.
3.7.2 Qualitative Data Analysis

The interviews were audio recorded and transcribed by a professional transcription service that signed a University confidentiality agreement prior to initiating the service. The interviews were digitally recorded and sent to the professional typing service via a secure network requiring a personalised login password. The investigator received the typed transcriptions via the same network. Accuracy of the transcriptions was checked by reading the content and re-listening to the recordings. Only a few misspelt medical terms required adjustment.

This process of listening to the recordings and following the transcripts allowed me to reflect on, and immerse myself in, the data. Immersion in the data occurs when it is extensively read and re-read, and there is a process of ‘dwelling’ on the data before focusing attention to detail (Tesch, 1990). It is precisely when researchers immerse themselves in the data that the rigour of qualitative data is most apparent (ibid.).

The first task towards developing relevant themes was to read and re-read the interview transcripts in their entirety. After re-reading the transcripts several times, they were coded to highlight all significant sentences and statements in relation to the aged care staffs’ understandings of a palliative approach, and their perceptions of how this approach was being applied in the hostel setting. Residents’/persons’ responsible transcripts were searched for their perceptions of their health, the provision of care and how they perceived their care being managed in the future.

Although clearly my professional experience in palliative care nursing makes me an expert in this field, I did take seriously the need to question my own assumptions about the data. To maintain some distance and be able to discriminate meaningful components in the data, analysis strategies were adopted from van Manen (1990) with the goal of developing meaningful themes. I examined the transcripts for common threads to obtain a ‘holistic’ view of the data. Morse and Field (1995, p. 141) describe the process of theme development as ‘...significant concepts that link substantial portions of the interview together’.
Evidence of methodological accuracy in qualitative research is described as ‘rigour’ (Donovan & Sanders, 2006). Speziale and Carpenter (2007) claim the rigour in qualitative research is ‘demonstrated through the researcher’s attention to and confirmation of information discovery’ (p. 49) with a view to accurately representing the participants’ experiences. In qualitative research, rigour is sought through establishing credibility and trustworthiness of the processes both of eliciting the data and of extracting findings from this data. Thus, to ensure rigour, the research process should be transparent and provide an ‘audit trail’ for scrutiny (Denzin & Lincoln, 1994; Donovan & Sanders, 2006).

The qualitative data in this study was initially coded using the software package NVivo 8 designed to assist with the management of very large quantities of data. The approach to the qualitative data analysis was guided by the work of van Manen (1990) using thematic data analysis and involved the following stages: initial descriptive categories, interpretative coding, identification of categories, and identification of themes. Themes were identified inductively, that is, they were developed from the data rather than from predetermined theory. Due to there being two groups of interview participants (residents/persons responsible and aged care staff), analysis required focusing on one group at a time. As detailed earlier, this involved reading and re-reading of the transcripts several times during which initial codes were developed. To begin with, line-by-line coding of the resident and person responsible transcripts using NVivo 8 software produced the first level of coding or open coding (Coffey & Atkinson, 1996; Straus & Cobin, 1998) whereby 55 free nodes with 557 statements were extracted from the data (see Appendix 13 for examples of the early coding process).

After the initial coding using NVivo software, manual coding was used grouping computer data sheets to develop possible categories and eventually themes. The data was re-read and the recordings of the interviews listened to again to extract all significant sentences and statements. This process allowed me to get a deeper sense of meaning and examine differences and similarities in the data. To prevent drifting from the meaning of codes during this process of coding, memos were written about their meaning (Creswell, 2009). Sub-categories were then grouped together to form larger
categories capturing the main dimensions of issues. During this process of coding and creating categories and possible themes, I displayed the various stages of coded data in a range of tables to facilitate comparison (Miles & Huberman, 1994). The steps taken during the early process of developing themes from initial coding to categories are highlighted in Appendix 13. Continuous comparisons were made between words, sentences, paragraphs, codes and categories, the purpose of which was to identify similarities and differences in the data (Holloway & Wheeler, 2010, p. 179).

Once the initial themes were developed from the resident and person responsible interviews, I moved on to the aged care staff interviews. Initial line-by-line coding using NVivo 8 software with the aged care staff transcripts produced the first level of coding whereby 59 free nodes with 311 statements were extracted from the data (see Appendix 14 for example of the early coding process). The same steps as described for the resident and person responsible transcripts were conducted with the aged care staff transcripts.

Finally, level three coding was conducted, whereby all the categories and subcategories were united to form themes drawn from the features of the participants’ experiences (Ritchie & Spencer, 2004). During this process, I repeatedly met with my supervisors for peer debriefing in which the developing categories and themes were reviewed and questioned for a deeper understanding. The strategy of peer review, whereby another person reviews the interpretation of findings, adds to the accuracy and validity of the account (Creswell, 2009). This method of discussing and refining codes, categories and themes with my supervisor helped me to remain focused on data relevant to the research problems (Donovan & Sanders, 2006).

Sandelowski (1993) argues that auditability is another strategy for achieving rigour in qualitative research. Auditability refers to the clear explanation of the trail of decisions made during the progression of events in the study, from the beginning to the end. Auditability can be achieved by including the description of how the researcher became interested in the subject, how the researcher views the subject matter in the study, the specific purpose of the study, how participants became involved and were approached in the study, how data was collected and for what
period, and, finally, how data was analysed and presented. Evidence of these points is demonstrated in this thesis report.

### 3.7.2.1 Reporting Qualitative Data

In this thesis, quotations from the transcripts are used to illustrate the findings. The quotations use the participants’ own words and have been transcribed verbatim. A limitation of verbatim transcriptions is the loss of tones and inflections which give meaning to the words. In addition, since it is not possible to present all of the quotations, only a representative selection is given. To ensure participant anonymity, names and other identifying data have been removed from the quotes and participants are identified by pseudonyms and numbers (see Appendix 15). Square brackets [square] used within direct quotes from the participants’ responses indicate the author’s words while ellipses (...) indicate where words not relevant to the discussion have been omitted from the transcript without altering the meaning of the text.

### 3.7.3 Integrating Quantitative and Qualitative Data

In this mixed method design, data was collected concurrently, but analysis occurred separately. The dilemma of mixed methods designs is how to integrate the findings where each research approach was used to address different aspects of the research problem. While a significant amount of data collected was collected using the two approaches and can independently give different perspectives to the phenomenon being studied, I have synthesised the data, using the pertinent findings of one approach to enhance the findings of the other approach. The aim of blending the data was to provide a more robust account of the older persons’ health status and needs and to describe how aged care staff provide care to these high-level care residents within hostel settings. This synergy of data occurs in Chapter Eight, the discussion chapter.
3.8 Ethical Considerations

3.8.1 Residents / Persons Responsible

Prior to commencing the study, all potential participants were given an Information Statement which outlined the project and assured participants that all information given would be treated confidentially during the analysis stage and that anonymity would be preserved in published results. A written Consent Form was completed by all participants taking part in the questionnaires and interviews. Residents/persons responsible participants were reassured that participation or withdrawal from the study would not in any way affect their future treatment or care provided by the aged care facility (nil participants withdrew).

In the event of participant becoming fatigued or distressed during the questionnaire or interview, data collection would be stopped. The participant would be given the opportunity either to suspend the questionnaire or interview for a short time, or to suspend participation and recommence another day, or to terminate participation and withdraw from the study with a request that the information collected not be used. Should a critical issue arise during interviews, this would be discussed with the participant, and, if necessary, with the appropriate manager/coordinator. Being a registered nurse with expertise in the specialty of palliative care and accustomed to working with patients with a life-threatening illness who may experience fatigue or distress related to their condition, I felt confident in being able to assess participants for any such need.

A few issues were experienced in relation to the qualitative data collection. During one interview, the participating resident began to moan and cry. I asked the participant whether she wanted to stop the interview but she explained that she was experiencing an episode of intermittent pain which she assured me would pass. When I offered to call a staff member to attend to her, she explained she was ‘frightened’ to tell staff. I remained concerned about the severity of her pain but the resident insisted on continuing with the interview. Only when the interview was finished did she give me permission to approach and inform the manager of her situation.
One person responsible became tearful during her interview and given the opportunity to stop. She declined, explaining that she wished to continue, stating that she was still grappling with coming to terms with her husband’s cognitive decline and his need to be permanently placed in the hostel.

During the interview, several residents diverged to talking about their families and recounting events that had occurred during their lives. While I listened attentively to their stories for a period of time, I would need to gently steer them back to the research question. I recall interviewing one resident just prior to lunch. I could hear staff in the corridors talking to residents as they directed them to the central dining room. I reminded the resident I was interviewing that it was now lunchtime and we needed to wind up our interview. He was not concerned about this and was intent on completing his story. A PCA interrupted on two occasions to check whether the interview was finished and whether she could now take the resident to the dining room in his wheelchair. On each occasion the resident sent her away. I grew increasingly concerned that he would miss lunch altogether and eventually I had to end the interview. I then wheeled the resident to his place in the dining room.

A small number of residents, once the interview had commenced, requested further reassurance that the information would remain confidential. This was despite reading or being read the Information Sheet and Consent Form prior to commencing the interview. On two occasions, the resident felt they might ‘get in trouble’ and feared retribution for their negative comments voiced in the interview. Needless to say, I reassured them that everything they said would be treated confidentially and re-explained how the information would be non-identified. On two occasions, once the interview had been completed, the residents requested that the audio recording be played back so that they could hear what they sounded like.

3.8.2 Residents’ Medical Records

Medical records were accessed on site, at a location specified by the facility. No records left the premises or were taken from the location nominated by the facility. To
ensure confidentiality, information pertaining to a participant’s medical record was non-identified at the time of data collection. No names or contact details were collected on the data extraction form. That code was the only form of identification appearing on the audit sheet which otherwise captured only de-identified demographic data. The maximum number of records the researcher was able to hold at any one time for data extraction was determined by the organisation.

3.8.3 Aged Care Staff

All potential participants were given an Information Sheet which outlined the project and assured participants that all information given would be treated confidentially during the analysis stage and that anonymity would be preserved in published results. A written Consent Form was completed by all participants taking part in the interviews. Participants were assured that they could withdraw from the research at any stage without prejudice, in particular without affecting their relationship with their employer (nil participants withdrew).

One staff participant became tearful during the interview and given the opportunity to cease the interview. The participant declined and we continued with the interview. Once the interview was completed the researcher invited the participant to talk about what was distressing her. She revealed that recalling the memory of a particular resident with whom she had developed a strong attachment had evoked this reaction. Being able to vocalise this feeling clearly reduced the distress she had been feeling.

I also experienced some emotional moments listening to the stories told by staff and residents. One particular event that still brings tears to my eyes was the story relayed by a manager about a resident’s death and how the other residents rallied in the corridor to farewell this person. She explained that normally staff tried to keep residents in their rooms when removing the body from the floor. But on this occasion, several residents formed a line along the corridor to farewell this particular person and pay their respect. The full story of this incident is detailed in Chapter Seven, p. 213.
3.8.4 Data Storage

Participants were given an identifying code number, the master list of which was kept separate from the data in a locked filing cabinet in the investigator’s office at the University of Sydney. A register was also created by the researcher, and stored separately from non-identified data. All other confidential material (digital recordings, coding information and audit forms) were stored in a secure location at the investigator’s office at the University of Sydney. All confidential material will be destroyed seven years after publication (National Health & Medical Research Council, 2007). Digital recordings were wiped following transcription and checking for accuracy, as required by the ethics committee. Any identifying information was removed from interview transcripts, and these were stored in a password protected file on the researcher’s computer.

3.8.5 Dissemination of the Findings

Participants were informed that results from the study might appear in publications including in the investigator’s doctoral thesis (as documented in the information sheet) but were assured that no identifying names would be used. At the end of the study, the intention is to feedback the study findings to the participants and other interested staff. A written summary of the study’s findings will be sent to interested participants and to the participating aged care facilities. The participants will also be invited to attend an informal gathering for presentation of a summary of the findings.

Preliminary findings of the study have been presented at several state and national conferences so far. Further dissemination of findings through presentations to relevant conferences and the submission of papers to appropriate peer-reviewed journals is anticipated.
3.9 Conclusion

A mixed-method strategy combining concurrent qualitative and quantitative data approaches was used in this doctoral study so that the complexities surrounding a palliative approach in the care of high-level care residents living in hostel settings might be better understood. By using more than one method, it was anticipated that a more complete and deeper picture of the phenomena being studied would be obtained. The quantitative and qualitative results are presented in the separate chapters following, while the integrated results from both components of this research are discussed in Chapter Eight.
CHAPTER FOUR:

Descriptive Characteristics of the Resident Participants, Organisational and Managerial Data

This chapter presents the results and analysis of the quantitative data. Quantitative data collection was undertaken to specifically address the first research aim; to describe high-level care residents living in hostels in relation to their demographic information (e.g., age, gender, marital status and family support), medical illnesses, co-morbidities, physical functioning, individual symptoms and/or cluster symptoms.

Descriptive statistics were used to summarise the characteristics of the 93 high-level care (HLC) residents participating or participating by proxy (that is using the person responsible on behalf of the resident), the prevalence of symptoms and the number of symptoms per resident, associations between symptoms and diagnosis, and the functional status and psychosocial well-being of participating residents. This included examining frequency distributions, means, standard deviations and confidence intervals for normally distributed data and median and interquartile ranges for skewed data. The tools used to measure symptoms in this study included the Patient Outcome Score (version 2) and the Edmonton System Assessment System; functional status was measured using the Barthel Index. To identify symptom clusters, comparison of means, standard deviations, and 95% confidence intervals of the symptom measures, functional status and current major diagnoses were examined. The final section summarises and draws attention to the key points that are significant for this research and which are discussed in more detail in Chapter Eight.

Two geographically different residential age care facilities participated in the study. This study did not seek to compare the results across the geographical sites, and
overall there was limited variation in the data. However, where differences exist, these will be pointed out in the relevant sections

4.1 Profile of Hostel Resident Participants

4.1.1 Dependency Levels

The RCS was the funding instrument in place at the time of recruitment and data collection and was used as the criteria to determine high-level care residents in this study. As noted in the glossary, the RCS comprises of 20 questions, which are given variable response weightings (A – D) which can total a score of 100. Classification levels one to four are the highest scoring categories, indicating the resident is requiring high-level care. The percentage of residents classified as requiring high-level care in the participating RACFs is shown in Figure 4.1. A total of eight hostels participated in the study, three from the rural site and five from the metropolitan site. Of the total 412 hostel beds available at the sites, 58% (n= 237) of residents were classified as requiring high-level care according to the RCS 1-4 categories.

![Figure 4.1: The proportion of residents classified as high-level care versus the total number of hostel beds in the two geographical sites](image-url)
Interestingly, the results show a considerable difference between the percentage of residents requiring high-level care in the rural facility and those requiring high-level care in the metropolitan facility during the period from May 2008 to December 2008. Among the three hostels at the rural site with a total of 78 beds, 95% (n=74) were classified as requiring high-level care. Among the five hostels at the metropolitan site with a total of 334 beds, 49% (n=163) of residents were classified as requiring high-level care. In view of this considerable difference, the data were further analysed, Figure 4.2 provides a further breakdown between the number of high-level care residents, and percentages of total bed numbers for all hostels included in this study (refer to footnote in Figure 4.2 for geographical site of hostel).

![Figure 4.2: Number of high-level care residents and percentage of total beds per hostel](image)

*Hostel 1-3 = rural site
*Hostel 4-8 = metropolitan site
As can be seen from Figure 4.2, the greatest proportions of high-level care residents were at hostels one, two, and three at the rural site and hostels four and six at the metropolitan site.

4.1.2 Separations from Hostel in Previous Six Months (2008)

The number of resident separations from a hostel was measured, as this to some extent reflects the ability of the facility/aged care staff to provide appropriate care for high-level care residents, particularly when the resident requires end-of-life care (Grbich, Maddocks, Parker, Brown, Willis & Hofmeyer, 2005). Separations in this study included death in the hostel and permanent transfer to another setting. Managers were asked to report on the number of resident separations over the previous six months (see Appendix 10). Data were collected from the hostel manager who manually checked the database on a month-by-month basis as this information was not routinely collated. The six-month timeframe for this retrospective data collection was comparable at both sites: For the metropolitan site, the period included January to June 2008; for the rural site, it included December 2007 to May 2008. The number of resident separations that occurred among the eight hostels during this timeframe was 17% (n=72). Of the 72 resident separations, 18% (n=14) of residents had died in the hostel and 82% (n=60) had been transferred to another setting (acute hospital or another aged care facility) and did not return (see Figure 4.3). It should be noted that there was a small number (n=6) of separations for which details were not available. As reflected in Figure 4.3, higher number of transfers to another setting occurred at the metropolitan site compared to the rural site. Details regarding residents’ outcome of transfer to another setting, such as death in acute hospital setting or nursing home, were not known for all hostels and have therefore not been included.
4.1.3 Hospital Admissions or Emergency Department Visits over Previous Six Months (2008)

Managers were asked to report on the number of episodes residents who had required a hospital admission or emergency department visit during the previous six-month period (the same as for separations) and provide the reason for transfer. Data relating to these were only available for seven of the eight hostels. Hostel eight from the metropolitan site with a total of 73 beds was unable to supply this data. Therefore, data for resident hospital admission or emergency department visit was across a total of seven hostels. Among the seven hostels with a total of 339 beds, 37% (n=126) of all residents had required a hospital admission or emergency department visit over the past six months. The reasons for these admissions or visits have been grouped according to eleven common issues experienced by older people identified in the literature (Brandt et al., 2006; Ingarfield et al., 2009) and are presented in Figure 4.4 below.
Figure 4.4: Reason for resident admission or visit to an emergency department over a six-month period

* data unavailable for five residents from Hostels 1 to 7, and for all residents from Hostel 8

The most frequent reason for residents admission to hospital or visited an emergency department was the result of a fall. As can be seen in Figure 4.4, of the total 126 hospital admissions/ emergency department visit, nearly a third of them were due to a fall (29%, n=35). This was followed by septicaemia / infection (17%, n=21) and frailty (13%, n=12) as the most common reasons. The category ‘other’ has been created to group the 19 admissions or visits to an emergency department that were less frequently experienced conditions or reasons. Figure 4.5 below details the 13 subcategories within the ‘other’ group (n=19).
4.1.4 Participating Residents / Persons Responsible

As noted in Chapter Three, a total of 58% (n=237) of residents in the eight hostels of the two residential aged care facilities (RACFs) were classified as requiring high-level care according to the Residential Classification System (RCS). Of these potential 237 candidates, over a third participated in the study (39%, n=93), 30% (n=72) being residents and 9% (n=21) were persons responsible. Of the 21 persons responsible for the resident and who participated in the study, 62% (n=13) were the resident’s spouse, 33% (n=7) were daughters and 5% (n=1) was a nephew. While attempts were made to contact sons listed as the person responsible for a resident, the only one who expressed an interest at initial contact did not actually participate due to other family commitments; other sons were not available.
4.1.5 Socio-demographic Characteristics of Residents

Socio-demographic characteristics of the high-level care resident participants presented here were collected from the residents’ medical files by the researcher and are shown in Table 4.1. Slightly more women than men participated in the study. The age of the participants ranged from 68 to 100 years. The combined mean age for both women and men was 86.33 years (SD 6.12). Nearly two-thirds of residents were widowed. In line with the participant criteria, all participants spoke English and one was bilingual. Of the 93 participants, 93% (n=86) were born in Australia, 5% (n=5) were born in the United Kingdom, 1% (n=1) was born in the United States of America and 1% (n=1) was born in Russia.

Just under half (44%, n=41) of the residents were living alone prior to hostel admission, 30% (n=28) were living with a partner, 13% (n=12) were living with an adult child, 12% (n=11) were living in another hostel, and 1% (n=1) was living with another family member. Prior to admission to the RACF, 51% (n=47) of the participants were living in a house, 18% (n=17) were living in a unit, 18% (n=17) were living in a self-care unit in a retirement village and 13% (n=12) were living in another hostel.

The amount of carer support available in the home environment can influence the ability of the person with a chronic complex illness to remain in that environment (Kristjanson et al, 2003; ABS, 2008). Over half the residents (53%, n= 49) listed two to three persons as carer supports; 86% (n=80) of those listed were their adult children.
Table: 4.1  Socio-demographic characteristics of hostel residents (*n*=93)

<table>
<thead>
<tr>
<th>Socio-demographic Characteristics</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age groups</strong> *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-69 years</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>70-74 years</td>
<td>1</td>
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</tr>
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<td>75-79 years</td>
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<td>9</td>
</tr>
<tr>
<td>80-84 years</td>
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<td>19</td>
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<td>85-89 years</td>
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<td>43</td>
</tr>
<tr>
<td>90-94 years</td>
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<td>15</td>
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<tr>
<td>95 years +</td>
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<td>11</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45</td>
<td>48</td>
</tr>
<tr>
<td>Female</td>
<td>48</td>
<td>52</td>
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<tr>
<td><strong>Marital status</strong></td>
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<td></td>
</tr>
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<td>60</td>
</tr>
<tr>
<td>Married</td>
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<td>25</td>
</tr>
<tr>
<td>Single</td>
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<td>8</td>
</tr>
<tr>
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</tr>
<tr>
<td>Australia</td>
<td>86</td>
<td>92</td>
</tr>
<tr>
<td>UK</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>USA</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Russia</td>
<td>1</td>
<td>1</td>
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<tr>
<td><strong>Language spoken</strong></td>
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<td></td>
</tr>
<tr>
<td>English</td>
<td>93</td>
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</tr>
<tr>
<td><strong>Living status prior to hostel</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>41</td>
<td>44</td>
</tr>
<tr>
<td>With partner</td>
<td>28</td>
<td>30</td>
</tr>
<tr>
<td>With child</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>With other family</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other Hostel</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td><strong>Previous accommodation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House</td>
<td>47</td>
<td>51</td>
</tr>
<tr>
<td>Unit</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td>Self-care unit in RACF</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td>Hostel</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td><strong>Carer support prior to entry</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nil</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>1-2 people</td>
<td>52</td>
<td>56</td>
</tr>
<tr>
<td>3-4 people</td>
<td>26</td>
<td>28</td>
</tr>
<tr>
<td>5-6 people</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>7 or more</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

* (combined mean age for both women and men = 86.33 years, SD 6.12)
4.1.6 Primary Health Diagnoses

As there is a strong link between ageing and chronic diseases, such as cardiovascular disease, cerebrovascular disease, chronic kidney disease, chronic obstructive pulmonary disease, and cancer (AIHW, 2009), it is important to gain an understanding of the health problems of residents in hostel settings. The primary health diagnosis was obtained from the participating residents medical records by the researcher.

The primary health diagnoses of participating residents have been grouped into nine diagnostic groups (refer to Figure 4.6). The ‘neurological’ group included cerebrovascular accident, meningioma, and brain injury from a motor vehicle accident, Parkinson’s disease and dementia. The ‘cardiac’ group included ischaemic heart disease, chronic congestive heart failure, cardiomyopathy, aortic valve block and aortic valve leakage. The ‘respiratory’ group included chronic airway limitation or pulmonary fibrosis. The ‘connective tissue and bone’ disorders included osteoarthritis and Paget’s disease. The ‘mental health’ group includes depression and bipolar affective disorder. The ‘renal’ group refers to a diagnosis of chronic renal failure. The ‘endocrine’ group included a diagnosis of diabetes. The diagnostic group ‘other’ included less common disorders, such as degeneration and chronic back pain, which do not fall into the categories already mentioned.

Figure 4.6: Grouped primary health diagnoses of resident participants
As can be seen from the chart in Figure 4.6, the primary health problem for the majority of residents (96%, n=89) was a non-malignant diagnosis. Of the few malignant diagnoses (4%, n=4) that did exist, three residents were diagnosed with prostate cancer while one had an unknown primary cancer.

The eight categories of non-malignant diagnoses were represented as follows: neurological disease (49% n= 44), cardiac disease (14%, n=13), respiratory disease (8%, n=7), connective tissue and bone disorders (7%, n=6), endocrine disorders (4%, n=4), mental health disorders (4%, n=4), renal disease (2%, n=2), and other (9%, n=8) (see Figure 4.7). The most common current health problem for all residents was a neurological disorder (49%, n=44) of which dementia accounted for 32% (n=29) and cerebrovascular accident (CVA) accounted for 17% (n=15). For women, the second most common grouped health problem was ‘other’, followed by a cardiac or CVA diagnosis. For men, the second most common current health problem was CVA diagnosis, followed by the grouped health problem ‘other’ or a cardiac diagnosis.

![Figure 4.7: Grouped non-malignant primary health diagnoses](image-url)
4.1.7 Concurrent Health Problems

The presence of multiple health conditions tends to be associated with more severe disability, and multiple concurrent illnesses can influence the decision processes for treatment (ABS, 2003). This study identified that over half the residents had three or more concurrent health problems (53%, n=49) (Figure 4.8). The range of concurrent health problems was between 0 and 9 with a median of 3 concurrent health problems (Interquartile range: 2-4). Multiple concurrent health problems were identified and included health problems such as, hypertension, osteoarthritis, depression, anxiety, chronic airways limitation, transient ischaemic attacks, chronic pain, diverticular disease, glaucoma, leg ulcers, depression, macular degeneration and duodenal ulcers.

![Number of concurrent health problems among resident participants](image)

Figure 4.8: Number of concurrent health problems among resident participants
4.1.8 Length of Time in Hostel

Length of time since initial admission into the hostel was collected from the resident’s medical record and was recorded in weeks, months and years, and then re-categorised into fourteen groups as shown in Table 4.2.

Table 4.2: Length of time since hostel admission

<table>
<thead>
<tr>
<th>Length of time in months</th>
<th>Number of participants</th>
<th>Percentage</th>
<th>Cumulative percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 3 months</td>
<td>3</td>
<td>3.2</td>
<td>3.2</td>
</tr>
<tr>
<td>3 - &lt; 6 months</td>
<td>6</td>
<td>6.5</td>
<td>9.7</td>
</tr>
<tr>
<td>6 - &lt; 9 months</td>
<td>6</td>
<td>6.5</td>
<td>16.2</td>
</tr>
<tr>
<td>9 - &lt; 12 months</td>
<td>12</td>
<td>12.9</td>
<td>29.1</td>
</tr>
<tr>
<td>12- &lt;15 months</td>
<td>4</td>
<td>4.3</td>
<td>33.4</td>
</tr>
<tr>
<td>15 - &lt;18 months</td>
<td>8</td>
<td>8.6</td>
<td>42.0</td>
</tr>
<tr>
<td>18 - &lt; 21 months</td>
<td>10</td>
<td>10.8</td>
<td>52.8</td>
</tr>
<tr>
<td>21 – &lt; 24 months</td>
<td>5</td>
<td>5.3</td>
<td>58.1</td>
</tr>
<tr>
<td>2- &lt; 3 years</td>
<td>10</td>
<td>10.8</td>
<td>68.9</td>
</tr>
<tr>
<td>3 - &lt; 4 years</td>
<td>12</td>
<td>12.9</td>
<td>81.8</td>
</tr>
<tr>
<td>4 - &lt; 5 years</td>
<td>7</td>
<td>7.5</td>
<td>89.3</td>
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<tr>
<td>5 - &lt; 8 years</td>
<td>4</td>
<td>4.3</td>
<td>93.6</td>
</tr>
<tr>
<td>8 + years</td>
<td>6</td>
<td>6.4</td>
<td>100</td>
</tr>
<tr>
<td>TOTAL</td>
<td>93</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

The length of time residents had lived in their current hostel ranged from 1 month to 276 months (23 years). As the data were positively skewed, the median length of time was 19 months (Inter-quartile range: 10 - 40 months). More than two-thirds of the residents (69%, n=69) had resided in their current hostel for 13 months or more.
4.1.9 Length of Time Categorised as High-level Care in the Hostel

The length of time a resident lives in an RACF impacts on the staffs’ familiarity with them as individuals and with their wishes, priorities, and beliefs, as well as how they want to be cared for towards the end of life (Froggatt & Payne, 2006). Therefore, any examination of a palliative approach in the hostel setting would need to consider the high-level residents’ length of stay. Also, as residents who have a progressive chronic condition often have a different illness trajectory compared to people with cancer and may have more prolonged needs, it is important to examine the length of time a resident requires high-level care (Lynn, 2001). The length of time residents had been categorised as requiring high-level care according to the RCS collected from the resident’s medical file has been grouped into fourteen categories as shown in Table 4.3 below.

Table 4.3: Length of time categorised as requiring high-level care

<table>
<thead>
<tr>
<th>Length of Time</th>
<th>Number of participants</th>
<th>Percentage</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 3 months</td>
<td>4</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>3 - &lt; 6 months</td>
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<td>8.6</td>
<td>12.8</td>
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<td>6 - &lt; 9 months</td>
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<td>9.7</td>
<td>22.5</td>
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<td>9 - &lt; 12 months</td>
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<td>20.4</td>
<td>42.9</td>
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<td>12- &lt;15 months</td>
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<td>49.4</td>
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<td>6.5</td>
<td>55.9</td>
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<td>18 - &lt; 21 months</td>
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<td>12.9</td>
<td>68.8</td>
</tr>
<tr>
<td>21 – &lt;24 months</td>
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<td>5.4</td>
<td>74.2</td>
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<td>2- &lt;3 years</td>
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<td>9.7</td>
<td>83.9</td>
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<tr>
<td>3 - &lt; 4 years</td>
<td>8</td>
<td>8.6</td>
<td>92.5</td>
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<tr>
<td>4 - &lt; 5 years</td>
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<td>5.4</td>
<td>97.9</td>
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<td>5 - &lt;8 years</td>
<td>2</td>
<td>2.1</td>
<td>100</td>
</tr>
<tr>
<td>8 + years</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>93</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>
Data for the length of time a resident was categorised as high-level were positively skewed, the median length of time was 15 months (Inter-quartile range: 9-24 months). Sixty-three percent (n=59) of the 93 residents were categorised as high-level care on admission to the hostel.

4.1.10 Residents’ Functional Ability / Dependence

The functional ability of a person reflects their level of dependency and highlights the degree of care and assistance required (Fogel, Hyman, Rock & Wolf-Klien, 2000). It is thus important to examine the functional ability of hostel residents in facilities where staffing numbers and skill mix differ from those in nursing home settings.

In this study, the total Barthel Index (BI) score was assessed to determine participants’ overall general functional ability and dependence, as well as an individual item score to identify specific functional needs. As personal care assistants provide the majority of hands on care to residents in hostels, residents’ functional ability was established by the researcher asking the personal care assistant assigned to that particular resident to respond to questions related to their activities of daily living. The BI was recorded on the day of the resident’s participation in the study. The results are presented in Figure 4.9 below.
As can be seen in Figure 4.9, the total BI scores ranged from 10 to 90. Although the literature offers different interpretations of the scoring and cut-off points, the most frequently cited range score of 60/100 is when the person is considered to have moderate to slight dependence and a score of 40/100 is where the person is considered to have moderate to severe dependence (Cabarnero-Martinez, Cabrero-Garcia, Richart-Martinez & Munoz-Mendoza, 2009). In this study, 24% (n=22) of residents scored 40 or below and 28% (n=26) of residents scored 60 or above on the BI. The majority of residents (72%, n=67) scored 50 or below with 50% (n = 47) scoring 45 or below in the assessment. This indicates that the majority of residents were very dependent for most activities.

The reliability of the BI when rated by the personal care assistant was measured to yield a Cronbach alpha score of 0.69. The alpha coefficient ranges from 0 to 1, with higher values indicating greater reliability. According to Bowling (2006) there is no agreement over the minimum acceptable standards for scale reliability. The present reliability findings of the BI when rated by staff in this study (0.69) were comparable to that obtained by van der Putten and colleagues (1999).

The total BI score and individual item scores were assessed for normality of distribution. Data were normally distributed for the total BI score with a mean score of 47.37 (SD 14.26; minimum score: 10, maximum score: 90; 95% CI: 44.43 to 50.30).
Data for the individual BI items were positively skewed for bathing, grooming and the residents’ ability to climb stairs indicating that residents were more dependent in these activities (see Table 4.4).

Table 4.4: Barthel Index scores for individual items

<table>
<thead>
<tr>
<th>Activity</th>
<th>Mean/ Median</th>
<th>SD/ IQR</th>
<th>95% CI of the mean</th>
<th>Dependent/ needs help (n, %)</th>
<th>Independent (n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeding a</td>
<td>6.13</td>
<td>2.46</td>
<td>0.62 - 6.63</td>
<td>69 (74%)</td>
<td>24 (26%)</td>
</tr>
<tr>
<td>Bathing b</td>
<td>0.00*</td>
<td>0.00-0.00</td>
<td>0.00 - 0.00</td>
<td>76 (82%)</td>
<td>17 (18%)</td>
</tr>
<tr>
<td>Grooming c</td>
<td>0.00*</td>
<td>0.00-0.00</td>
<td>0.00 - 0.00</td>
<td>9 (100%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Dressing d</td>
<td>3.66</td>
<td>2.46</td>
<td>3.14 - 4.16</td>
<td>91 (98%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Bowels a</td>
<td>6.07</td>
<td>3.52</td>
<td>5.34 - 6.80</td>
<td>58 (62%)</td>
<td>35 (38%)</td>
</tr>
<tr>
<td>Bladder</td>
<td>5.43</td>
<td>3.66</td>
<td>4.67- 6.18</td>
<td>64 (69%)</td>
<td>29 (31%)</td>
</tr>
<tr>
<td>Toilet use a</td>
<td>5.21</td>
<td>2.65</td>
<td>4.67 - 5.76</td>
<td>78 (84%)</td>
<td>15 (16%)</td>
</tr>
<tr>
<td>Transfers c</td>
<td>9.14</td>
<td>3.09</td>
<td>8.50 - 9.78</td>
<td>83 (89%)</td>
<td>10 (11%)</td>
</tr>
<tr>
<td>Mobility</td>
<td>9.68</td>
<td>3.67</td>
<td>8.92 - 10.43</td>
<td>74 (80%)</td>
<td>19 (20%)</td>
</tr>
<tr>
<td>Stairs a</td>
<td>0.00*</td>
<td>0.00-0.00</td>
<td>0.00 - 0.00</td>
<td>93(100%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

(n=93) a = maximum score of 10; b = maximum score of 5; c = maximum score of 15
*IQR = Interquartile range

To highlight the variance in residents’ functional abilities, individual BI scores from items one to ten were split into two groups based on the score: dependent/needs help (0,5) and independent (10,15). As illustrated in Table 4.4, the resident’s daily functioning ability indicates a clustering of scores for most items at the low end of the scale indicating the majority of residents in this study were dependent and needed assistance.

All residents were dependent/need help with grooming and stairs. This was followed closely by residents’ need for assistance with dressing (98%, n=91), transfers (89%, n=83), toilet use (84%, n=78), and bathing (82%, n=76).
4.1.11 Physical, Psychological and Spiritual Wellbeing as Rated by the Patient Outcome Score (Version 2) (POS, V 2)

The key principle embedded in a palliative approach to care is the prevention and relief of suffering through early detection and treatment of any physical, psychological, social or spiritual issues identified (Kristjanson et al., 2003). Therefore, an assessment tool which covers all of these domains offers an opportunity for all symptoms affecting the individual to be identified and the quality of palliative care provided measured (Hughes et al., 2004). In order to assess participants’ needs in all of these domains, the POS, v 2 tool was used.

All residents/persons responsible completed the POS, v2 assessment on the day of data collection with assistance from the researcher. The questions were read to the resident or person responsible and the researcher circled their responses on the questionnaire. The 72 residents were asked to recall if they had experienced any of the ten items specified on the POS tool over the past seven days and, if so, to rate their experience according to the specified Likert scale. On average, the POS, v2 questionnaire took approximately ten minutes to be completed. However, on several occasions, residents wanted to expand on their symptoms and health history. In these circumstances the researcher had to sensitively bring the resident back to the items on the questionnaire.

Several residents found it difficult to answer Question Eight regarding self worth (‘Have you felt good about yourself as a person’) while one resident was unable to answer this item. It must be noted here that 9% (n=21) of the participants were proxies (persons responsible) and thus the 21 persons responsible were rating their opinion of the ten items on behalf of residents with dementia. As pointed out in Chapter Three, with subjective items such as psychological symptoms and pain, proxies may overestimate these symptoms.

Internal consistency of the POS, v2 ratings by residents and persons responsible were measured using Cronbach’s alpha. According to Hearn and Higginson (1999), the Palliative Care Outcome Scale (earlier POS version which includes the same questions) has good internal consistency, with Cronbach alpha of 0.65 reported when
rated by patients and 0.70 when rated by staff. In the present study, the overall POS scores as rated by the residents and persons responsible were combined and achieved a consistency score of 0.65 (n=93). When the data were separated according to residents and persons responsible, the Cronbach alpha for residents was 0.66 (n=92), thus a score comparable to that reported by Hearn and Higginson (1999). Since one resident was unable to respond to Question Eight related to self-worth, only 71 residents were included in this calculation. For persons responsible, the Cronbach alpha was 0.60. According to Klien, Sollereder and Gierl (2002), sample size might influence reliability estimates. In this study, the person responsible group consisted of 21 participants compared to 72 participants in the resident group, which potentially contributed to a lower Cronbach alpha.

The total POS, v2 summary score and individual item scores for residents and persons responsible were assessed for normality of distribution. Data were normally distributed for the total POS score with a mean score of 8.82 (SD 5.78; minimum score: 0, maximum score: 23; 95% CI: 7.63 to 10.01). Data were also normally distributed for most individual POS items, but not for Item Five (sufficient information, median score of 0.00), Item Nine (wasted time, median score of 0.00) and Item Ten (personal affairs, median score of 0.00) which were positively skewed, indicating that both residents and persons responsible in this study did not have issues related to these items. It must be noted here that a normal distribution would be highly unlikely in a diverse group of high-level care residents, that is, that a skewed distribution would be considered ‘normal’ for this population.

In keeping with the intention to not employ classical statistical significance testing, 95% confidence intervals (CIs) were used to assess the appropriateness of combining data. The details of these are reported in Table A, see Appendix 16. ‘Sufficient information’ was the only item with a completely non-overlapping CI, while ‘other symptom’ had a relatively small amount of overlap. For all other items, the 95% CIs indicated that the mean (or median) for one group predominantly fell within the plausible range of values for the other. In addition, the 95% CIs for the two groups of total POS scores showed overlap: residents (CI: 7.82 – 10.62) and persons responsible (CI: 5.15 – 9.70). Based on these results, POS data were combined. For individual and
total POS scores, the 95% CIs were generally wider for the persons responsible, indicating less precision in the measurements, which is most likely due to the smaller sample size.

To identify the severity of the individual POS scores from items one to eight (which focuses on physical, psychological, social or spiritual issues), data were split into two groups based on the score: nil to moderate problem (0,1,2) and severe to overwhelming problem (3,4) (see Appendix 16). POS scores for Items 9 and 10 varied from the above and were therefore split into slightly different groups: nil/moderate (1, 2) and severe to overwhelming (4). Table 4.5 highlights the mean POS scores for each symptom and the severity percentage for each symptom.

**Table 4.5: Patient Outcome Scores (POS, v2) for individual items and severity of symptoms**

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean/ Median</th>
<th>SD / IQR</th>
<th>95% CI</th>
<th>Mild/ moderate (n, %)</th>
<th>Severe/ Overwhelming (n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain ^a</td>
<td>1.11</td>
<td>1.16</td>
<td>0.87 - 1.36</td>
<td>81 (87%)</td>
<td>12 (13%)</td>
</tr>
<tr>
<td>Other symptom ^a</td>
<td>0.87</td>
<td>1.03</td>
<td>0.60 - 1.02</td>
<td>85 (91%)</td>
<td>8 (9%)</td>
</tr>
<tr>
<td>Resident anxiety ^a</td>
<td>0.91</td>
<td>1.16</td>
<td>0.67 - 1.15</td>
<td>79 (85%)</td>
<td>14 (15%)</td>
</tr>
<tr>
<td>Family anxiety ^a</td>
<td>0.75</td>
<td>0.98</td>
<td>0.54 - 0.95</td>
<td>90 (97%)</td>
<td>3 (3%)</td>
</tr>
<tr>
<td>Information ^a</td>
<td>0.00*</td>
<td>0.00-1.00</td>
<td>0.00 - 0.00</td>
<td>86 (93%)</td>
<td>7 (7%)</td>
</tr>
<tr>
<td>Support ^a</td>
<td>1.56</td>
<td>1.75</td>
<td>1.20 - 1.92</td>
<td>60 (65%)</td>
<td>33 (35%)</td>
</tr>
<tr>
<td>Depressed ^a</td>
<td>1.05</td>
<td>1.34</td>
<td>0.77 - 1.33</td>
<td>74 (80%)</td>
<td>19 (20%)</td>
</tr>
<tr>
<td>Self worth ^a</td>
<td>1.67^b</td>
<td>1.35</td>
<td>1.39 - 1.95</td>
<td>66 (71%)</td>
<td>26 (28%)</td>
</tr>
<tr>
<td>Wasted time ^b</td>
<td>0.00*</td>
<td>0.00-0.00</td>
<td>0.00 - 0.00</td>
<td>91 (98%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Personal affairs ^c</td>
<td>0.00*</td>
<td>0.00-0.00</td>
<td>0.00 - 0.00</td>
<td>89 (96%)</td>
<td>4 (4%)</td>
</tr>
</tbody>
</table>

(*n = 93) * - one participant was unable to answer

^a: range of scores 0, 2, 3, 4; ^b: range of scores 0, 2, 4; ^c: range of scores 0, 2, 4.

*= median IQR = Interquartile range

While the majority of participants reported nil/moderate problems in physical, psychological, social and spiritual domains, over a third of the residents and persons responsible on behalf of residents (35%, n=33) rated their inability to share feelings with family or friends (support) as severe to overwhelming. This was followed by
28% (n=26) who rated having a low self worth as severe to overwhelming, and a fifth of residents and persons responsible who rated depression (20%, n=19) as severe to overwhelming.

Item 11 was an open-ended option to identify the issue of greatest concern or any problem previously not identified and these were reported in free text. Almost half (47%, n=44) of the residents or persons responsible were able to specify a main problem. Main problems were specified by residents or persons responsible were documented by the researcher in free text and then categorised into four groups, physical, psychosocial, practical and medical concerns, to correspond with the overall domains assessed within the POS tool. Physical problems included a physical symptom or health condition causing physical problems. Psychological problems included problems related to emotional aspects or issues which created concern or stress for family. Practical problems included issues that affected the resident’s way of life in the hostel. Medical concerns included concerns regarding recurrent infections.

Among the participants, 47% (n=44) identified a main problem. Figure 4.10 highlights the issues of greatest concern to the participants. Within these four categories, the most common problems highlighted by the participants were psychological concerns (50%, n=22) and physical (40%, n=18).

Figure 4.10: Main concerns identified in Item 11, Patient Outcome Score
Among psychological concerns, 21% (n=9) identified anxiety as source of their psychological concern, this was followed by behavioural issues (12%, n=5), fear of falling (10%, n=4), separation from spouse (5%, n=2) and feelings of isolation and boredom (4%, n=2). Among the physical concerns, 21% (n=9) identified pain as source of their physical concern, this was followed by reduced mobility (10%, n=4), general decline in condition (7%, n=3) and loss of sight (4%, n=2).

4.1.12 Assessment of Symptoms as Rated by the Edmonton System Assessment System (ESAS)

The Edmonton Symptom Assessment System (ESAS) instrument was used to assess the presence and severity of residents’ psychological and physical symptoms and their global sense of wellbeing (Pautex, Berger, Chatelain, Herrman & Zulian, 2003).

The ESAS consists of nine items rating the severity of multiple symptoms and a tenth item in which any additional symptom not listed can be listed in free text. In this study, both the overall symptom burden, using both the total symptom score and individual symptom score was assessed. For further details regarding the tool and its methods of reporting and interpreting responses refer to Chapter 3, p. 79.

Internal overall consistency of the nine ESAS items when rated by residents and persons responsible combined achieved a Cronbach alpha score of 0.69 (n=93), indicating a reasonable internal consistency. When the data were split according to residents and persons responsible, the Cronbach alpha for residents’ ratings was 0.70, while that for guardians dropped to 0.62. No previous studies could be found where a similar population (older people with chronic illnesses) or person responsible proxies were used to identify the Cronbach alpha. However, once again the small size of the person responsible group (n=21) may have contributed to the low Cronbach alpha.

All participating residents or persons responsible participating on their behalf completed the ESAS assessment on the day of data collection with the assistance of the researcher. Participants were asked if they were currently experiencing any of the nine symptoms specified on the ESAS tool and asked to rate the symptom (0= nil, 10=...
worst possible). The assessment took approximately 10 to 15 minutes to complete. Again, some residents expanded on their symptoms and health history, requiring the researcher to sensitively bring their focus back to symptoms experienced on that day.

The combined total ESAS and the individual item scores for residents and persons responsible were assessed for normality of distribution. Data were normally distributed for the total ESAS score with a mean score of 23.74 (SD: 13.75; minimum score: 1, maximum score: 60; 95% CI: 20.91 to 26.57). Data were also normally distributed for the individual ESAS items apart from nausea, shortness of breath, depression, anxiety, and drowsiness, which were very slightly positively skewed indicating that residents and persons responsible did not have major issues with these symptoms. Again, it should be recognised that a normal distribution for all items would be highly unlikely in a diverse group of high-level care residents.

As previously stated, the intention of this study was to combine the resident and person responsible responses of the individual ESAS item scores. The 95% CIs for the individual ESAS items for the two groups, residents and persons responsible are shown in Table B, Appendix 17. A non-overlapping CI was found for ‘appetite’. ‘Pain’ and ‘anxiety’ showed the smallest actual overlap while the other symptoms (with the exception of ‘nausea’, which could not be calculated) appeared to overlap completely or mostly, indicating that the mean (or median) score for one group fell predominantly within the plausible range of the other. In addition, the 95% CI for the total ESAS score for the residents (CI: 21.24 – 27.93) and persons responsible (CI: 15.4 - 26.24) overlapped. Based on these results, combining the two groups was considered appropriate. For individual and total ESAS scores, the 95% CIs were generally wider for the persons responsible, indicating less precision in the measurements which is most likely due to the smaller sample size.

To identify the severity of symptoms, individual symptom scores from items one to nine were split into two groups based on symptom severity: nil to mild (<5) and moderate to severe (5-10). A cut-off score equal to or greater than 5 has been frequently used when determining severity of symptoms with the ESAS (Dudgeon et al., 1999; Modonesi, Scarpi, Maltoni, Derni, Fabbri, Martini, Sansoni & Amadori,
Table 4.6 highlights the mean ESAS score for each symptom and the severity categories nil/mild and moderate/severe.

| Symptom            | Mean | SD/ IQR | 95% CI      | Nil/ Mild (n, %) | Moderate/Severe (n,%)
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>2.55</td>
<td>3.10</td>
<td>1.91 - 3.19</td>
<td>64 (69%)</td>
<td>29 (31%)</td>
</tr>
<tr>
<td>Tiredness</td>
<td>4.44</td>
<td>3.28</td>
<td>3.76 - 5.12</td>
<td>42 (45%)</td>
<td>51 (55%)</td>
</tr>
<tr>
<td>Nausea</td>
<td>0.00*</td>
<td>0.00-0.00</td>
<td>0.00 - 0.00</td>
<td>88 (95%)</td>
<td>5 (5%)</td>
</tr>
<tr>
<td>Depression</td>
<td>0.00*</td>
<td>0.00-4.00</td>
<td>0.00 - 2.00</td>
<td>71 (76%)</td>
<td>22 (24%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.00*</td>
<td>0.00-4.00</td>
<td>0.00 - 2.00</td>
<td>72 (77%)</td>
<td>21 (23%)</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>0.00</td>
<td>0.00-4.00</td>
<td>0.00 - 0.00</td>
<td>72 (77%)</td>
<td>21 (23%)</td>
</tr>
<tr>
<td>Appetite</td>
<td>3.52</td>
<td>2.70</td>
<td>2.96 - 4.07</td>
<td>49 (53%)</td>
<td>44 (47%)</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>4.40</td>
<td>2.62</td>
<td>3.86 - 4.94</td>
<td>33 (35%)</td>
<td>60 (65%)</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>0.00*</td>
<td>0.00-2.50</td>
<td>0.00 - 0.00</td>
<td>73 (79%)</td>
<td>20 (21%)</td>
</tr>
</tbody>
</table>

(n=93) * median IQR = Interquartile range

The percentage and number of participants who reported a symptom were tallied and converted to a percentage of all participants (see Figure 4.11). As detailed previously, a cut off score of five to ten was used to determine moderate to severe symptoms and a cut off score of one to four was used to determine mild symptom severity. The blue columns in Figure 4.10 show the proportion of participants who reported a symptom, while the red columns show the proportion of the total sample that reported moderate to severe symptoms. The total sample (n = 93) was used as the denominator in both instances. Where symptoms were reported, they were predominantly described as moderate to severe, with the exception of nausea. Of great concern is the finding that 65% (n=60) of residents rated negative feeling of wellbeing as moderate to severe, indicating the participants did not feel ‘good’ about themselves as a person. When psychological symptoms (depression and anxiety) are combined (47%, n=43), nearly half of the residents who participated experience moderate to severe psychological issues. This raises questions about how psychosocial symptoms are screened. This
was followed by tiredness, issues with appetite, pain, drowsiness, shortness of breath, and nausea.

Figure 4.11: Prevalence of symptoms in the total sample and proportion of symptoms rated moderate to severe using the Edmonton Symptom Assessment System.

Since it is not uncommon for a person with a chronic illness or life limiting condition to experience multiple symptoms (Tranmer, Heyland, Dudgeon, Groll, Squires-Graham & Coulson, 2003; Paice, 2004), the number of symptoms experienced at one time was analysed. The tally of all symptoms recorded on the ESAS totalled 353 symptom episodes. All residents experienced multiple symptoms at any one time, ranging from two to nine symptoms with a mean of 4.68 symptoms (SD 1.9). Moderate to severe symptom ratings by residents or persons responsible were analysed further. The number of multiple moderate to severe symptoms experienced at one time ranged from zero to eight with a mean of 2.9 symptoms (SD 1.9).
Question 10 on the ESAS provides an opportunity to identify any additional ‘other’ symptoms not listed on the instrument. Only a small proportion of participants (11%, n=10) named and rated an additional ‘other’ symptom. Responses to Question 10 were categorised by the researcher into two groups, physical and psychosocial issues. Among the physical symptoms, 20% (n=2) identified bowel or bladder control as an additional symptom, this was followed by general decline in condition (20%, n=2), and dry-retching (10%, n=1). Among psychological symptoms, 50% (n=5) identified behavioural issues as an additional symptom.

4.1.13 Assessment for Symptom Clusters

A comparison of the means, standard deviations and 95% confidence intervals of the total POS score, total BI and total ESAS score for each primary diagnosis was conducted to examine whether a specific diagnostic group could be identified as having poorer outcomes. Due to low numbers in several of the diagnostic groups these results should be interpreted with caution.

Table 4.7: Comparison of mean total POS, Total BI and Total ESAS scores and diagnoses

<table>
<thead>
<tr>
<th>Primary Diagnosis (n)</th>
<th>Total BI (mean, SD)</th>
<th>95% CI</th>
<th>Total POS (mean, SD)</th>
<th>95% CI</th>
<th>Total ESAS (mean, SD)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal (2)</td>
<td>22.50 (17.68)</td>
<td>-136.33 - 181.33</td>
<td>11.00 (2.83)</td>
<td>-14.41 - 36.41</td>
<td>30.00 (11.31)</td>
<td>-71.65 - 31.65</td>
</tr>
<tr>
<td>Neurological (46)</td>
<td>45.22 (14.18)</td>
<td>41.01 - 49.43</td>
<td>8.93 (5.76)</td>
<td>7.22 - 10.60</td>
<td>21.52 (10.99)</td>
<td>18.26 - 24.79</td>
</tr>
<tr>
<td>Other (7)</td>
<td>57.14 (11.13)</td>
<td>46.85 - 67.43</td>
<td>12.00 (6.68)</td>
<td>5.82 - 18.18</td>
<td>36.57 (16.76)</td>
<td>21.07 - 52.07</td>
</tr>
<tr>
<td>Respiratory (7)</td>
<td>47.14 (6.99)</td>
<td>40.68 - 53.60</td>
<td>10.00 (7.04)</td>
<td>3.48 - 16.52</td>
<td>31.00 (16.30)</td>
<td>15.93 - 46.07</td>
</tr>
<tr>
<td>Cardiac (13)</td>
<td>50.00 (12.25)</td>
<td>30.51 - 69.49</td>
<td>7.38 (4.19)</td>
<td>4.85 - 9.92</td>
<td>22.77 (11.28)</td>
<td>15.95 - 29.58</td>
</tr>
<tr>
<td>Cancer (4)</td>
<td>50.00 (12.25)</td>
<td>36.53 - 63.46</td>
<td>4.00 (2.82)</td>
<td>-1.51 - 9.51</td>
<td>7.25 (3.40)</td>
<td>1.83 - 12.67</td>
</tr>
<tr>
<td>Endocrine (4)</td>
<td>53.750 (4.78)</td>
<td>46.13 - 61.37</td>
<td>10.00 (6.83)</td>
<td>-0.87 - 20.87</td>
<td>28.50 (26.05)</td>
<td>-12.96 - 69.96</td>
</tr>
<tr>
<td>Mental Health (4)</td>
<td>47.50 (16.58)</td>
<td>21.11 - 73.89</td>
<td>6.75 (6.65)</td>
<td>-3.83 - 17.33</td>
<td>19.25 (14.48)</td>
<td>-3.79 - 42.29</td>
</tr>
<tr>
<td>Connective tissue (6)</td>
<td>41.66 (6.83)</td>
<td>34.50 - 48.84</td>
<td>9.00 (7.21)</td>
<td>1.43 - 16.57</td>
<td>28.17 (14.93)</td>
<td>12.50 - 43.84</td>
</tr>
<tr>
<td>Total</td>
<td>47.37 (14.26)</td>
<td>8.82 (5.78)</td>
<td>23.74 (13.75)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Confidence intervals were examined to determine the plausible range that would be seen in a larger population of high-level care residents in residential aged care facilities with the same diagnoses. For the BI, all confidence intervals overlapped, indicating that the population means of the BI for the different primary diagnosis groups are unlikely to differ. The most precise confidence interval was found in the ‘neurological’ group; this is possibly related to the larger sample size in this group or may indicate that the BI scores for this group are more closely clustered around the mean, indicative of less variability in the scores. Of interest is that the upper limit for the ‘neurological’ confidence interval did not extend above a score of 50, indicating that the wider population of high care residents with a neurological diagnosis are likely to be physically dependent. This was also the case for the ‘connective tissue’ group. The widest confidence interval, indicative of greater variability in the data, was found in the ‘mental health’ group, although there was considerable variability in the ‘cardiac’ and ‘cancer’ groups as well.

Overlapping confidence intervals were also found for the POS, indicating that the ‘true’ population means of these diagnosis groups are unlikely to differ. The narrowest (most precise) intervals were found for the ‘neurological’ and ‘cardiac’ diagnoses, while the widest (most variable) were found for ‘endocrine’ and ‘mental health’. The relatively low upper limits for ‘neurological’, ‘cardiac’ and ‘cancer’ indicated that, in these groups, population means are unlikely to extend into the worse (higher) outcome range.

Results for the ESAS showed that the 95% CI for ‘cancer’ did not overlap with ‘neurological’, ‘other’, ‘respiratory’ or ‘cardiac’, indicating that ESAS scores in the wider population of cancer residents in aged care are likely to be lower (less severe) than those other groups. ‘Endocrine’, ‘mental health’ and ‘connective tissue’ were very variable and overlapped with all other confidence intervals.

In particular, the confidence intervals for the renal diagnostic group (n= 2) illustrated a wide variance among the Barthel, POS and ESAS scores, which could indicate a lack of precision in the measurement but is more likely to be related to the small sample of two participants in the study.
4.1.14 Conclusion

The results of the quantitative investigation indicate that over half of the residents residing in the participating hostels were requiring high-level care according to the RCS 1-4 categories. The majority of these residents were over 85 years of age with a primary chronic non-malignant diagnosis and multiple co-morbidities. The scores obtained from the BI Index highlighted that the majority of residents who participated in this study were physically dependent for most activities. Many of the participants experienced several symptoms at any one time. A high proportion of residents overall experienced significant feelings of negative well-being and psychosocial symptoms according to both the POS, v2 and ESAS scores. These results highlight poor symptom identification and management in these settings. No relationship could be found between functional ability and symptoms, primarily because spiritual and psychosocial issues were prominent and sample sizes in some of the symptom categories were small. However, residents with a non-malignant diagnosis were more likely to be less functional and have more symptoms than residents with a cancer diagnosis. A relatively low number of deaths occurred within the hostel settings. This study demonstrates that despite both residential organisations opting to provide ageing-in-place, this tends not to extend to end of life care.

4.2 Managerial Data

4.2.1 Staffing Levels and Ratios

The literature highlights that staffing factors, such as turnover, staffing ratio and skill mix, worker stability, agency staff use, training and the way care is organised, influence the quality and effectiveness of care in residential aged care facilities. Since hostels are now managing residents with high dependency levels and complex care needs, it is particularly important to evaluate the staffing levels in these facilities.
Hostel managers were asked for information on the total staffing numbers, staff ratios per shift and use of agency staff or casual staff per month. Table 4.8 provides an overview of the total daily hostel staffing numbers per shift.

Within the eight hostels, five managers were RNs. In two hostels, a PCA was the supervisor of the hostel with a RN from another facility as back up if required while one hostel had an EEN as a supervisor. Within all eight hostels, PCAs provided most of the hands-on daily care to residents. For some hostels, there was a short six-hour shift in place to provide maximum assistance at the busiest times such as a morning shift or evening shift. For the majority of hostels, one PCA was rostered on duty for the night shift. The exceptions were Hostels 1, 4 and 6, which had the higher numbers of high-level care residents and total number of beds, where the number of PCAs rostered on night duty ranged from 1.5 to 3.

### Table 4.8: Total daily hostel staffing numbers per shift

<table>
<thead>
<tr>
<th>SHIFT</th>
<th>Hostel 1</th>
<th>Hostel 2</th>
<th>Hostel 3</th>
<th>Hostel 4</th>
<th>Hostel 5</th>
<th>Hostel 6</th>
<th>Hostel 7</th>
<th>Hostel 8</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. of beds</td>
<td>52</td>
<td>13</td>
<td>13</td>
<td>63</td>
<td>52</td>
<td>83</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td>No. of HLC residents</td>
<td>48</td>
<td>13</td>
<td>13</td>
<td>55</td>
<td>19</td>
<td>52</td>
<td>20</td>
</tr>
<tr>
<td>AM</td>
<td>1 RN 1 EN 7 PCA</td>
<td>1 PCA 2 PCA (1 short shift)</td>
<td>1 PCA 2 PCA (1 short shift)</td>
<td>1 RN 1 EEN 8 PCA</td>
<td>1 EEN 3 PCA</td>
<td>1 RN 2 EN 9 PCA</td>
<td>1 RN 1 EEN P/T 4 PCA</td>
<td>1 RN 4 PCA</td>
</tr>
<tr>
<td>PM</td>
<td>2 PCA</td>
<td>2 PCA</td>
<td>2 PCA</td>
<td>1 EEN 5 PCA</td>
<td>2 PCA</td>
<td>2 EN 4 PCA - split</td>
<td>3 PCA</td>
<td>3 PCA</td>
</tr>
<tr>
<td>NIGHT</td>
<td>2 PCA</td>
<td>1 PCA</td>
<td>1 PCA</td>
<td>1.5 PCA</td>
<td>1 PCA</td>
<td>3 PCA</td>
<td>1 PCA</td>
<td>1 PCA</td>
</tr>
<tr>
<td></td>
<td>Agency per month</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>12</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Casual per month</td>
<td>10</td>
<td>‘A lot’</td>
<td>‘A lot’</td>
<td>15</td>
<td>2</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>AM staffing ratio (PCA: Resident)</td>
<td>1 : 7</td>
<td>1 : 6</td>
<td>1 : 6</td>
<td>1 : 8</td>
<td>1 : 6</td>
<td>1 : 9</td>
<td>1 : 16</td>
</tr>
</tbody>
</table>

*RN = registered nurse; EEN = endorsed enrolled nurse; EN = enrolled nurse; PCA = personal care assistant*

*Bolded text in AM column = the person in charge of the hostel*
In all hostels, a ‘roving’ RN from within the residential age care facility was available during the evening and night shift if required. All hostels maintained a casual pool of aged care staff to call on when required. This ranged from 1-2 per month to ‘a lot’ (exact figure could not be supplied by manager). Only the metropolitan site used agency staff. In particular, Hostel 4 required the highest number of agency staff on a regular monthly basis. Overall, it appeared that staff employed at the rural site had been employed for longer periods than those at the metropolitan site.

The staffing to residents ratios was calculated on the busiest shift (morning) and ranged from 1:6 to 1:18. The lowest staffing ratio of PCA to resident was in Hostel 8 where there was the smallest number of high-level care residents (23%). This particular hostel was split into two sections with a road between the two buildings, which created greater distance for staff to be able to supervise/monitor the resident. In all hostels, the high-level care residents were dispersed throughout the hostel. Therefore, a PCA could be assigned to providing care to a mixture of dependent and independent residents.

### 4.2.2 Staff Roles and Task Designation

The designated hostel manager/supervisor role entailed completing dependency paperwork, holding meetings, doctor’s rounds, chairing hand-over and supervising staff; for the registered nurse managers the role additionally encompassed administering schedule-eight medications such as Durogesic (opioid) patches. The endorsed enrolled nurse’s role encompassed assisting with medications, reviewing and attending to dressings and administering blister-pack medication. PCAs not only provided all hands-on care to residents, they also performed simple dressings, administered medications via blister packs and assisted with other duties such as kitchen hand if required. All staff attending to residents on a daily basis required updating about the personal care provided on the ACFI data computer system.
4.2.3 Conclusion

The managerial data regarding staffing levels at the hostels revealed that the metropolitan site employed a higher number of ENs or EENs in their daily skill mix than the rural site. Apart from at one hostel, the hostel managers at the metropolitan sites were primarily RNs. At both sites the majority of hands-on care was provided by PCAs. While both sites had a casual pool of staff to call on when required, the rural site never used agency staff. Variations in hostel staffing ratios were noted.

4.3 Organisational Resources

4.3.1 Available Policies to Support a Palliative Approach

Organisational policies which can provide support and guidance for the delivery of a palliative approach were reviewed by auditing the policies held in each hostel. As detailed earlier, a palliative approach incorporates the principles and philosophy of palliative care and encompasses a broader perspective in providing care that is not limited to the final days or weeks before dying. In order to meet the Standards of Care for accreditation purposes, aged care facilities are required to have in place broad policies related to ‘palliative care’ (Aged Care Accreditation and Standards Agency, 2009a), however, no specific policies are detailed in the aged care accreditation standards.

Within the metropolitan site, most hard copies of policies were incomplete but a bank of policies could be accessed via the intranet and each nurses’ station was equipped with a desktop computer. Within the rural site, all policies were available in hard copy format. Table 4.9 details the organizational policies available at each site. The specific policies as listed in Table 4.9 were based on the evidence-based Guidelines for a Palliative Approach in Residential Aged Care (Australian DoHA, 2004a) and additional policies considered important by the researcher were added, which directly related to aspects of a palliative approach and the provision of care at end-of-life.
Table 4.9: Availability of policies to support a palliative approach at the RACFs

<table>
<thead>
<tr>
<th>Policy Name</th>
<th>Rural Site</th>
<th>Metropolitan Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Advance care planning</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Support/counselling for patients</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Guidelines for death in RACF</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Death &amp; Dying</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Referral to specialist palliative care services</td>
<td>via CNS</td>
<td>via manager</td>
</tr>
<tr>
<td>Symptom assessments</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Use of subcutaneous medication</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Use of subcutaneous fluids</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Use of syringe drivers</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Care plans / documentation</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>After-hours medical cover</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Family conferences/ multidisciplinary</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Referral to specialist services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Speech pathologist, dietician)</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Cultural diversity/ issues</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Enduring Power of Attorney</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Bereavement support</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Support/counselling for staff</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Medication reviews by pharmacist</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Volunteer support</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Skin integrity</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Use of complementary therapies</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Restraint free</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Wound management</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Falls-related injuries</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

Y = policy present  N = nil evidence of policy

The rural site held most of the policies contained within the audit checklist. Exceptions included, policies related to conducting family conferences or multidisciplinary meetings. However, a form had been developed and used to
document outcomes at these meetings. The other exceptions included policies related to medication reviews by a pharmacist, use of subcutaneous medication, after-hour’s medical cover and referral to specialist palliative care services. While an after-hours medical cover policy did not exist, a memorandum posted at the nurses’ station regarding after-hours palliative care advice was available. The local specialist palliative care service did not provide on-site consultations to the facility but was available for phone advice. Consequently, the residential aged care facility employed a part-time (0.5 Full Time Equivalent) Clinical Nurse Specialist (CNS) in palliative care to provide consultations and liaise with the local specialist palliative care service if required. Multiple symptom assessment policies were available and included protocols for identification of end-of-life symptoms and care pathways.

The metropolitan site did not have policies related to advance care planning, use of subcutaneous fluids, referral to specialist services (speech pathologist, dietician), bereavement or volunteer support. Bereavement support for residents was available from staff, and previous residents who had died were acknowledged and remembered at the monthly residents’ meetings. It was unclear whether volunteers played a role within this metropolitan facility. In several residents’ medical files, a form entitled ‘Palliative Care Plan’ was used to document advance care directives such as, ‘not for resuscitation’, with areas to write additional information. The policy for symptom assessment included pain and behaviour management only. No policy for referral to the local palliative care service was found, however, all managers were aware of the local specialist palliative care service and referral was made in collaboration with the general practitioner. No policy for the use of syringe drivers or the administration of subcutaneous fluids could be found, at this site in hard copy or via the intranet.

4.3.2 Available Procedure Guidelines to Support a Palliative Approach

Procedure guidelines can ensure compliance with regulatory and accreditation requirements and enable staff to follow the same practice and standards of care. Ideally, these guidelines and/or procedures would match the policies of the organisation.
The procedure guidelines folder at each hostel was audited against the criteria in Table 4.10. The criterion used was developed from the researcher’s knowledge and expertise in the field of palliative care. No procedure for inserting and monitoring subcutaneous needles could be found at the rural site despite the existence of subcutaneous fluid administration and syringe driver policies. Only one of the metropolitan hostels held a hard copy guideline/procedure for inserting and monitoring subcutaneous needles (no policy was found on the intranet) despite the facility holding a policy on the use of subcutaneous medication. No guideline/policy for use of Transcutaneous Electrical Nerve Stimulation (TENs) machines could be found at either site.

Table 4.10: Procedure guidelines relating to a palliative approach

<table>
<thead>
<tr>
<th>Procedure Name</th>
<th>Rural Site</th>
<th>Metropolitan Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to refer to palliative care</td>
<td>Y</td>
<td>only 1 hostel</td>
</tr>
<tr>
<td>Bowel management / enemas</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Use of subcutaneous needles</td>
<td>N</td>
<td>only 1 hostel</td>
</tr>
<tr>
<td>Use of syringe drivers</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Use of subcutaneous medication</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Subcutaneous fluid administration</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Mouth care/ assessments</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Use of alternating pressure mattresses</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Wound management</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Safe feeding techniques</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>PEG feeding</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Additional-Care Planning</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

\[\text{Y} = \text{policy present}\quad \text{N} = \text{nil evidence of policy}\]

A guideline/procedure related to the use of alternating pressure mattresses could not be found at these metropolitan site despite a policy related to skin integrity which
recommended the use of such mattresses. A guideline/procedure for subcutaneous fluid administration could not be found at either site. Finally, a guideline/procedure for percutaneous enteral feeding tubes could not be found at the rural site.

While neither of the two institutions held all policies and guidelines/procedures as listed on audit sheets, the rural site held the majority of these. The on-site position of a CNS in palliative care at the rural site may have influenced the practice of ensuring that policies were put into place through guidelines or procedures for staff to follow. In particular, the rural site had developed a specific palliative care planning tool - \textit{The Care Planning Guidance Tool – IF and THEN Model} (Abbington, 2009). They received funding from the Department of Health and Ageing out of the Local Palliative Care Grants Program initiatives to develop this tool. This comprehensive guideline package uses specific palliative care assessment tools (such as ESAS, the Abbey pain scale and an End-of-life pathway), user instructions, end-of-life symptoms with explanations of possible contributing factors and management suggestions. All rural site staff, inclusive of PCAs, were aware of the CNS position and the process of referral. A referral form had been developed in which the reason for referral and degree of urgency was to be recorded. If urgent referral was required, the CNS could be contacted via mobile phone. At the metropolitan site, many of the PCAs were not aware of the process of referral to palliative care. However, one hostel did hold brochures about the local specialist palliative care service.

\textbf{4.3.3 Educational and Other Available Resources on a Palliative Approach}

The availability of resources and education regarding palliative care demonstrates the commitment of the organisation to ensure all staff are provided with opportunities to develop the skills and knowledge to implement this approach to care. Educational and additional resources regarding a palliative approach were audited by reviewing the noticeboards, displayed pamphlets and by asking staff how they obtained this type of information. The findings are displayed in Table 4.11.
Table 4.11: Palliative care resources and education at each RACF site

<table>
<thead>
<tr>
<th>Resources / Education</th>
<th>Rural Site</th>
<th>Metropolitan Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copy of the Guidelines for a Palliative Approach in RACFs</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Copy of the Pain in Residential Aged Care Facilities – Management Strategies</td>
<td>CNS Office</td>
<td>only 3 hostels</td>
</tr>
<tr>
<td>In-services regarding palliative care</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Palliative care brochure</td>
<td>CNS Office</td>
<td>N</td>
</tr>
<tr>
<td>Information re local PC service</td>
<td>CNS Office</td>
<td>only 1 hostel</td>
</tr>
<tr>
<td>Advance Care planning brochures</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Relevant books</td>
<td>held in library</td>
<td>held in library</td>
</tr>
<tr>
<td>Internet access</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Intranet access</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Display of upcoming conferences regarding palliative care</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Further education details re palliative care course</td>
<td>CNS Office</td>
<td>Manager’s office</td>
</tr>
</tbody>
</table>

_Y = policy present_  
_N = nil evidence of policy_

While managers/ supervisors at all sites were aware of *The Guidelines for a Palliative Approach for Residential Aged Care*, no hard copy of these could be found at any hostel site. A copy of the Pain in Residential Aged Care Facilities – Management Strategies was available in most of the hostels (Australian Pain Society, 2005). Each facility had a library in which staff could access available palliative care books and request others. Brochures explaining the meaning of palliative care and / or a palliative approach were held in the CNS’s office at the rural site to be given to residents or family members when required. The metropolitan site did not have any information pamphlets regarding palliative care or a palliative approach for residents.
or family members. In-services were conducted monthly at both sites and, according to the topics displayed on the agenda on the individual hostel noticeboards, palliative care issues were frequently addressed. At the rural site, in-services were conducted by the CNS at the rural site and by a local specialist palliative care service at the metropolitan site. Staff at both sites were aware of this education resource.

Upcoming conferences regarding palliative care topics were also displayed on the notice boards of the rural site or available at the CNS office. The metropolitan site did not display upcoming conferences but information was available through the manager. Information regarding courses in palliative care was available through the CNS at the rural site and through the manager at the metropolitan site.

Advance care planning brochures were displayed and available for residents and families at the rural site. No such brochures were found at the metropolitan site. All staff (inclusive of PCAs) at the rural site were aware of the need to contact the CNS in palliative care for referrals to palliative care. Only one hostel at the metropolitan site held written information on the local specialist palliative care service. However, all managers were aware of the local specialist palliative care service.

4.3.4 Conclusion

The organisational data in relation to end-of-life care issues (such as advance care planning, use of subcutaneous fluids, syringe drivers and bereavement support) revealed gaps and the metropolitan site had fewer policies with matching guidelines or procedures than the rural site. Educational and additional resources regarding a palliative approach were provided to staff at both sites. However, neither site was able to demonstrate that they held a copy of *The Guidelines for a Palliative Approach for Residential Age Care*, despite this resource having been widely disseminated by the DoHA to all RACFs in Australia.
The results of the descriptive statistics are discussed in the context of the qualitative findings and the pertinent literature in Chapter Eight. Next, the findings from the qualitative analysis will be discussed in Chapters Five, Six and Seven.
CHAPTER FIVE:

Resident perceptions: transitioning towards the end of life

The previous chapter has provided a descriptive numerical account of the high-level care resident participants. I will now move to exploring the residents’ actual perceptions of their health. This chapter will achieve is to give a voice to the 72 high-level care residents and 21 persons responsible participating on behalf of high-level care residents with dementia. It needs to be acknowledged here that, while participating persons responsible were asked to respond as closely as possible to how they felt the resident would respond, inevitably from time to time they also talked about their own experiences of their loved one’s situation.

Qualitative interviews were undertaken to specifically address the second research aim. That is, to explore health issues for this group of residents, their understandings of how these are being managed and how they would like them to be managed into the future. The findings will be discussed under the headings of themes and subthemes that emerged from analysis of the interviews. A description of each theme is provided at the beginning of each section, and each section includes exemplars from the interview transcripts. The overarching theme of this aspect of the research was transitioning towards the end of life.

Phillip’s story provides a brief introduction: his experiences of moving to hostel care are in many ways typical of those of other residents. As the researcher who conducted all of the interviews, I was privileged to meet and talk with Phillip, an 85-year-old resident diagnosed with bipolar affective disorder, cardiac issues, alcohol dependency, sciatica, and Parkinson’s disease.
When I interviewed Philip, he had been living in one of the rural hostels for four months. Because of his multiple health issues, he had been experiencing difficulties managing his self-care needs at home, requiring additional support until he was admitted to the hostel.

When asked about his current health status, Phillip told me he was not happy about his reduced physical capabilities and needing to use a ‘trolley thing’ to get around. He then went on to provide me with details about his ‘pretty rough…family life’. His brother had been an alcoholic and suffered from severe depression, and Phillip found him dead at age 42. His mother also suffered depression and had attempted suicide. One of his sons had died in infancy, but he told me that he still had ‘two good boys’. Prior to moving to the hostel, Phillip was receiving assistance at home from community aged care services. When a bed became available at the hostel he moved in. Although Phillip was struggling at home with multiple health conditions, his stated reason for moving to the hostel was ‘for the boys’ sake’, to ease their stress in having to make frequent visits.

Phillip’s initial thoughts about hostel life were that it was a place where he did not ‘want to be’. After an initial period of some difficulty adjusting to this new environment, Phillip felt that he had little choice but to ‘settle yourself in’. His assessment of the staff was that they were ‘real good’. In particular, there was one personal care assistant who, knowing that Phillip loved prawns, would ‘bring me some prawns…she was a nice girl’. Phillip said he had been on the same medications for his bipolar affective disorder for seven years and had chronic insomnia and that he was hoping for ‘something that might help more’ with this ongoing problem. Phillip had been identified as having poor self-esteem, depression and a very poor appetite, but he felt ‘at home’ in the hostel and said that he wanted to remain there for as long as possible - as ‘long as I get’. However, he held little hope for his future, stating, ‘there’s only one way out of here…the nursing home or up in the cemetery…there’s no immediate future…we’re all on the one boat’.
Phillip’s experiences of multiple health issues, the need to move to a residential aged care facility, the problems associated with settling in to this new environment and uncertainty about the future were shared by many other residents in this study and represent the principal theme of transitioning towards end of life.

This chapter explores the experiences of transitioning towards the end of life through resident and persons responsible descriptions of the move to a residential aged care facility, a place where they would potentially spend their remaining life and perhaps eventually end their life.

Analysis of the interviews revealed that loss of physical functioning and a general deterioration was expected by participants as part of ageing and not seen as ill health. Death was seen as the outcome of the ageing process, rather than as a result of an illness. Participants associated admission to a hostel with a final decision that would mean spending the rest of their lives there. As one resident explained, ‘Well I don’t think there’s much else for me. Stop here till I conk’ (Resident (R): Robert, 89 yrs), or as encapsulated by another resident, Charlotte: ‘…this is the beginning of the end, you come…here to die, that’s what it’s all about, you just come up here and you stay here till you die (R: Charlotte, 86 yrs).

Transitioning towards the end of life was seen as a natural progression in life. Embedded within this theme are the subthemes: The meaning of health; Why am I here?; Adjusting to life in a hostel; Being ‘cared for’; and Uncertainty about the future. Each will be described in detail.

A move into a hostel was identified as a major life change for both the resident and their family. Many residents believed they had few choices about their situation and that moving to the hostel was a forced decision which they had to find a way to accept. Many residents questioned the need for being in a hostel. This questioning related to their perception of their current health status, which most believed was ‘good’, and any decline in physical functioning was regarded as part of the normal ageing process, not as a result of a medical condition or illness.
Increasing need for physical assistance at home and difficulties associated with living alone, as well as the need to reduce their perception that they caused stress to family members, were frequently cited reasons for agreeing to move to the hostel. For most, there was a period of adjusting to this new environment; for some participants this could take considerable time. A small number felt it was never going to be possible to really settle into this new life.

Despite their initial unwillingness to be in a hostel, residents felt that they were being ‘cared for’ there. As time passed, residents and persons responsible developed strong interpersonal connections with staff, other residents, and families. These connections were experienced as ‘becoming a family’ and the facility itself becoming ‘homelike’. When considering their future needs as their condition deteriorated, both residents and persons responsible expressed uncertainty about what lay ahead and held fears for the future as the resident transitioned towards the end of life.

5.1 The Meaning of Health

The interviews began with the question ‘How do you see your (or resident’s name, in the case of interviewing their person responsible) health at the moment?’ Analysis of the interviews revealed that the majority of residents perceived their current health status to be good with no serious problems or issues. It must be noted here that all residents in this study were classified as requiring high-level care and that, as reported in Chapter 4, the majority of them had a chronic illness, and over half had three or more concurrent health problems. Despite these complexities, residents did not relate their current health status or abilities to the consequences of a medical condition. That is they did not see themselves as ‘ill’ or ‘unwell’, but understood changes in their health as part of a natural progression of ageing. Residents discussed the meaning of health status in terms of their physical and mental functioning, often comparing themselves to their peers.
Typically, residents reported rarely needing medical attention and being healthy for most of their life. For example, Trevor, a 96-year-old resident, had ischemic heart disease, four co-morbidities (chronic airways limitation, osteoarthritis, bowel cancer and hypertension) and poor functional ability. Yet, despite his chronic health conditions requiring multiple hospital admissions, Trevor felt he ‘had pretty fair health. My heart’s still going…coming on winter I’d have to be in the hospital with my heart… this is about the fourth year…I still feel a bit of pain… now and again but that’s nothing. I just make the best of it all’ (R: Trevor).

Another resident, June, had a primary health condition of osteoarthritis with chronic pain as well as cardiac issues and diverticulitis. June had poor physical functional abilities and rated her current pain severity as moderate. While she acknowledged that her various health conditions posed a few difficulties at times, she perceived her health as being good overall. As she said ‘I have very good health but occasionally I might have a few things, but I think my health is pretty good’ (R: June, 91 yrs).

As expressed by Sam, a 90-year resident with chronic cardiac failure, chronic airways limitation, and depression:

…it’s pretty obvious that my health won’t improve…my age is against that, and my history…I’ve heart problems…it simply means that I can just hope to survive in…comfortable situation as I can …that’s all part of being old …we all have some effect of age and I suppose I’m one of the more fortunate ones and I think to myself well I look like I might make it without getting too bad (laughing) ah I’m 90 (R: Sam).

Sam hoped to reach the ‘end of life’ without ‘serious’ health problems that would limit his functional capacity. A similar expectation that their physical condition would deteriorate with age and anticipation of these changes was expressed by others. As Trevor described, ‘nothing gets better in your life when you get to this age…like your water supply and your bowels…they get a bit worse…but if you can still manage…you’re doing alright (R: Trevor, 96 yrs). One person responsible, a daughter, spoke about her mother who had been living in the hostel for 18 months requiring
high-level care. She had moderate dementia with three co-morbidities and poor functional status. She saw her mother as having been ‘physically quite strong but she’s now getting quite fragile which is not surprising. She’s 88, so one would expect that’ (PR: Sophie).

While a few residents acknowledged that their health was ‘not so good’, they were not contemplating any ‘end of life’ plans. In fact, they remained hopeful that further treatments would be beneficial. Sarah, a 92-year-old resident, argued that she would still be able to have her third pacemaker inserted despite her end-stage chronic heart condition of cardiomyopathy. While Sarah’s circumstances may be perceived as suggesting that she ought to be considering end-of-life care, this approach was not part of her agenda. Another resident with pulmonary fibrosis and four co-morbidities including cardiac issues, osteoarthritis, diabetes, and hypertension saw her health as something that fluctuated: ‘…something that is not static. It just sort of tends to go down a little every couple of days and don’t seem to be able to chase it, to catch it, make it stationary’ (R: Sarah).

These residents had little control over their health status and seemed determined to make the best of the situation. Don, an 86-year old man with asbestosis, Paget’s disease, and spinal cord stenosis, was confined to a wheelchair, requiring oxygen 24-hours a day. Don talked about his multiple health issues and the disabilities he had suffered throughout his life:

*I developed asbestosis and that’s been a problem with me ever since. You might’ve noticed... I’ve got shortness of breath... I can’t talk for long periods...as well as that I have...peripheral neuropathy, that’s why I can’t write like I did... It’s impossible to write a letter...I could make my signature legible but to write a letter would be hopeless...but I’ve also got trouble from radiation... I was in Japan... I was at Hiroshima soon after the bomb dropped...and the doctor said I would have a high degree of radiation... problems... but this problem I have now is I had this urinary tract operation... I’ve got tubes hanging out of me everywhere and a bag on my leg and this is something I’ve got to put up with for the rest of my life (R: Don).*
Despite experiencing multiple symptoms, including tiredness, anxiety, shortness of breath, drowsiness, and family anxieties, which he rated as severe, Don did not see himself as seriously ill or as needing to consider or plan for his end-of-life care.

A small number of residents perceived their health to have improved since admission to the hostel. One person responsible, whose husband had suffered significant cognitive deterioration due to dementia, had renal failure, a hip replacement and a stroke, felt ‘he’s so much better physically’ (Person responsible (PR): Janet). His improvement in physical health was attributed to the 24-hour care provided in the hostel. Another resident, Jill, also felt that her health had improved since being in the hostel. Jill had multiple chronic illnesses including cardiac issues, peripheral vascular disease, bronchiectasis, chronic renal failure and chronic leg ulcers. As a direct result of her peripheral vascular disease, she developed a chronic leg ulcer that required the amputation of her leg. Despite these considerable health issues, Jill described her health as good and improved: ‘…well my health’s been pretty good, really. I find since my leg [was cut] off…it was touch and go when I had my leg cut off… I’ve sort of built up, and I’m much better now than I was’ (R: Jill, 91 yrs).

Residents often rated their health status by comparing it to that of other residents. Their perception of ‘good health’ and the ability to function normally was judged against other residents whom they saw as being in ‘poor health’. Several residents described other residents as frail and needing ‘attention and they’re over 90… so there is a big majority that needs a lot of help’ (R: Andrew, 85 yrs). Surrounded by peers who were deteriorating physically and mentally, residents were constantly monitoring and gauging themselves against other residents, which influenced how they interpreted and experienced their own health condition.

Overall, the majority of residents believed they were in good health, despite their chronic medical diagnoses and multiple co-morbidities, and that the decline in their functionality was a result of the normal ageing process, not illness. Residents’ indication that their health was good prompted me to ask them why they were in the hostel.
5.2 Why Am I Here?

From the interviews it emerged that many of the participants questioned the reasoning behind the need to move to a hostel. Multiple contributing factors were described as a precursor, leading to admission to a hostel. These included: advice from medical staff following an acute hospital admission, living alone with limited supports, the need to be in a safe environment, difficulties in meeting the care needs of the individual in the home, and the need to reduce stress on family members. Despite these many factors, many residents in this study did not consider their care needs as sufficient to warrant admission to a hostel and did not recognise deterioration in their condition. Many therefore questioned why am I here?

For individuals with chronic and complex conditions, remaining at home as their care needs increase can become problematic. Not only does the disease trajectory of many chronic illnesses make it difficult to predict and adjust care requirements in the home environment, living alone or having limited social support exacerbates their vulnerability. As a result, transfer to a residential aged care facility may be required to ensure their needs are met as their overall condition deteriorates. However, since many residents in this study did not consider their care needs as high-level or recognise deterioration in their illness, it is not surprising that some residents did not feel they really needed hostel care and some therefore questioned the decision to move them there.

In many instances, admission to the hostel was prompted by medical staff following an acute hospital admission, at a time when residents can be very vulnerable. Jane, a 92-year-old widow with cardiac issues, diabetes and hypertension, had been living alone in her home. After an acute hospital admission ‘the doctors… decided I should have to come here, see, and that’s how I’m here’ (R: Jane). Jane had been admitted to the hostel for high-level care nine months prior to our interview, but was still wondering why she was there.

Similarly, Joe, an 82-year-old resident with Parkinson’s disease, ‘was advised to come here by medical…people’, but still did not understand the need for being in the hostel.
Joe had lived in several hostels and had resided in his current hostel for 36 months; he had been re-classified as requiring high-level care shortly before our interview took place. Another resident, who at the time of her interview was still grappling with the idea of being in the hostel, was ‘hoping to get out soon’ (R: Stella, 84 yrs). Despite living there for the past 18 months and requiring high-level care for mild dementia, depression and polio causing mobility issues, she still felt she would be able to live at home again.

Several residents identified that it was their decline in functionality that prevented them from remaining independently in their own home. Beth, a 97-year-old widow with no living relatives, was admitted to hospital after a cerebrovascular accident (CVA) and with five co-morbidities (chronic cardiac failure, glaucoma, cataract, anemia, ulcerative oesophagitis) requiring multiple medications. She had been living by herself in a house. Beth described the reason for admission as ‘I couldn’t cope and I had a bit of a stroke too. I’m better off’ (R: Beth). Clinically, she had significant residual right hemiplegia and on-going difficulty with verbal communication.

For others, being in a safe and secure environment was an important factor in the decision to move to a hostel, particularly when they had been living alone. Betty, a 100-year-old woman with macular degeneration and three co-morbidities (depression, trans-ischaemic attacks, atrial fibrillation), had been living with her husband in a self-care unit within a residential aged care facility until his death prompted her to move into a hostel. While Betty’s health was beginning to deteriorate, she interpreted her reason for moving to the hostel as going to a place where she would feel secure, with staff available 24-hours a day to monitor her:

I had several falls and I had a kind of stroke and various other things, and finally I had a fall. They thought they had to replace my hip but they didn’t…and I broke a bone in my foot but they said I’d have to go where I could have help because I couldn’t, I wouldn’t be safe on my own, so they brought me over here (R: Betty).

Providing a safe environment was a high priority for families and informal carers of individuals with behavioural and cognitive issues. At home, persons responsible were
constantly concerned about the care their loved one required and found it difficult to maintain a safe environment. Family members of residents with dementia regarded a significant decline in mental functioning, in particular behavioural issues, as the point when they considered admission to the hostel. They described their inability to provide the physical care needed. One person responsible, a daughter, described her dilemma and the hardship of making the decision to place her mother in care:

...we kept her at home for a long time...but she started to get on buses when I was at work...[and] a couple of times...[she] was gone all day and when she came home, she was exhausted and couldn’t tell us where she’d been. So it was really hard to make a decision...we still took another 12 months... she has to be here because, you know, we’ve got such busy lives, and that sounds like you don’t want your parents at home but...we work, so at least she’s got company here (PR: Tracey).

Another person responsible, Gerard, was having extreme difficulties providing the basic care for his wife who had been admitted to the hostel for high-level care three years prior to the interview, and, as he explained ‘...physically I couldn’t do it... all the things you are supposed to do... like give her a bath. I wasn’t able to do it... she is so much better off here than she was at home’ (PR: Gerard).

Many residents recognised that their reduced functioning often required increased support from their family and that this created stress for the family. In response to this family stress, residents reluctantly agreed to hostel admission. However, residents did not see that the admission was due to illness but rather a need to reduce the stress on their families. Jack, a 92-year-old widower, diagnosed with mild dementia and two co-morbidities (diabetes and depression), had been living alone in a house. When I spoke with Jack he had been in the hostel for 15 months, requiring high-level care. He had reluctantly agreed to the admission so that his family could get on with living their lives: ‘the kids… they’ve got their jobs. You can’t expect them to look after me all the time... you’ve got to go somewhere’ (R: Jack).
For others too, the decision to move to a hostel was made to be ‘fair’ to their families. They did not want to hinder or be responsible for putting their children’s lives on hold. As one resident said: ‘…why I came was for the boys’ sake. They used to call on me every day at home. It wasn’t fair to them. It was getting them down. I mean they're coming here every night too, I don’t expect them [to] but they do’ (R: Phillip).

5.3 Adjusting to Life in a Hostel

While residents questioned the need to be in a hostel, once the move occurred there was a period of adjusting to life in a hostel. Many residents felt they had little choice but to accept the situation and become accustomed to this new environment. Some long-term residents continued to grapple with the situation and associated hostel life with living in an ‘institution’. Within hostels, rules and regulations govern the operational structure; therefore, residents needed to adjust to the rules and regulations, and in many instances accept that life in a hostel meant a loss of autonomy and control. Many participants spoke about coming to terms with the separation from their loved one. Over time, the majority of participants accepted and adjusted to life in a hostel, however, a small number felt it was never going to be possible to really settle into this new life.

Moving to a hostel was something many residents felt they had little choice about. As one resident stated, ‘I’ve got used to it, accustomed to the place…I can’t do anything else. I don’t see that I can’ (R: Annette, 100 yrs). Sally, another resident felt more strongly about the change: ‘there’s a sense of nothingness about it… It’s just somewhere where I’ve been dumped. They didn’t know what to do with me so they put me here’ (R: Sally).

This ‘sense of nothingness’ was perhaps what prompted some residents to liken life in the hostel to life in an ‘institution’. The perception of a physically impersonal atmosphere appears to have played a significant part in that. Sally, a 97-year-old widow with macular degeneration, a pacemaker, hypertension, and considered ‘frail’,
had been living in the hostel for 12 months when I met her. On the day of the interview, Sally was experiencing multiple symptoms. She was identified as having severe depression, anxiety, pain, as well as a very low perception of her wellbeing and self worth. Despite remarking on the kindness of the staff, she felt the hostel was ‘an institution…There’s nothing personal about it. It’s strictly impersonal’ (R: Sally).

Tom, another resident experiencing severe depression and anxiety, and a very poor sense of wellbeing and self worth, also associated life in a hostel with being institutionalised with little choice: ‘…it’s hard to describe, so you turn around and you say ‘I’m institutionalised’. I have to do it whether I like it or not. Now, at this stage, where am I going to go?’ (R: Tom, 89 years).

Some of the difficulty in adjusting to the new environment was related to the rules and regulations governing the operational structure of the institution. New residents in a hostel needed to ‘learn who to ask’ (R: Joseph) and adjust to the rules and regulations; this was part of surviving in the hostel. These same rules and regulations made several residents feel that they had lost their independence and control. As a result they felt restricted.

Jimmy, an 83-year-old resident with chronic back pain, was struggling with the reality of not being in control of his medications which he had successfully managed for years prior to his hostel admission. For him this loss of autonomy was a great source of frustration:

*I’ve been on tablets for 30 years…Now, I’ve got to wait for them to come to deliver the tablet to me. That give[s] me a pain. I have to sit at that table…until they get around…up to half an hour…I hate that …that’s wrong and, and I don’t know what else they could do…we’re supposed to make ourselves fit into it but I just can’t fit into it (R: Jimmy).*

Although Jimmy had already been living in the hostel for 10 months, he clearly continued to struggle with ‘fitting in’ to the hostel environment where he perceived he had no control over managing his medications.
Many residents attempted to maintain their independence and were therefore reluctant to ask for assistance. Julie, an 88-year-old resident who suffered from chronic pain related to her sciatica, spoke about her struggle to maintain her independence with her personal hygiene: ‘I don’t want them bathing and showering me and all that. I like my independence and when I haven’t got the pain I’m alright’ (R: Julie). Asserting her independence was more difficult when Julie experienced episodes of pain such as on the day of the interview, when she rated her pain ten out of ten.

Many of the residents and persons responsible in this study described ways in which adjusting to hostel life was made easier. This was achieved both by the ambience, the delivery of care and the freedom of being able to move around the hostel as they pleased. Residents were encouraged by the hostel to surround themselves with belongings from their previous home to make their rooms more homely, familiar, which gave them a sense of personal identity: ‘I like it in here and you see all my friends put them big photos and hang them on the wall there and everything’ (R: Trevor).

One person responsible felt the freedom her mother had to roam and wander freely within the safe setting of the hostel eased any difficulties in adjusting to this new environment:

*It’s like home. Well, it is and they give them [the residents] the run of the place you know where...mum likes to walk ... with the veranda here that’s closed in, she just walks around all day* (PR: Christine).

Other residents continued to struggle with their adjustment and described the hostel as ‘just a place to come and stay – but...I’ll be here forever. I’m not going to get better’ (R: Bill, 78 yrs). Some residents described feeling closed in and trapped and where they had lost control over everyday decisions. As Henrietta, a resident who had lived in the hostel for 54 months at the time of her interview, expressed:

*Well, I don’t know, it’s just you get depressed watching four walls. That’s how I feel and then I think, well, it’s what I call home now and I’ve got to live with it...you cook for yourself and... you have your own thoughts and... recipes... and
then when you’ve got to give that all away, it becomes hard, it was a bit hard to take (R: Henrietta).

Charlotte also continued to have difficulties adjusting to life in the hostel and was hoping to return to her villa. After four months of living in the hostel, she had begun to lose hope and had given up asking about the possibility of returning to her home.

I said to him [the doctor] what about [going] home? And he said ‘this is your home’… ‘this is home’, so…I haven’t said any more. That was a while back (R: Charlotte).

For the majority of residents, the food provided was a major concern and reinforced another loss in their lives. This was a universal complaint common to both the rural and metropolitan sites. Many residents disliked the food and the lack of choice, which they felt was part of being in an institution. As highlighted by one resident:

…the food is, is our biggest trouble here at the moment…we have meetings and things like that but, I mean, ah, it’s very hard I suppose to, ah, to ah, you, you can’t please everybody. I mean we don’t get rump steak (R: Martin, 92 yrs).

Although many residents felt that in being admitted to a hostel they had lost their autonomy, their ability to make choices and, in general, lost their independence, some residents accepted hostel life with equanimity. As Jack said: ‘I wouldn’t give a bugger if I was camping along a river… I wouldn’t worry. That’s how I think about it’ (R: Jack, 97 yrs).

One resident felt that the caring attitude of staff allowed her some control over the way her care was provided: ‘the staff have been unfailingly kind and friendly…instead of just ordering you to do something, they ask you…or sort of talk to you about it nicely, kindly, probably call you ‘darling’(R: Annette).

Families of residents also had to make adjustments and become accustomed to changes when having their loved one in a hostel. They talked about the difficulties of making this adjustment, but realised they could no longer manage the degree of care required
to keep their loved ones at home. Consequently, entering the hostel was seen as being for the best. It ‘took the pressure off’ and meant that resident’s health was ‘probably better because he’s here’ (PR: Rose).

Commonly, residents with dementia would ask family members repeatedly when they would be going home, stating that they were not happy in the hostel. As one person responsible, a spouse, reflected: ‘I think it wouldn’t matter where he was, he wouldn’t like it. He wants to go home and that’s, well, really, it’s just not possible’ (PR: Suzie).

Admission to a hostel often meant separation from a loved one, an emotional trauma that many family members and residents were still trying to deal with many months or even years later. While persons responsible reported a sense of relief that their loved one was receiving 24-hour care and supervision, it was still an emotional wrench. As Pam stated:

...as a wife or a carer, it’s very traumatic time, just to talk about it. Maybe after 63 years of married life, it’s a bit hard to accept. Yeah, I’m still getting upset, isn’t that awful. I feel it more than he does...I [get] very anxious before I come... depending on...what he’s like, what his mood is like, I guess...when I see him, and it takes about five minutes to know I’m right, I can handle all that...I hate leaving. The worst part is leaving them but once you get outside those doors, you feel relieved, you know that he is well looked after (PR: Pam).

Sue, another person responsible, a spouse, had initially felt guilty about placing her husband in the hostel. She still experienced on-going emotional stress because of the separation from her husband despite the fact that her husband had been in the hostel for five years:

I’m sort of getting used to it now but when we had to put him in, it just absolutely broke my heart. It was the worst day of my life but... you sort of accept it, it’s still hard now every time we leave him, it’s still hard to walk away and leave him (PR: Sue).
Residents also felt the impact of being separated from their loved ones. Jimmy, an 83-year-old resident, spoke about the separation difficulties he experienced being away from his wife. Jimmy’s wife had been admitted to a hostel some time before he had. When Jimmy’s care needs required his admission to a hostel, he could only be accommodated in a different hostel within the same residential facility. Jimmy was still grappling with why ‘they wouldn’t put us together… I don’t know why. I’ve been married…64 years this year…it’s bloody long time, isn’t it’ (R: Jimmy, 83 yrs). He was constantly concerned about his wife’s poor health and wanted to be close to her. He struggled physically to manage the walk to her hostel to visit her each day.

What has emerged from participants’ interviews is that this period of adjustment is extremely difficult for both families and residents. While many residents struggle with their loss of independence and autonomy, both residents and families feel emotional pain at being separated from loved ones.

5.4 Being Cared for

Despite being separated from family and needing to adjust to this new type of life, the majority of residents described a feeling of being cared for. This feeling of being cared for was attributed to the perceived qualities staff possessed. Age care staff were described as being attentive to the needs of the residents, and possessing a caring attitude. This resulted in an overall positive perception of the staff and satisfaction with the care provided. Several factors were identified that challenged the quality of care provided and the perception of being cared for. These included staff shortages, where residents were reluctant to impose requests on staff or ask for additional help, and inexperienced staff.

The majority of residents and persons responsible had a positive perception of the staff, describing the care as ‘good’ and personalised to meet residents’ individual needs. Staff were overall perceived as being attentive to the residents’ needs. The caring attitude of the personal care assistant or nurse influenced residents’ satisfaction
with the care provided. As Margaret explained, ‘they’re so kind to me and gentle and they have many laughs with me…I find that great…I love them’ (R: Margaret, 81 yrs). Another resident, Sarah, found the caring nature of the staff provided her with comfort, stating: ‘…the girls are very, very good, kind…the way they talk to you and the way they shower you…you feel comfortable’ (R: Sarah, 95 yrs).

As one person responsible, a wife, stated:

_Well from what I observed, it’s very good. They’re very caring, and they seem to look after them, and individually they seem to know… and they don’t force them to do anything. Like sometimes, my husband, if he hasn’t slept and he’s a bit tired and agitated… they just leave him be for a while until he’s over it, and then you know he can have his shower and his meals and everything. So I feel they’re doing a good job…they just seem to look to their needs carefully and they speak nicely to them (PR: Pat)._"

Families appreciated the skills staff possessed in being able to provide a gentle approach when managing residents with behavioural issues. Because of this approach, persons responsible were very satisfied with the care provided to their loved one, seeing it as ‘outstanding’ (PR: Rose). Families perceived staff as being dedicated to their work and treating the residents with ‘such respect and dignity’ (PR: Rose). Charlotte, an 86-year-old resident, felt that the staff really listened to the residents’ concerns, and ‘if anybody has a problem they’ll try and work it out’ (R: Charlotte).

It was apparent from the analysis of participating persons responsible that families perceived the quality of care provided remained consistent whether they were present or not. Within the hostels, there was an emphasis on open visiting and family access, including in secure areas, where family members were given the security codes. This open door policy on visiting allowed the care of residents to be transparent and clearly made families feel more secure in entrusting the care of their loved ones to the hostel staff:
[There] is access at any time you want. There’s no visiting hours and I have the magic numbers to get in and out at any time at all...So they can’t hide...they can’t turn it on when you’re around and turn it off when you’re not because they don’t know when you’re going to be around (PR: Jules).

Although the overall quality of care provided by staff was perceived as ‘good’, residents reported differences in the quality of care when there were staff shortages. During periods of staff shortages, residents were reluctant to impose requests on staff or ask for additional help because ‘they’re busy all the damn time, but they would do it, I’m sure, if you’d ask’ (R: Stella).

Residents were very aware of the workload of the personal care assistants and empathised with them because of the multiple tasks they performed. However, despite understanding the pressure and stress of the personal care assistants’ workload, residents perceived that reduced staffing levels influenced the ability to get their needs met in a timely manner.

There’s no staff hardly...there’s not enough...I mean I’ve been here all night and press a button and you don’t get anyone. They’re busy...Today is not enough care but that’s not the carer herself, it’s that there is...not enough staff...very busy, very busy...I can see they are very tired in the end because there are a lot of very sick people here around (R: Sarah, 92 yrs).

Residents also spoke to each other about the standard of care provided and shared frustration at having to wait for timely care:

I do think they could have more staff... well, it appears they don’t seem to have enough staff... a few other people [other residents] have commented to me, and I said, ‘how did you get on’ to the lady up the road here and she said, ‘oh’, she said ‘about 2 hours later’ or something like that... (R: Philippa, 82 yrs).

As the findings presented in Chapter Four showed, staffing shortages were more pronounced at the metropolitan site. This site also employed a larger number of agency staff, whereas the rural site had a pool of casual staff and rarely used agency staff.
There was also a higher retention rate of staff at the rural site. From the residents’ interviews it emerged that agency staff were not always in a position to ‘care’ in the same way as permanent staff, given the temporary nature of their involvement. As agency staff worked within the facilities on an ad hoc basis, they did not work within the same ethos of care or share in the culture of a relationship-focused approach. As one of the persons responsible put it: ‘the casuals that come in are not quite so caring’ (PR: Jules). One resident commented on the high turnover of coordinators who had been employed during the 60 months he had resided in the hostel: ‘they’re changing like you change your underwear’ (R: Tom).

One resident reported the staff shortage as related to the poor monetary rewards personal care assistants receive: ‘they don’t pay enough…if the staff got better benefits they… would stay and not leave’ (R: Tom); the same resident suggested that the organisation should increase their rates to maintain the staff and be more ‘competitive’.

Some residents perceived the cultural background of the personal care assistants as a factor influencing the quality of care provided and, in some instances, as creating additional challenges for residents. At times, residents found it difficult to understand personal care assistants whose first language was not English; sometimes they perceived them as being abrupt:

There’s umpteen nationalities, and a lot of them from the [X Region], and they can be a bit abrupt. You’ve got to take that as it comes, you know, and don’t be easily upset…I think it’s probably their background. A lot come from the [X Region] and… their English is not the best… you’re got to give… them a chance so I’m being too harsh on them but… no it could… be improved…the staff is the problem. They’re changing, changing all the time (R: Christopher, 89 yrs).

Older and more experienced personal care assistants were seen to be knowledgeable and more understanding of the needs of residents while inexperienced staff did not provide this high quality of care. As one resident stated: ‘they’ve [older staff] got more experience…the elder ones will know…what you’re going through’ (R: Henrietta, 78
yrs). Jill, a resident who had lived in the hostel for 18 months at the time of her interview, was concerned about the lack of supervision of the personal care assistants, particularly the younger staff who were new to the organisation. As she said:

...well it’s quite good really, but they’ve got so many young ones coming in that can’t understand what you’re saying at times, and you can’t understand them and... they don’t know what they’re doing...but really, I think they need more supervision...they’re quite willing some of them...to help (R: Jill).

One person responsible, a spouse, pointed out the advantage of retaining staff for long periods, stating:

they say they prefer to keep the same staff because the patients know them and they know the patients, and if they notice a change in the patient, then they know there is a problem, whereas if you get casuals in, they don’t understand the patients and some of them, she said [the manager], they do double shifts ... so they all seem to be quite happy working here (PR: Heather).

The overall picture that emerged from the resident and person responsible interviews was a positive perception of the staff and satisfaction with the care provided, and, although residents and families described factors that could influence the quality of care provision, they described a feeling of ‘being cared for’ in these hostel settings.

5.5 Becoming a Family

Becoming a family emerged from the data as a sense of unity and caring for one another through close interactions and relationships built over time between residents, staff and family members. The participants often used the word ‘family’ to describe this connection. The relationships that developed between residents, staff and families generated a sense of family within the hostel. Supportive relationships were evident, as occurs in a ‘family’ atmosphere. Special bonds developed which positively influenced resident and persons responsible perceptions of life in the hostel and the provision of care. Intertwined in the concept of becoming family was a sense that the
hostel was home, but for a few the hostel remained an institution that could never be considered home.

From the interviews it emerged that the relationships and close interactions between residents, staff and family engendered a sense of family, of unity and of being part of a community and caring for one another. There were many ways in which this sense of family manifested itself. The fact that staff became personally involved in the relatives’ lives, often exchanging photographs and discussing special events, made residents and their families feel recognised and cared about. As one person responsible, a spouse, expressed:

*I think the staff are wonderful... they’re friendly... I feel I can talk to them like they’re part of my family as well... I usually come on the same day of the week and I know those girls quite well... so yeah, we get on. We get on well. They look at photos of my grandchildren (PR: David).*

Families felt supported by the staff and included in this ‘family’ atmosphere. Sue, a person responsible who had been visiting her husband Calvin regularly since he was admitted to the hostel with severe dementia 15 months prior, was still emotionally struggling to come to terms with his cognitive changes. As a result, she often felt upset during her hostel visit and close to tears when it was time to leave:

*I’m a bit ... sooky and if they [staff] see me getting upset, they’ll race over, give me a cuddle, walk out the gate with me you know and just, just couldn’t be nicer. And I have never, ever, and I go down there a lot, I’ve never seen one of the staff be horrible to a patient yet (PR: Sue).*

As evident from Sue’s description, family members appreciated the staffs’ awareness of each resident’s fragility and the comfort they provided.

Persons responsible in particular noted that staff would help families who were having difficulties adjusting to their loved one being in the hostel by connecting them with other relatives who had similar experiences. This formed the basis for developing relationships between families and generating the sense of family across residents and
their immediate relatives. Rose, for example, struggled with the decision to place her husband, Kenneth, who had dementia, in permanent hostel care. Once Rose arranged for her husband to be transferred to the hostel, she reported being pleasantly surprised by the support provided by the hostel staff and the on-going camaraderie with other relatives.

*They put you in touch with the [other families]... when we came in they said to me, 'oh, you know, we must get you to meet X, ... you two have a lot in common'... or they would ring and say, 'look this new resident is coming in and the wife is...having great difficulty with the separation, could we give...her your number and you could just have a chat?' They look after us in that way...the relatives working together...we all have the same comment about the care (PR: Rose).*

Rose soon became one of the relatives who were providing support to other new families in the hostel. Rose felt that the bond she had developed with the staff and other relatives would continue even after her husband died. She was planning to maintain this relationship and to ‘continue to come… here to visit the other residents and the staff… because it’s part of my life now’ (PR: Rose).

Although the relationships that residents developed with other residents did not necessarily entail friendship or intimacy, it was considered important to engage in social relationships. Relationships had a positive impact on the resident and persons responsible perceptions of care. As noted by one daughter, having her mother in an environment where she was surrounded by other people, maintained her social skills. The fact that she had dementia, as did other residents, was irrelevant. And as John explained:

*She loves company, she does not like to be by herself, you know. She likes to integrate with the other ladies and she doesn’t know who they are or what their names are, and she’s been here six months living with them (PR: John).*

Trevor, a resident who had been living alone for some time prior to his admission to the hostel, explained that it initially took some adjustment to come to terms with
living with other people. He was philosophical about his relationships throughout life, saying that people either made a connection with someone or they didn’t. He did, however, think additional effort to get to know people was required when living in a hostel environment: ‘See, you’re living with someone aren’t you.’ (R: Trevor, 96 yrs).

As noted earlier, many residents considered their health to be better than that of other residents within the hostel. In these instances, residents took on a surrogate carer role, willingly assisting and helping other residents in need. Within all hostels, residents would sit with the same group of residents at meal times. As a result, some of these residents developed a special bond. For example, Henrietta, a resident who at the time of her interview had been living in the hostel for 54 months, spoke of how she frequently helped other residents at her table at meals or to monitor their medications when requested by staff. This was something she was able and willing to do and found rewarding. This was her contribution toward their relationship and gave her purpose.

A dear old lady…poor old pet, she’s 96…she can see about that far in front of her and she sits…beside me at the table for meals especially breakfast…they’ll [PCA] say ‘you watch her take her pills won’t you?’ so I’ve got to watch her take her pills. But I don’t mind doing that ‘cause she’s a dear soul and she sort of appreciates what you do for her, and she’ll have… some…brown sugar on her Weet-Bix, so I put that on for her, do things for her (R: Henrietta, 78 yrs).

Another resident described a similar scenario:

I’ve got four at my table and… they’re elderly and…they’re a bit hard to understand…You’re got to be a bit tolerant of them and help them. I’ve got a fellow who sits at my table and I cut his meals… up for him. I do that – help him.
I don’t say everybody does it, but I’m a bit of a softie (R: Christopher, 89 yrs).

While both Christopher and Henrietta required high-level care and had complex medical conditions themselves, they believed their current health was better than that of other residents at their table and saw this as an opportunity to help. For other residents, being more able than their fellow residents, both physically and mentally, presented challenges to building relationships with them ‘because a lot of them are
very deaf, can’t hear you and are psycho-demented, so you’ve really got no one to talk to. It’s just hard’ (R: Sarah, 92 yrs).

Developing relationships was sometimes challenging. For some, having or maintaining a conversation with a resident with dementia was not possible. Even being around them negatively influenced their own sense of wellbeing. Harry, for example, an 86 year old resident who did not consider himself ‘old’, did not want to join the other residents at meal times. Being surrounded by his peers who were frail, and cognitively impaired made him feel depressed.

“I’ll be 87 soon…they’re old people and…they slop their food and…I can’t stand that, and the main one here, [the manager] she’s trying to get me... to go down there more often, but then I come away and…I wish I hadn’t gone…I’m selfish, I suppose, but…they don’t talk. They just sit there and slobber and…it’s very depressing with some patients. I mean we’re all getting old but, ah, it doesn’t make you…feel good (R: Harry, 86 yrs).

Several other residents held similar views to Harry. Being confronted with other residents who were frazier than they were discouraged many from participating in the activities in the main lounge room:

You know, it’s very hard... you go out into the lounge for morning tea and half, or nearly all of them, will be asleep, and same with dinner – they’ve got to be brought out and they’re not with it, you know. It makes it very hard (R: Jill, 91 yrs).

Most residents felt that building good relationships with staff was important and positively influenced their perception of life in the hostel and the provision of care. Sam, a resident who had been living in the hostel for nine months when he was interviewed, felt he had developed a good rapport with the staff and found them to be generous with their time and willing to help with any problems.

Well I feel [I] have a good rapport with...the carers... They all care you know...if they can do something for you... they don’t hesitate... they’re all generous in what they can do for you and what they offer you...I feel that this place is
perhaps as good as you could find, particularly when it comes down to the personal nature of the relationship between staff. You’re only got to mention something and they will do it (R: Sam, 90 yrs).

Many residents spoke of the close relationships they had with staff and how they were able to share stories and jokes, which made them feel special. As illustrated by one resident:

I’ve really got to love the staff and the girls and I’d like to take them home with me, so fond of them...they’re so kind to me and gentle, and they have many laughs with me, and I can laugh back with them, and I find that great, and I find them great. I love them, very kind...I have many jokes with them and they have jokes with me (R: Margaret, 91 yrs).

Henrietta felt honored with the special private one-on-one moments she was able to share with a personal care assistant.

You got to ring the bell if you want them, but in the morning mostly, one of the young girls will be popping in and saying ‘hey X, I’m coming in here to have a yarn’. They’d shut the door a bit... sit down for 5 minutes... and have a yarn to me. One of them would come in and say ‘quick, is the kettle boiling’ and I’d say. ‘yes’, ‘good, we’ll have a cup of tea, quick’. She’d drink a cup of tea while she’s talking to me and away she’d go (R: Henrietta).

It was through these special relationships that residents and persons responsible felt that staff developed insight into their problems and were able to identify problems in a timely fashion because ‘these people understand you… if you’re got something wrong with you…they pick up something’ (R: John, 90 yrs, depression). As one person responsible, a daughter, stated:

...if dad would let on more how he’s feeling and what’s happening with him, it would be a lot better,...instead of him just saying he’s alright when he’s not...I think the girls here are starting to pick up on, on that. They can, by the look of him they can pick when he’s, yeah, he’s not doing well (PR: Alison).
Communication was an important factor in developing the relationships. Families wanted to be kept informed of changes no matter how great or small. As illustrated by one person responsible:

*I know they’re looking after him and I can always ring up and ask, which is a very big thing, and they’ll let me know, you know, whichever staff is on, they all know who I am, and they all sort of let me know what’s happening (PR: Emily).*

Within hostel settings, staff knew all the residents and providing such information was clearly a factor that contributed to establishing a sense of family within the hostel.

### 5.6 Uncertainty about the Future

*Uncertainty about the future* is a theme that encapsulates how participants saw their future care being managed. There was recognition of a likely further future decline but when that would occur was unclear. Uncertainty surrounded the possibility of whether a resident could stay in their current hostel as they deteriorated and approached the end of life. Participants described varying experiences they had witnessed with their peers which perpetuated this uncertainty. Most residents were unwilling to move to another facility, and overwhelmingly perceived a move as something negative and destructive which would sever the bonds and relationships that had developed with the staff and other residents. Underpinning this uncertainty was fear of the future. This fear was related to the possibility of transfer to a nursing home where residents and persons responsible felt the health status of the other residents would be poor and many would have advanced dementia. Such a move was associated with isolation and approaching death.

For many, it seemed that the idea of moving elsewhere was something they had not yet considered. Nor was it something they had yet discussed with staff. One person responsible, a daughter, whose mother had worsening dementia, felt the future was something that was difficult to discuss until it become absolutely necessary: ‘I guess
they’d go to the next stage. I’m not quite sure. I’ve never sort of gone into it. You are inclined to put it off, aren’t you?...You don’t want to think about that’ (PR: Sophie).

While there was recognition of another ‘stage’ that would follow, given the resident’s current condition, many persons responsible avoided the discussion of the inevitable transition to end-of-life.

Stella, a resident who at the time of her interview had lived in the hostel for 28 months, had not considered whether she might need to transfer to a higher care level in the future. Reflecting on her future care needs she seemed to feel that since other residents in the hostel had been around a lot longer than she had, she still had time before any end-of-life care decisions needed to be made: ‘I don’t know, I’ve never asked. No, I’ve never asked… I should imagine you must stay, like, there’s a lot of people here who have been here a lot longer than I have’ (R: Stella).

For Stella, the length of time a person had been in a hostel was the precursor to the need to transfer, rather than the person’s individual health status.

While residents and persons responsible had a sense of uncertainty about their future care needs, many had an understanding of the limits of care within the hostel setting. That is, once the care needs exceeded the limits of the current hostel, there was a process of transferring to the next level of care within a residential aged care facility. For some residents there was a sense of inevitability about this transfer, for others it was a source of uncertainty and fear of the future.

Residents and persons responsible had variable perceptions of what ‘the next level’ care entailed. Some believed they would be moved to the next level of hostel care or the nursing home within the facility. Christine, a daughter, the person responsible for a resident with dementia, believed the next stage would be to the nursing home:

  Well, I think they’ve got to be, they’ve got to be mobile for starters…they can’t cope [staff in the hostel] with people that are not mobile. So, once they get to the
stage where they can’t, you know, get up and walk around, then they shift them to
the nursing home (PR: Christine).

Most residents were aware of a system in place where residents transferred to another
facility when their condition deteriorated. Katherine, an 89-year-old widow with
macular degeneration, voiced her thoughts on the various levels within the transfer
process:

...you get transferred down into XX Wing [another hostel]... is just a little bit
more care than here... but if you go down to the nursing home, you’re really a
bed patient, you know, so there is that level that you go on to and then you
always say, well the next one will be over on the hill [cemetery] (R: Katherine,
89 yrs).

Thus, transferring entailed another hostel or nursing home. There was a perception
among residents and persons responsible that if you required transfer to the nursing
home your condition was very poor. As stated by one resident: ‘...if you do get very,
really bad, I think they move you to the nursing home part...well, if I get any worse, I
go to the nursing home’ (R: Geraldine, 90 yrs).

This process of moving to higher levels of care and eventually the nursing home was
common among residents, particularly nearing the end of life.

For a few residents, moving to another section was not of concern to them. Jack, who
had been living in the hostel for 17 months at the time of the interview, believed that a
move to the nursing home would ‘be no different... It’s just the same thing’ (R: Jack),
while others saw this as an opportunity to receive more necessary care. Martin, a 92-
year old widower with severe osteoarthritis and multiple co-morbidities, felt that
transferring to another hostel was a natural progression. It was ‘a follow-up of
life...well, I wouldn’t expect to stay here and lie in a bed or sit in a chair here and
have...all meals brought in...that would be to me depressing...I think therefore, you
should go to one of the other hostels with more care’ (R: Martin).
While residents were unsure of the future, many were hopeful that they would be able to remain in their current hostel. The majority of residents voiced a reluctance to move, and anticipated feelings of loss with any move. Overwhelmingly, a move was seen as negative in that it would sever the bonds and relationships that had developed with the staff and other residents. Polly, who had lived in the hostel for 11 months at the time of her interview, felt settled surrounded by other residents she had grown up with from the local district. She had no intention of moving elsewhere:

*I don’t want to move, I think I’ll stay here and I want to ’cause all these woman are people I knew years ago. I don’t want to move. If they tell me, if I have to...if I got worse, I’d have to go over there...where all the funny people in their wheelchairs [are] and I couldn’t stand that, I couldn’t stand...I want to stay in this room...I just want to stay, I’ve settled here (R: Polly, 84 yrs, Barthel Index-35).*

Bettina, an 87-year old resident, was concerned that a move to another facility with different staff and different rules would affect significant parameters of her life in the hostel:

*I’d rather stay here. I know it. I know the staff and they are nice. My husband can come and see me if he wants to. The rest of the family can come and see me anytime. They’re very big things when you are in ...the hostel (R: Bettina, 87 yrs).*

Married couples residing in the same hostel were concerned that relocating to higher level of care would entail being separated from each other: ‘we’d be split up then [If they moved me]. We don’t want to be parted. We’ve been married …sixty-six years’ (R: Richard).

Persons responsible for residents with dementia anticipated that a move to a different, unfamiliar environment would spark behavioural issues. They were also concerned about fracturing the resident’s routine. One person responsible was adamant that she would not agree to her mother being moved to another facility:
I don’t ever want my mother moved down there [high-level dementia unit], I just think, she is...astute enough to realise that this would be just terrible, this would finish her down there because they’re so much worse...she’s very...a personable lady, she would miss her friends terribly...she’s created, there’s a little group of them that sort of sit together and walk together and chat together...she functions well there, she knows where her room is, she can walk backwards and forwards and look over the garden and see her room and, umm, it’s really home to her and it would be just dreadful to see her move from there (PR: Tracey).

Tracey believed that a move to the nursing home would be like taking her mother out of her home, an environment she had not only become accustomed to for the past couple of years but that she felt comfortable in and that confirmed her sense of identity.

However, only a few residents believed they would actually be able to stay in their current hostel until they died. Reflecting on the condition of other residents around them gave them reassurance. As illustrated by Colin, a 96-year-old widower:

> I would say there are at least 10 or more that are permanently in wheelchairs and quite a few patients here are – come to the dining room, they’re still in their wheelchairs and they’re being fed so it’s, the way I look at it, as far as I say, you’re here until the happy ending (R: Colin, 96 yrs).

However, while some residents and persons responsible felt reassured by witnessing their peers staying, others had witnessed that deterioration of fellow residents resulted in a transfer to the nursing home or hospital. This process of transferring - observed by residents - reinforced their belief that they too would have to move at some point in the future. Because of the communal dining arrangements, this was often the first place where residents noted the absence of others. As one resident commented:

> When I go to the dining room... you see a couple of faces, they’re not there for a while... well they’re gone... they couldn’t look after them...staff couldn’t look after them. So I think I’m heading in that direction (R: Andrew).
Another resident recalled the transfer of one of her peers whose condition was poor: ‘she had cancer and [she] kept bleeding… it was too far gone to do anything and they moved her down to the nursing home’ (R: Henrietta); she died soon after the transfer. These experiences of peers reinforced residents’ concerns that a transfer was indicative of death being near.

Clearly, the greatest fear of many residents and persons responsible was being transferred to the nursing home. They equated such a move with end-of-life care and death. In order to reduce the possibility of becoming a candidate to be transferred, many residents tried hard to maintain their independence. Henrietta, who was experiencing severe pain and lethargy when interviewed, admitted to needing help to get out of bed but also stated that she attempted to maintain her personal hygiene needs in order to assert her ability to function independently:

“Well if I get worse…I go to the nursing home and that’s where I don’t want to be, that’s why…I still shower myself. I’ve got to have help to get out of bed but once I get out of bed I’m right and I go and… shower myself and dress myself and go to the toilet on my own. It’s only since I’ve had a crook arm that I can’t do a lot with but I still do what I can (R: Henrietta).

Analysis of the interviews demonstrated that hostel residents believed that residents in the nursing home tended to be in very poor health and suffering from advanced dementia. Polly, an 84-year-old resident with chronic renal failure, believed that if you are living in a nursing home environment surrounded by extremely ill and demented people you were likely not ‘to last long over there… you know, when you mix with people, the poor souls over there’ (R: Polly). Another resident, Jimmy, had similar thoughts and fears about the outcome of living in the nursing home with high numbers of people with advanced dementia: ‘that’s the end of you when you go over in there… it’s a bloody awful place…[surrounded by]… dementia [residents].’ (R: Jimmy).

While residents in the hostel had experienced living with people with dementia, they were also able to interact with many other residents who did not have dementia. Their perception of nursing homes as primarily caring for residents with advanced dementia
made many residents apprehensive and fearful of being transferred there. As expressed by Joan:

*I hope I never have to go there... because some of them are – we went and had a look at it [the nursing home]...and this man was sitting in the corner just muttering to himself and the staff were saying ‘come on, Johnny, hop up, Johnny’. It was depressing, most depressing ‘cause he wasn’t that old...he was definitely a write-off case, you know, terrible (R: Joan, 84 yrs).*

For Joan, being in a nursing home surrounded by residents with advanced dementia was something to be avoided, no matter what.

Persons responsible believed the consequence of transferring their loved one to the nursing home would result in them giving up on life. For instance, Trudy believed that her father, who had moderate dementia, would be capable of understanding he was in a different environment, and being surrounded by other residents more fragile than he was would destroy his will to live.

*I think in a nursing home...my father...he would know that this was sort of the end because, even though his condition last year, when he was extremely sick, he was able to verbalise to me that he thought he was going to die fairly soon, and I think...if he was put into a nursing home, he would sort of give up...So I think once they’re in a nursing home...this is the end...you...probably just want to lie down and go to sleep (PR: Trudy).*

Clearly, transferring to a nursing home was closely associated with dying and death.

5.7 Conclusion

The overarching theme to emerge from the interviews was that of transitioning towards the end of life. But, participants very clearly saw themselves as not dying ‘now’. One of the key findings from the interviews with residents and persons responsible is that, in spite of having multiple chronic health conditions and co-
morbidities, these high-level care residents perceive their health status to be ‘good’ and any deterioration was not seen as ill health but rather part of the normal ageing process. This perception poses challenges for aged care staff attempting to engage this population with the concept of a palliative approach.

Multiple contributing factors were described as precursors leading to a hostel admission. However, many residents questioned why am I here? Once the move into the hostel had occurred, there was a period of adjusting to life in a hostel, although for a small number of residents this was never possible. Despite this, the majority of residents described being care for and, as relationships built, residents, family members and staff equated these close connections with becoming a family.

Residents were uncertain about their future and feared the prospect of transfer to the nursing home should their condition deteriorate. This uncertainty about the future and the associated fear was reinforced when residents witnessed their peers being transferred. Residents and persons responsible felt unprepared for this possibility and associated it with impending death. They were also fearful of being surrounded by high numbers of residents with advanced dementia. The thought of transferring to a nursing home at the end of life was regarded as particularly problematic in that it would entail breaking the close relationships and bonds that residents, persons responsible and staff had established and developed over some time.

The majority of residents perceived transfer to another facility when their condition deteriorated as inevitable, but, clearly, the preferred place of end-of-life care as voiced by these residents (and persons responsible on behalf of their loved ones) was within the hostel.
CHAPTER SIX:

Aged care staff perceptions of providing care to high-level care residents: ‘we work with them’

This chapter outlines the findings from the interviews conducted with aged care staff - the seven hostel managers and 23 personal care assistants who participated in the study. Qualitative data was collected to specifically address the third research aim; that is, to explore age care staff understandings of a palliative approach and their perspectives on how a palliative approach is being incorporated into the care of their high-level care residents in hostel settings.

Analysis of the interviews revealed three main themes: the meaning of a palliative approach, an ethos of care, and creating a ‘community of care’. The meaning of a palliative approach is multifaceted and contradictions among staff exist regarding the appropriate timing of such an approach. However, there is consistency in the care provided by aged care staff to high-level care residents, through a shared and valued philosophy, an ethos of care, which underpins the development of a community of care. A community of care revolves around the key person, the resident, but it also includes their family as well as the aged care staff who provide the care. These themes developed from my analysis of these interviews and a description of each is provided at the beginning of each section. In addition, aged care staff experienced many challenges and constraints in trying to provide end-of-life in hostel settings and these findings are presented in Chapter Seven.

The following story from one manager provides a brief introduction illustrating the way in which a palliative approach can be implemented in hostel settings.
When I interviewed this manager, she spoke of a resident, Charlotte, who had recently moved from her house to a villa within the facility taking her beloved dog with her. After only being in the villa three months, Charlotte collapsed and required hospitalisation. In this crisis situation, her son, who lived close by, agreed to look after her dog. During Charlotte’s hospital admission, she was diagnosed with an unknown primary carcinoma but chose not to pursue any tests or treatment in hospital. Given her frailty and on-going needs, it was decided by her medical practitioner that she was no longer able to remain in her villa accommodation alone and was assessed and transferred to the hostel. However, after a short period, it was identified by the hostel staff that Charlotte’s biggest concern, and cause of significant distress, was the separation from her dog. Through negotiation with the facility management, the hostel manager was granted permission for Charlotte’s dog, Jana, to spend two nights a week on a regular basis in her hostel room. This flexibility on the part of the organisation to bend the rules kept the resident interested in living despite her poor prognosis. For the manager, reducing the Charlotte’s psychosocial distress was the most important factor:

So that was part of the palliative approach... we just sort of thought outside the square of what we thought a palliative approach was about. So that’s just an example of how we perceive it. That it’s not just confined to that box. Whilst there are guidelines, you can step outside that realm (Manager: 3).

This manager’s perception of providing a palliative approach, whereby the central focus was striving to meet the particular needs of a resident, was a shared and valued viewpoint expressed by aged care staff in this study.

This chapter begins by exploring aged care staff’s understandings of a palliative approach before examining how they see this as being implemented in to their work within hostel settings.
6.1 The Meaning of a Palliative Approach

The *meaning of a palliative approach* was complex and difficult for participants to describe. A palliative approach was seen as multifaceted, requiring a balance between physical and emotional care, with staff continually striving to provide ‘quality’ care. For aged care staff, a palliative approach meant bringing together a range of care processes perceived as important to ensuring the comfort and the delivery of high-quality care to residents, particularly as they approached their end of life:

[A] palliative approach is...being able to provide as much ...comfort...good nursing care, pain relief....adequate food and fluids...comfort care for the relatives coming in (Manager: 1).

Staff aimed to provide relatives with a sense of being enveloped within a circle of care, a community of care, where they did ‘what we can for the last few weeks or days’ (PCA: group C).

The timing of when to implement such an approach was disputed. For some it was appropriate when end of life was imminent, and for others a palliative approach should begin on entry to the facility. For some participants, a palliative approach was the focus of care at the end-of-life stage and incorporated the provision of ‘good nursing care’ – meeting the basic physical and emotional needs of the resident but also extending to the provision of ‘comfort care’ to relatives. For others, a palliative approach was also described as ‘holistic’ care which commenced from the beginning of a resident’s admission right through to end-of-life care and focused on identifying and meeting a range of potential needs:

*I understand palliative approach to be holistic ... from the beginning to...the end of the life treatment like the complete treatment right through like their cultural, spiritual or emotional, physical, all their needs, that they’re met (PCA: group A).*

However, many staff described a series of actions related to end of life care as opposed to the care of a resident and their family earlier on in their transition towards end of life. Staff indicated, for example, that when a resident was bedridden, they
would implement two-hourly turns to prevent pressure areas developing. They also performed half-hourly checks of the resident as they passed the room. In order to manage the increased physical needs of the resident, the staff often worked in pairs.

Within the concept of multifaceted care, staff considered the physical care needs and on-going physical assessment as important, but many aged care staff singled out emotional care as a vital component of quality care for high-level care residents. Often the needs of a resident required balancing the physical care needs and the emotional and spiritual aspects of care. As one personal care assistant said:

...you know the amount of care that you have to give them. Some you have to do more physical work for...others... the amount of care you give them, it’s more emotional than physical I think (PCA: 5).

Another personal care assistant spoke about the importance of providing emotional and spiritual support to residents to ensure a smooth and gentle ‘passing’ (PCA: group C). In her experience, many residents were aware when they were commencing the dying process and wanted to talk freely about their life and its meaning:

...a lot of them need to talk...and get things off their chest that they really don’t want to talk to relatives about...so ...you’re an advocate for them and you’re someone to listen to ...to counsel...to absolve a lot...of their feelings...we’ll take their secrets to our graves (PCA: group C).

By respecting residents’ emotional and spiritual needs and supporting them in these aspects of care, staff believed that they were enhancing the resident’s quality of life. Staff aimed to ‘promote quality of life rather than quantity’ (Manager: 6). Providing such ‘holistic’ care required additional effort whereby staff extended themselves above and beyond their normal duties. A palliative approach was described as care that was ‘special care…[requiring] extra care’ (PCA: 1). One personal care assistant gave an example of what she meant by providing this ‘special’ care to a resident in her care:
Little things like brushing hair, she loved the 4711 cologne so I’d put all that on. Change nighties instead of, you know, once a day we’d do it twice a day. She couldn’t get up to have a shower so it was a bed wash, and if we did get her up, it would have been in a chair... for half an hour, so that was special, especially in this unit where all the dementia residents have to be able to walk, that was a big thing for us (PCA: group A).

Clearly aged care staff believed that providing a palliative approach involved doing certain things in addition to normal routine care that were of particular importance, of physical or emotional relevance, for that resident.

Investing time to get to know the resident and their family and talking to them about their lives helped staff to meaningfully engage with residents. This was one way of enhancing the quality of life for residents and families and provided staff with knowledge of the ‘special’ things that mattered to the residents. Some staff believed the physical aspects of their work became secondary to promoting quality of life by providing emotional support to the resident. As one manager said:

...you get a picture of who this person was and what their life was like. So then when relatives come in and when we’re dealing with them, they can say, you know ‘so, tell me, you travelled in your life with your husband and, and you were a tailor...’ so... it actually brings it back down to, it’s not just clinical...clinical is secondary to quality of life (Manager: 6).

Focusing on these multifaceted aspects of care allowed staff to develop a ‘holistic’ view of the resident and helped them to identify changes in a range of areas that might indicate deterioration in their wellbeing, and that they were approaching the end of life. As one manager noted:

There would be a combination of things. Obviously, it would be a decline in their...health status, their emotional state...their ability to... undertake daily tasks...their interaction with others. I think it’s...a combination of all those things that we take for granted in everyday life...I can see that...in any of those areas there is a decline (Manager: 3).
As the resident’s condition began to deteriorate, aged care staff would become more alert to nuances in their status, looking for patterns of change and focusing on detecting any unmet needs. Specifically, they would look for signs such as the resident losing ‘their daily interest in life…they lose that…then…appetite, mobility…and [refuse] medications’ (PCA: group E). With residents who had dementia, ‘the first thing’ staff noticed was a change in their mannerisms after which they would ‘watch for everything else’ (PCA: group A). A change in mannerisms is usually a sign that ‘something isn’t quite right’ (PCA: 4).

The interviews with aged care staff revealed general agreement that a palliative approach entails multifaceted, ‘holistic’ care that finds a focus on the residents’ physical and emotional needs, and that takes into consideration resident and family vulnerabilities during this time. There was also a common perception that providing a palliative approach requires additional time to allow the staff to both assess and address the residents’ unmet needs. However, in describing these elements it was evident that the participants were describing this in the context of end of life care, and knowing when to implement such an approach was difficult.

One of the fundamental aspects of a palliative approach is the understanding of when such an approach should be implemented. The interviews with personal care assistants and managers indicated that opinions diverged on this question. Contradictions and confusion existed among the staff about the timing of when to implement a palliative approach. Staff acknowledged that it was difficult to know when to implement a palliative approach and that this difficulty stemmed from misconceptions surrounding the term. For some, a palliative approach should commence on the day of admission and for others, at resident’s end of life. One manager summarised the problem as follows:

...people...get confused of when a palliative approach should be used, okay. Palliative approach still by most people is when that person is probably at the end of life and we’re talking minimal lifespan’ (Manager: 1).
Certainly for some staff, the term ‘palliative’ was equated to care of a person expected to die within a short time, and suggested to them that a palliative approach was appropriate only at the ‘last stage of life’ (Manager: 5), ‘…when mere days or weeks remained’ (Manager: 4). As one group of personal care assistants stated: ‘…my understanding is to make the resident as comfortable as possible in probably their last few days or it could be weeks’ (PCA: group E). And as another group of personal care assistants stated: ‘I understand…it’s the end of life… care till the end…the final journey’ (PCA: group C).

However, as manager one pointed out, while a palliative approach was caring for people ‘in the end stages of their life’ or ‘in the end stages of an illness that’s terminal’, problems arose when ‘I … have somebody here that’s going to go on for the next two years but has a terminal illness’ (Manager: 1).

Some staff felt a palliative approach should begin earlier in the resident’s transition to end of life trajectory. They indicated that consideration of implementing such an approach earlier was often prompted by a resident exhibiting signs of pain, lack of mobility or lack of cognition. Staff felt it was important to monitor and manage these issues to encourage independence for as long as possible, thereby assisting the resident to live a fulfilling life. As one personal care assistant explained:

_I mean palliative care, everybody just thinks it’s just death straight up and you’re only here to look after them for two weeks and they’ll die. I think it’s not. It’s ensuring that their life is lived to the fullest and as independently as they can and for as long as possible (PCA: group G)._

While staff acknowledged that residents had chronic and complex conditions which were not reversible, they also recognised that there was often a long period before the terminal phase was reached. Thus some staff interpreted a palliative approach as a long-term commitment to providing quality care, which in many cases could last for years. As one manager stated:
I think a palliative approach is a long term approach. I guess...seeing what’s involved in the care of the...resident and looking at what can be done for the long term and at their end stages (Manager: 2).

And as one personal care assistant pointed out:

...people have been palliative for five and six years...so I think...that’s bit of a misconception when someone says “oh they’re palliative”. They say “oh they might not last the week”, well five years down the track...they’re still trotting around” (PCA: group C)

Some staff felt that the point when a palliative approach needed to be implemented was when the resident was categorised as ‘high-level’ and had complex needs. As one manager stated:

[Many residents have] chronic illness...that does not improve and renders the resident very frail and weak...something must be done to prepare them if their condition does not improve (Manager: 3).

On the same basis, some staff believed that a palliative approach for high-care residents ‘should start on the day they come in here…they very rarely go out the front door…this is the last stage’ (PCA: 5). Thus the focus should be on looking ‘at what can be done long-term for them’ (Manager: 2).

Interestingly, the term ‘palliative approach’ was not explicitly used by aged care staff in their interactions with residents in these hostel settings. While aged care staff had a good understanding of the principles and philosophy that underpin a palliative approach, there was little distinction made between a ‘palliative approach’ and ‘palliative care’. Many of the examples given by staff in their explanations of the meaning of a palliative approach were about residents nearing their end of life. While staff referred to residents as ‘being palliative’, this was not the language they used when speaking to residents or families about their current situation. The language staff often used when speaking to residents and families was ‘we need to consider this is
maybe the beginning of the end” (Manager: 4), rather than, for example, ‘we need to consider a palliative approach’.

Aged care staff recognised the large proportion of high-care residents in hostels as ‘a sign of the times; the Government’s supporting them to stay at home’ (PCA: group A). As one personal care assistant put it: ‘if you’re not high-care, you’re not accepted in this environment, if you don’t have certain needs, because it’s not worth it’ (PCA: 3). One manager suggested that a palliative approach could be ‘for high-care residents and it doesn’t necessarily mean it has to be end of life’ (Manager: 3).

Another suggested that the impact of the Government’s ‘Ageing in Place’ policy had created a shift in the complexity of care requirements of residents in hostels such that a palliative approach was perhaps appropriate for most residents:

Previously] If you couldn’t walk to the dining room well you were nursing home...there [was] no such thing as wheel chairing you out for every meal and now I could say ...nearly all of ours are palliative in a way...they’re completely different (Manager: 6).

Considering the increased level of care now necessary in hostels, a few staff felt that discussing a palliative approach at the time of admission could ease the difficulties of approaching discussions regarding end of life care later. In their view, rather than waiting for a crisis event to occur, discussions about the resident’s wishes and future care needs helped to dispel misconceptions regarding a palliative approach. As one manager stated:

I think if you put that in place from day one, it makes it a lot easier for you later... rather than... you’re admitted, this is your room... this is the activities room, that’s the dining room, and then nothing is ever mentioned until they decline, and then you come in and say ‘oh look, we’re considering a palliative approach’ and then the word is very scary. If it’s mentioned early on...I think you dispel a lot of myths...you might have more doors opening, more willing (Manager: 3).
What this data reveals is that there were variations and contradictions in staff understandings of the appropriate timing for implementing a palliative approach and that staff rarely openly engage in the discourse of a palliative approach. The following section discusses the way in which aged care staff who are working with high-care residents were committed to an ethos of care.

6.2 Aged Care Staff’s Ethos of Care

From the interviews it was apparent that aged care staff shared and valued a common philosophy, an ethos of care, in which care is individualised, relationship centred, requiring collaboration and shared decision-making between the resident, family, and staff. Staff strived to provide quality care by incorporating and promoting these aspects into the provision of care for each resident and their family. Within this ethos of care, relationship-centred care, whereby strong bonds were developed between staff, residents, and families, led to the creation of a small, intimate community. Collaboration with the resident, families and staff, and promoting honest and direct communication were also considered important and led to shared decision-making.

Staff saw individualised care as an ideal to strive towards. Within the context of a ‘holistic’ palliative approach, this meant that staff needed to develop an understanding of a resident’s personal needs: ‘you … have to know their spiritual and cultural needs…because that’s a personal thing’ (PCA: 1).

As noted earlier, personal care assistants in hostel settings provided the majority of hands-on care to the residents. They saw providing this care as the basis on which a deeper attachment to the resident and a sense of ‘knowing the resident’ were developed. It was often during this type of personal care that residents divulged stories about their life. One personal care assistant referred to this as the ‘the shower of truth’, since intimate conversations would frequently take place when she was assisting residents in the shower:
We’re really the closet ones to them [residents]…they devour [divulge] everything, you know, “the shower of truth” we call it. You know, in the shower…the most vulnerable time and you’ve got to be talking and that’s when things sort of flow don’t they?…in the shower of truth (PCA: 4).

At one metropolitan site, a description of the resident’s life history and family information was collected on admission. Staff saw this as a helpful means to creating a picture of the resident and developing an understanding of their life story; it gave them the background knowledge to interact with the resident and family, which enhanced the development of their relationship with them.

According to personal care assistants, these life stories and the extended personal contact and intimate care they provided enabled them to develop intimate knowledge of a particular resident and to better meet their needs. Staff discussed the ability to recognise resident and family needs as a fundamental tenant of ensuring quality care. Through ‘knowing the resident’ and providing care day after day, they were familiar with what was ‘normal’ for a particular resident and attuned to noticing subtle changes and signs of deterioration. Thus they would know ‘as soon as there’s something off with them’ (Manager: 3). As stated by one personal care assistant:

    ...if you’re been working with them for a couple of years you know them that well that you can pick up there’s some – alarm bells ringing that something’s wrong (PCA: group C).

Various subtle changes in mobility, pain, behaviour or body language could indicate a resident’s deteriorating condition, and often personal care assistants were able to sense deterioration when it occurred:

    Oh, it could be pain, it could be a lack of mobility, it could be a lack of cognitive…disabilities, it’s what you see as changes as you go in each day and... it’s hard to say, it’s your own common sense [that] tells you someone’s deteriorating (PCA: 2).
Frequently, staff were able to detect changes without even consciously looking for signs:

_A lot of it is intuition but I mean even if you get somebody new here or something you can tell by...their facial expression or the things that they do that something’s not quite right (PCA: 5)._  

Staff did not, however, rely solely on their intuition to identify changes in a resident’s condition; they also sought to identify clinical markers through assessments:

_You’re [have] got to look for fatigue...like more tiredness, breathlessness, their vital signs decreasing...like heart...and pulse rate...Their skin can give it away like in the colouring...either they’ll be pale or they’re yellow or...they get colder...you’re looking for...body temperature decrease (PCA: group A)._  

However, the clinical indications the staff identified were physical signs indicative of a person at the end of their life. This highlights the difficulties, and perhaps even contradictions, that exist in examining a palliative approach. While several participants emphasised a palliative approach as beginning early in the resident’s admission, in all of the examples from the practice described, most participants were clearly describing how they implemented a palliative approach at the end of life. This reflected a lack of clarity in relation to how and when to introduce a palliative approach earlier in a resident’s admission, and the lack of agreed indicators that could be useful to aged care staff earlier on in the resident’s transition to end of life, and would also assist in deciding when best to commence a palliative approach.

Incorporating multiple assessment tools into the resident’s assessment helped facilitated the identification of any issues. Some of these tools included pain scales, behavioural charts, blood pressure graphs and weight charts. As one personal care assistant stated, ‘we’ve got everything…and it’s all done…a lot of monitoring isn’t it’ (PCA: group A).

‘Knowing the resident’ also allowed a level of trust to develop between aged care staff and families such that families became confident that staff were in a position to
provide quality care and advice. Thus staff were able to help guide families through decision-making processes regarding a resident’s care. Families often sought further comfort and explanations from aged care staff following general practitioner visits. This is ‘because families really trust nursing care staff’ (Manager: 3) to assist them to interpret medical information.

One manager relayed a story about a resident with severe dementia in which the family was concerned about a possible skin cancer. The family wanted some sort of surgical intervention without considering the potential consequences of such an event. In contrast, the clinical decision-making process taken by the hostel manager was based on an ethical framework, within which she considered the benefits and burdens of such a procedure.

*We’ve got a guy [*a dementia resident*] with a big lump on his leg, it looks like a skin cancer...that really needs to be excised but the problem is that this guy, whenever he’s had a minor skin tear or anything, *he* picks and picks at it... the family kept saying something has to be done, maybe send him off to a plastic surgeon and I said ... ‘that’s fine, but think big picture: if you send him off to the plastic surgeon and he has that excised. He doesn’t leave a Band-Aid on when he’s got a skin tear. If he’s got a donor site...we are going to set him up for all sorts of problems because we’re going to end up with him picking and pulling ... there’s going to be infection, let’s just wait...because the intervention to get rid of that lump is going to be far worse than leaving it alone’...and so the family then agreed, ‘yes, we can see where you’re coming from’ (Manager: 6).*

Again, this demonstrates the ethos of care whereby aged care staff sought to provide high-quality care by focussing on the individual needs of the resident and family and it provides an example of the level of trust that had developed between this family and the manager of the hostel.

A feature of this relationship-focused care was that staff saw themselves, the residents and their families as members of a community within the hostel. The intimate bonds between residents and staff, and family members and staff that developed within this community created a family-like atmosphere. Staff believed that, because of the
strong relationship, residents came ‘to rely on us like family’ (PCA: 3). This connectedness was described as ‘dignifying’ (PCA: group F) because through this connection, care in the hostel was equated to being ‘like if they were being nursed at home’ (PCA: group F), as illustrated in the following quote:

_It’s their home, they’re comfortable,…So, you know, I mean…it’s family…it is, and their family is like our family…one big happy family really (PCA: group F)._

One personal care assistant viewed caring for these residents as being similar to caring for her grandparents, the closeness she experienced as being stronger than just that of a professional caregiver: ‘It’s like seeing nana, everyday you come in and see nana and grandpa, everyday, you know’ (PCA: group H).

When a resident did not have any family or was estranged from family, the staff advocated for the resident and became their ‘family’ surrogate decision maker. Aged care staff often referred to this relationship as becoming extended or surrogate family. One manager told the story of a resident estranged from his daughter. The resident was in the terminal phase of his disease. The manager contacted the daughter to inform her of his poor condition, giving her the opportunity to resolve past issues and visit him. However,

...his daughter did not want to be involved. I told her that he was dying; I couldn’t obviously give her a timeframe and asked whether she wanted to see him or not – and she just said, basically...she didn’t want to see him until he was dead. So that was fairly hard for him...[it] was very difficult for him to accept that she didn’t want to see him...she’d seen him 12 months before and tried to patch things up but... they couldn’t resolve their issues. So really, the staff here, they were his next of kin...we were his family (Manager: 6).

In this situation, the role of the age care staff as professional caregivers also involved providing the support of a surrogate family.

Intertwined in the concept of ‘like family’ was the perception of the hostel as being the resident’s home and by extension, their family’s home:
They have their own things here and their surroundings and they get used to the place and the family knows the staff and the resident gets...familiar with the staff. I think it makes a difference to them...it’s because it...doesn’t feel like an institution...it’s like their home...to the family. 'Cause it’s the resident’s home...I think the family then feel like it’s an extension of their home as well (PCA: group E).

Maintaining the same staff was seen as essential to developing the closeness and family bond that allowed residents to view the hostel as their ‘home’ and the aged care staff as ‘surrogate family’, something that was particularly important when a resident entered the terminal phase of their life:

We don’t have a lot of turnover, so they get to know all the staff, they get to know when staff are working, when they’re not, they get to know all the routines...so it becomes quite a family type thing...so when they do become ...end-stage, it’s quite nice because it, the staff know the relatives so well, they know the residents...it’s really like dying at home (Manager: 6)

Aged care staff not only shared a commitment to providing quality care to residents, they were also supportive of each other. Staff were attuned to the needs of other staff members and often shared their workload. When a particular team member was experiencing emotional difficulties in regard to a resident’s deterioration, staff would seek to support them:

If someone wasn’t handling the whole situation all that well, we would probably just suggest to them ‘look, don’t worry about it, I’ll look after it’, because there’s no point in that person being a totally emotional wreck in a place like this...when there’s other things that can be done, so we kind of step into...their shoes for them (PCA: group D).

This culture of enhancing relationships within hostels also extended to new staff commencing work at the facility. New staff were allocated to the same residents for a period of time. At handovers, the staff who had been there longer would provide tips regarding a particular resident’s likes and dislikes so that they could begin to develop a deeper understanding and knowledge of those residents.
The interviews with aged care staff revealed that they were committed to providing high-quality care to residents with chronic and complex needs, and that they regarded the creation and development of close family-like relationships as central to achieving this goal.

6.3 Creating a ‘Community of Care’

The shared and valued ethos of care, in which care is individualised, relationship centred, requiring collaboration and shared decision-making, underpins the creation of a community of care. Aged care staff saw the provision of care in the hostel setting as being about creating and maintaining a community of care with these shared connections and values. Within these hostel settings, a community of care revolves around the key person, the resident, but it also includes their family as well as the aged care staff who provide the care. A community of care begins to be created from the moment a resident arrives in the hostel, where staff begin to develop a sense of ‘knowing the resident’ through providing hands on care each day and through learning about their life histories. As time goes on, relationships build between the resident, their family and staff. Communication and collaboration within a community of care is on-going. Staff in this study were not only committed to the residents and their families, they wanted to work together with them and other staff to create a collaborative community of care around each resident.

Staff saw collaboration with other staff, the family and the key person, the resident, as crucial to delivering high quality care. Collaboration was particularly important when decisions about current and future care needs of the resident needed to be made. When a resident began to exhibit signs of deterioration, staff became more vigilant: ‘…like you regularly check every time you go past the door you’ll look in anyway…just to check on them and make sure they’re okay’ (PCA: 3). This watchfulness stemmed from the shared commitment of staff to providing quality care for the resident. If they noticed something being ‘not quite right’ (PCA: group A), they would discuss their
observations with other staff. If they also noticed these changes in a resident, it confirmed the need to act:

>Once you think ‘oh, that’s a bit odd’...you’ll notice it and you note it and you...pass it on to everyone else, but then if it keeps happening, like once a week or a couple of times a week...then you see a pattern. Everybody...notices it and as you’re talking with your handovers, you’ll point it out that ‘yeah that happened to me on that shift’ and it sort of comes out...then you show it to the supervisor and say ‘hey, we’ve got a problem’ (PCA: 3).

Thus discussions about how best to meet the new care needs of the resident progressed to consultation at all staff levels. Where there was concern that the resident was approaching end of life, meetings would be held to discuss with staff the possibilities of providing end-of-life care within the hostel. The following quote illustrates this collaborative approach:

>What I’ve done in the past is...actually ask the staff how they feel about it [keeping the resident for end-of-life care]...okay, this is what the family wants to do, this is what the resident wants to do, ‘what do you reckon, guys, like, can we do this?...what do we need in place to do it?’ So if they [PCAs] need extra support or something like that, yeah...that’s how we managed one particular resident that died here (Manager: 1).

Throughout this collaborative decision-making process, the residents were always central, always the first point of communication unless there were cognition issues. Staff listened ‘to what the resident wants first’ (Manager: 5), then they contacted the family. From the moment a resident required hostel care, families were made aware that they would be included in decisions regarding the resident’s care. As illustrated by one manager:

>From the very first day when a resident comes to XX hostel we make it perfectly clear that family members are a part of their care. So I think that’s where we’ve opened the doors from the very first day (Manager: 3).
Communication with families regarding resident events or changes was seen as a high priority within the hostel setting. Staff would usually either phone or speak to the resident’s family face-to-face to make them aware of changes. Staff saw this open and honest communication as reinforcing the collaborative processes and facilitating planning between the staff and family. Staff revealed that residents often tried to hide issues from family or downplay them ‘because they don’t want them [family] to worry or they don’t want them to know…We know the real story…it’s a bit of a shock when you tell people what we’re finding with their parents…then we work out a plan’ (PCA; group G).

Their open and direct style of communication with families was not only a means of sharing information regarding the resident’s changes; it also provided an opportunity to educate families about the pathway of a particular disease:

“When we talk about things and care needs, you have to broach it with the family straight up, you know. This is the diagnosis, this is what the doctor said…and start planning…the only thing that may not impact on that is if a resident has asked that the family not be informed…we’ve got an obligation or we feel… part of that is family support and keeping them educated on illnesses and how things are going. So that’s…the holistic care of a resident…[it] is support to families (Manager: 4).

One manager detailed the communication strategies she used when talking to families about future care needs, particularly when end-of-life care might be necessary. She would usually begin by outlining the resident’s medical problems and their response to previous treatments. Following this, the most recent medical prognosis was provided. The manager would then gently suggest that: ‘…maybe we should be starting to think about the beginning of the end… if she doesn’t come out of this condition…we need to prepare maybe…[for] end of life’ (Manager: 3).

Although the personal care assistants, who provided the majority of hands on care to residents, wanted to converse with families about any concerns they had about a
resident, they did not always have the time to do so in detail. As one personal care assistant stated:

*Sometimes there’s support needed … from the PCAs … we speak to the family and let them know that [their loved one is having a] good or bad day today… how their pain’s going, you know, like alleviate their concerns. If it gets too much and they want further information, then I’ll put them on [to] the supervisor and the managers… because we’re more on the floor doing it … rather than [having] a great deal of time to [talk] to the family, unfortunately (PCA: group H).*

Personal care assistants’ workload demands often impeded their ability to spend time and communicate with families. Despite staffs’ shared commitment to strive to meet the needs and wishes of residents and their families within the supportive environment this community of care represented, it was not always possible to provide end-of-life care in this setting. Thus a deteriorating resident might need to be transferred to the nursing home. The type of care staff wanted to provide and the actual number of staff available to provide this care were factors that played a significant part in the decision to transfer a resident:

*We start to look at… our current staffing levels. [If] we cannot support their health needs and for them to have the best possible care, we need to transition them on to where they can get it. That’s how we assess it here (Manager: 3).*

Although managers usually applied set criteria when deciding whether or not a resident needed to be transferred, this decision was sometimes also made collaboratively. Personal care assistants believed their input into the discussion about the resident’s care needs was taken seriously, and that carers and management were aware that additional care required ‘a big team effort’ and everyone to be ‘on board’ (PCA: group G). Thus, if the team felt unable to sustain the care needs of a particular resident, the resident would be transferred to another facility. As one personal care assistant explained:

*[On] some occasions the hostel coordinator ask the staff if they’re capable or willing to have the resident have palliative care here because they’re not willing to provide extra staff – so we have extra work with the same number of staff –*
and staff can say ‘not really, we better move the resident to another facility’
(PCA: group D).

Similarly, if the team felt they could manage, management staff would not necessarily insist on moving the resident to another facility, particularly when there was a ‘sentimental attachment to particular residents [meant] we’ve kept them here for a very long time’ (PCA: group D).

Staff clearly strove to maintain the resident within their community of care but, at times, particularly when an acute event occurred, this was not possible:

We try so hard not to send [residents] to hospital... [but] where we know they’ve got an infection that’s not going to clear up with oral antibiotics ...they’re not able to breathe with a chest infection and [it’s] really, really bad... we can’t get orals into them so we send them to hospital (Manager: 6).

As identified in Chapter Four, only a small percentage of residents remained in the hostel until death in spite of the ‘ageing in place’ philosophy. However, it was sometimes possible to manage end-of-life care in the hostel through hands-on collaboration with the family, as illustrated in the following example:

I mean one of the reasons why the girls felt okay about who’s staying here and not going to hospital was that the family members wanted to stay and provide some of the care. So that actually took some of the burden off the staff. I think if we had to look after somebody totally, we just couldn’t do it...you know, if we’re got say three staff...on an evening shift and one person’s taken up feeding somebody, that’s two staff for the other 64 residents so...it’s just impossible (Manager: 1).

When a resident’s condition deteriorated and the decision was made to maintain the resident in the hostel for end-of-life care, additional steps were taken to ensure the close monitoring of the resident. The manager at one hostel (metropolitan site) spoke about setting up the resident’s room as a ‘palliative care room’ to allow better monitoring of frequent care needs. Frequent care needs were identified as ‘second-
hourly mouth care…fluids…second-hourly rubbing of the heels, the back…put a tape player in there so you’ve got quiet, soft music in there’ (Manager: 5). Once the room was set up in this way, all staff were then aware of the situation and watched over the resident collectively: ‘everybody takes it on board, they all take ownership’ (Manager: 5).

Communication was an essential part of the collaborative provision of care. There was a commitment by aged care staff to keep families, other staff and other residents informed. Aged care staff had various ways in which they informed each other. Verbal handovers as well as notation of changes or concerns in the ‘day book’ were ways in which all staff were kept up-to-date on the resident’s condition. When an issue or concern could not be resolved within the unit, the designated personal care assistant would take the problem to the next level of the communication channels, which followed a line of command all the way to ‘even the Director of Nursing…if it’s real bad’ (PCA: 1). Frequently this would prompt a case conference to be called:

We continuously have…case conferences and staff get-togethers to discuss each and every resident when there’s an identified problem to see…what we can implement…how we can liaise with the doctor, if we need to call XX or [the] palliative care nurse…so it’s an accumulation of a lot of things (Manager: 3).

This collaborative process not only supported the hands-on care staff in solving care issues and being able to provide high quality care to residents, it also made them feel that they were taken seriously. Clearly, the communication strategies and collaborative decision-making processes with the resident, their family and among staff helped to strengthen and build trusting relationships and was a vital component for developing a community of care.

6.3.1 Interconnected Communities of Care

As noted above, within a community of care, members have shared connections and values. But these connections also extend to include other residents and their families, thus creating interconnected networks of communities of care within one hostel. Links
were developed between staff and families, family members with other families and residents with other residents. One resident, Beth, spoke about other residents as ‘friends’ and stated that because she had ‘a lot of friends here’, she wanted to remain in her current hostel rather than be moved elsewhere. As reflected in the example cited in Chapter Five (p. 162), several residents spoke of the many ways they helped other residents. This was valued by the residents, reflecting their contribution to care, and a ‘fellowship’ among residents:

A dear old lady…poor old pet, she’s 96…she can see about that far in front of her and she sits…beside me at the table for meals especially breakfast…the girls don’t seem to pass things to her…so…they’ll say ‘you watch her take her pills won’t you?’, so I’ve got to watch her take her pills. But I don’t mind doing that ‘cause she’s a dear soul and she sort of appreciates what you do for her, and she’ll have… some…brown sugar on her Weet-Bix, so I put that on for her, do things for her (R: Henrietta, 78 yrs).

Staff also contributed to the development of these interconnected communities by linking family members with other family members. Therefore, relationships and connections between all members begin to evolve, creating interconnected communities of care within a hostel. As detailed by Rose (Chapter Five, p. 161), staff initially put her in contact with another family member to help ease the distress she was experiencing when she initially placed her husband in the hostel. Drawing on this experience, Rose went on to become one of the relatives who staff would call on to help provide support to other new families in the hostel. Rose had developed such a strong bond and connection to this community that she stated that even after her husband died, she would continue to offer this support to other families as this community had become ‘… part of my life now’ (PR: Rose).

The connection between staff and family was also seen when family became residents. As outlined by Polly, a resident, who shared with me during the research the bond and special relationship she had developed with one personal care assistant (Brian) when her husband was living in the hostel, prior to her admission. Over the many months she visited her husband she came to know Brian as he cared for her husband. When Polly’s
husband was dying, Brian made a promise to Polly’s husband that he would look after her after he died. When Polly required hostel placement few months later, she was reassured to see Brian and felt confident in the care that would be provided.

Interconnectedness between staff and families was also evident. The interconnectedness may come through a shared experience and through structured activities that brought people together. For example, several family members from the same hostel attended meetings on a monthly interval and once a year arranged a weekend away together.

In reviewing and analysing my field notes this was particularly evident. I noted the number of times that interviews were interrupted by family members of other residents stopping to check in on the person I was interviewing. In most instances this was a quick greeting as my interviewee explained that they were in the middle of an interview, and agreed to catch up after I had finished. In one instance, after initially greeting my interviewee, the family member went on to explain how her weekend away had gone. Later, I observed this same family member elaborating on her recent family holiday and sharing photographs from her holiday with staff members. As I noted in my field diary, there was a strong sense of shared interest in the wellbeing of all those in the hostel, and a detailed knowledge of the different members, be they staff, residents or family. This went beyond a superficial ‘hello’ and ‘how are you’; evidenced throughout my observations was a sincere interest in the wellbeing of others. Thus, interconnectedness extends outside the boundaries of care between particular family members, staff and residents.

Therefore, a community of care is not bounded, it is connected and intertwined with other communities of care, and, in fact, within one hostel whole networks of interconnected communities can exist.
6.4 Conclusion

The understanding of a palliative approach varied among staff in terms of when to implement this type of care. These aged care staff seemed to use ‘palliative care’ to denote end of life care but did not engage with the discourse of a ‘palliative approach’. There were differences of opinion about whether a palliative approach should begin at the end of life or earlier in the resident’s disease trajectory. Despite the lack of consensus on this issue, the meaning of a palliative approach was understood as a ‘holistic’ approach to meeting the resident’s needs whereby staff provided ‘special’, additional care beyond their normal duties. The most significant finding was that, within hostel settings, aged care staff subscribed to an ethos of care and strove to provide quality care to high-level care residents with chronic and complex needs by creating a community of care around each resident. Aged care staff enveloped the resident and family in a culture of support and caring, where the emphasis was on meeting their needs. Not only was the concept of a community of care evident, but each community can potentially expand and develop into multiple interconnected communities of care.

Within the broader concept of a community of care, many of principles of a palliative approach were being incorporated into the care staff provided. In aiming to provide individualised care, staff collaborated with the resident, family, and other staff about the resident’s current and future care needs. Staff promoted open and direct communication, and demonstrated a commitment to improving the quality of life of residents through close monitoring and identifying of unmet needs. There was an integration of psychological and spiritual aspects of care and an emphasis on relationship-focused care. This was evident in how staff sought to support residents to live as actively as possible until their death.

Communication was a key to the success of this approach to care and enabled staff to share the journey with the resident and family. The concept of a community of care is explored in detail, drawing on both qualitative and quantitative data as well as extant literature, in Chapter Eight.
The following chapter reports on the many challenges and constraints aged care staff experienced in trying to provide end of life care within this community of care.
CHAPTER SEVEN:

Dying in Place?

The previous chapter has highlighted how aged care staff strive to provide quality care to residents who have chronic and complex conditions, and how, within the concept of a community of care, they interpret and adapt a palliative approach to providing care to these residents. However, the findings presented in the previous chapter have suggested that it is not always possible to provide end-of-life care in these settings.

This chapter drawn from the interviews with aged care staff, will expand on the factors that they saw as impacting on their ability to provide end-of-life care in the participating hostels. The primary themes to emerge were the challenges identified by age care staff in meeting end of life care needs of residents, and both positive and negative emotional consequences of end-of-life caring for staff providing end-of-life care.

7.1 Challenges Identified by Aged Care Staff

Overwhelmingly, aged care staff identified staffing resources as a major constraint to providing end-of-life care in the hostel setting. Most importantly, the number and skill mix of the staff were usually inadequate to enable the provision of end-of-life care. Compounding this situation were secondary factors, including: pressure from relatives to keep the resident in the hostel despite their care needs exceeding the capabilities of the staff; pressure from the acute hospital system to take a resident back into the hostel despite a significant change in their care needs; and the lack of space in the confined hostel rooms to enable the provision of appropriate care to residents so that they can ‘die in place’.
7.1.1 Low Staffing Numbers and Workload Issues

Since a resident’s deterioration towards end of life significantly increased their care needs, the number of staff available to provide care was a critical factor in determining whether the hostel could accommodate a resident for end-of-life care. As one manager stated:

...it depends on the number of staff I’ve got...I mean...yes, we’ll kind of manage that if we can here...but if we know it’s a longer term thing, it makes it really difficult because, I mean, when you’re only got – well, I have now got four[staff] for 65 residents but I’ve only got three in the afternoon. I’ve only got one at night so if they need 2nd hourly turns and they need two staff to do it, then it makes it really difficult. So that’s where I ...kind of draw the line I guess, that if they need two staff at all times for all transfers and they’re needing that 2nd-hourly, they need to go because we just can’t provide that (Manager: 4).

Managers and personal care assistants commonly saw the decision to transfer a resident as prompted by reaching the point where a resident required two staff members to assist with their needs. During night shifts, where there was only ‘one person on duty in here’ (PCA: 5), the need for two people to manage the resident’s care presented a significant challenge ‘so they normally move out to the nursing home’ (PCA: group G). If an individual resident required additional supervision to ensure their safety, this would prompt the decision to have them transferred:

My criteria is, if they can’t safely walk in their room, I can’t have them...we just go ‘this is the line’ and it might be very hard,...we’re not doing the resident any favour, you’re not doing your staff any favour (Manager: 5).

Staffing numbers could be increased through the availability of more funding. While this could potentially be achieved by completing high-level resident assessments (Aged Care Funding Instrument), hostel managers frequently felt too constrained by the multiple other requirements within their workload to find the time needed to complete these assessments. Most managers faced a dilemma between dealing with increasing amounts of paperwork and clinical imperatives:
...you know, it’s a catch 22...if you don’t free me up in order to do the assessments [Aged Care Funding Instrument] to get more funding, then I can’t get them done... I’m on the floor doing so much clinical work. So... it’s a tension that I have (Manager: 5).

While staff were often keen and willing to stretch their resources to provide end-of-life care for residents in the hostel, this created substantial increases in their workload and stress. Often, staff felt pressured to keep residents in the hostel even when their high care needs exceeded the hostel staff capacity to meet them, and, in many instances, this meant that staff were unable to fulfil all of their responsibilities. As one manager said:

I know the push is to keep people in here as long as possible before we transfer them but it actually creates a real difficulty for the staff when...people are needing a lot of one-on-one because it means that the other staff members that are left holding the floor are so, so busy that they just, you know, can’t get their work done (Manager: 3).

Significant workload demands also affected hostel managers. Managers reported being stressed and frustrated by the workload demands. This was particularly so for managers who were the only registered nurse in the facility – the case for five out of the eight hostels included in this study. The hostel manager’s role often included a clinical load, administrative and management duties. As highlighted by one manager, they often experienced conflicts between these roles:

...it makes it really difficult now. I mean, because I’m...the only RN, I’m the only one that can do the Norpsan [opioid] patches. I’m the only one that can do certain things legally so, yeah...it’s really hard (Manager: 1).

Deciding to provide end-of-life care was emotionally stressful; staff felt torn between wanting to provide the best quality of care for that particular resident and meeting the care needs of other residents. They felt a degree of guilt about ‘neglecting’ other residents within their community, which made them question the quality of care. As one personal care assistant said:
...no matter how emotionally attached you are to the resident there are times that, there are another 53 [other residents] with the same number of staff and especially in the afternoon to assist that there are only two staffs. You question yourself ‘am I doing a good job?’ (PCA: group E).

Thus, caring for a resident whose condition was deteriorating affected the staff workload and limited their capacity to provide care to other residents. However, when staff were unable to meet their own standards of care because they ‘only [have] two staff members for 54 residents and one has extreme needs’, it also made them feel inadequate as carers: ‘Even …if they’re not physical, there are emotional needs and you feel like… not really good enough to provide…full support’ (PCA: 1).

The decision to stretch resources to providing end-of-life care in the hostel frequently depended on the anticipated time the resident had left to live. Estimating a timeframe was especially important considering the collaborative process by which decisions regarding the resident were made. For a resident ‘you know is going to be going [dying] in like a week or a couple of weeks then you know there’s a timeframe and you can sort of stretch the resources’ (PCA: 3) but if it is ‘six to nine months…in that case [it would] be better to put them in a facility where they use lifters… for the resident’s own good’ (PCA: 5).

7.1.2 Pressure from Families and Acute Care Hospitals

Aged care staff in these facilities were struggling to manage the ever-increasing needs of residents with the same low staffing numbers. They also had to contend with pressure from families and acute hospital system. One hostel manager gave an example of the pressure families put the hostel staff under: one resident in her hostel had been on the nursing home waiting list for some time during which she had had repeated falls. The manager was very concerned about her care needs and the risk presented by her condition, given low staffing numbers in the hostel. Eventually, one of the falls resulted in an acute hospital admission. While she was still in the hospital, the family was asking the hostel staff:
...to take her back...because we had managed her for so long...[after a discussion with the clinical manager at the hostel] I just said: 'she's at risk, she's a dementia resident, she can fall anytime, I don't have [a] nurse 24 hours going into her room', so she went to the nursing home (Manager: 1).

The acute hospital system also put hostel staff under pressure to accept residents back as soon as possible after an acute medical admission, often before hostel staff - given the skill mix of the hostel setting - could reasonably be expected to meet the resident’s complex care needs. Even when aged care staff were concerned for the wellbeing of a resident returning to the hostel environment, they often felt powerless to decline such requests. One personal care assistant described an incident where a resident had fallen and had probably fractured her neck of femur, requiring immediate hospital admission. Later that same evening, when the personal care assistant was about to finish her evening shift, she received a call from the registered nurse in the hospital’s emergency department wanting to transfer the resident back. The personal care assistant asked:

...‘does the doctor realise where she’s coming back to? You know...this woman’s going to need high care overnight’... and she said ‘yes, I explained that to him, he said “just nurse her in bed”. I said, ‘well, that’s easier said than done’. But anyhow she came. I waited ...and settled her in bed...but...the doctor sent her back...on Paracetamol...that was something that was [of] concern...we took her back and kept her [on] 4th-hourly Paracetamol...and the next morning...the manager stepped in and she went down to the nursing home...got orders for pain [killers] and that sort of thing...I just felt...a bit let down by the system (PCA: group B).

In this situation, the personal care assistant felt that the acute hospital staff - no doubt under pressure themselves - were imposing pressure on hostel staff through an expectation of responses that exceeded the capabilities of the hostel.

Another manager felt the hostel’s relationship with the local hospital had improved and that they now had a good working relationship. He said:
...we try so hard not to send to hospital but if there is a fracture or we know that they’ve got an infection that’s not going to clear up with oral antibiotics, they can just [have] 24 hours, 48 hours of IV fluids...especially these guys [dementia residents]...what normally happens is...they go sick really fast...they’ll...not be able to breathe with a chest infection and be really, really bad...not responding to fluids...so we send them to hospital...the hospital is really good now...they know [hospital staff] that [when] the IV fluids are working when [the resident] starts getting up and so the minute they start getting up and wanting to get out of bed [the hospital] send them back and then we start the oral antibiotics (Manager: 6).

7.1.3 Meeting the Resident’s Needs with the Available Skill Mix

While aged care staff were keen to provide end-of-life care to residents, they were concerned about meeting the needs of high-level care resident’s with the available skill mix. Of particular concern was whether personal care assistants had the training and skills to meet complex care needs, particularly on shifts where there was limited support. For the majority of hostels (see Chapter Four, section 4.2.1), a single personal care assistant was rostered on duty for the night shift with one roaming registered nurse across the residential organisation. One manager was concerned about how the limited training and skills of personal care assistants would impact on the care of a resident requiring subcutaneous medication to control their complex symptoms. He felt the quality of care could be compromised by their lack of knowledge and skills, and gave an example of a previous incident where this had been the case:

...we had a resident here who was on sub-cut Morphine, sub-cut Haloperidol and sub-cut Domperidone, and what happened one night is that the staff overnight did not check the site and...it ultimately became inflamed and they just stopped...the infusion without alerting the duty RN and only the following day, when someone checked, it was found that the pump was actually stopped without [being] reported so that was...a mistake from the hostel side ... Preferably...infusion pumps...in palliative care should be [administered by a] registered nurse according to the policy of the organisation, but it would be good to have the care staff actually understand... the functionality of the pump because
an RN is not always there...we have such a high turnover of staff, the training in how to care for the pump is not always up to date with everyone (Manager: 4).

The hostel at which this occurred was Hostel Four at the metropolitan site, where 87% of residents were classified as high-level care (Chapter Four, section 4.1.1), and where residents often remained until end of life rather than being transferred to the nursing home section. Staff in this particular hostel perceived their workload to be ‘higher …than [at] any other hostel…it’s much higher here than it is in the nursing home’ (Manager: 4). The manager of this hostel explained that they often took the overflow of residents from the nursing home. The constant, heavy workload for personal care assistants at this hostel seemed to influence the high turnover rate of staff. The manager explained that personal care assistants had told him, ‘I’m not coming [back] because there’s…way too much to do on the list ...to do for the day’ (Manager: 4).

The same manager felt that insufficient training of personal care assistants influenced the quality of care provided. In many of these hostels, personal care assistants were responsible for completing multiple assessment questionnaires. However, this manager felt that personal care assistants did not fully understand the purpose of these assessments or the significance of their result, thus assessment tools were perceived as just another task to complete during their shift:

You have your daily pain charts that they’re [PCAs are] supposed to complete...except...that...care staff don’t understand why they have to do it, they just see it as another workload...When someone is on PRN medications...[it] needs to be given for breakthrough which is something they still don’t understand, as much as you explain it... the bowels...have to each shift [be] tick[ed] whether or not the resident’s bowels have been open for the day...from that you can actually see if it’s small...or just a smear on the pad [then] you know that that person is constipated...the staff don’t understand (Manager: 4).

Despite the manager’s concern over the lack of training and skills of staff, personal care assistants were very aware of educational opportunities and felt there ‘are lots of courses...always updates...[and] its ongoing’ (PCA; group F). Not only did staff attend face-to-face education but written material was ‘always lying around…and they
have the Aged Channel…that you can go and look at different things…there’s usually quite a bit’ (PCA; group G). At the metropolitan site, personal care assistants were required to complete ‘three [learning] modules, one is actually [on] palliative care’ (PCA: group E). Many personal care assistants were satisfied with the educational support provided, but wanted more education about death and dying.

Staff stated that you had to be prepared and open to ‘moving up a level in nursing…to be able to meet those demands and requirements for [residents’] health [needs]’ (PCA; group A). One personal care assistant was excited by the amount of knowledge she had gained working in this particular hostel and felt, ‘I’ve got to the point where I don’t want to leave this section…because I’ve learnt so much here and I am still in the process of learning’ (PCA: group 2).

A limitation to providing care to high-level care residents, particularly those at the end of life, was in regard to medication administration. The administration of strong opioids (Schedule Eight medications) lies outside the scope of the personal care assistant role. Given that hostels relied primarily on personal care assistants to provide hands-on care, a resident’s need for such medication was frequently the point at which it was decided to transfer the resident to a nursing home. This was because ‘when they’re up to that stage where they’re requiring that much medication, injections and so on, it’s beyond us…it’s gone beyond …just oral medication and patches’ (PCA: group F). Therefore, only being able to ‘nurse them up to a certain point’ (Manager: 5) became frustrating for staff.

Since the handling of Schedule Eight medications lies outside the scope of the personal care assistant’s role, some hostels relied heavily on the ‘roaming’ registered nurse to fulfil this role if required. As one manager said:

...if they’ve got a patch, or even if it’s an injection... the RN can come and give it. So after hours... the staff know to monitor if the person is in pain or is complaining about pain, they then ring the RN and say, ‘can you come and review this resident, he’s complaining’ or ‘he’s making noises’ or ‘it’s time for
his 4th-hourly pain relief’. So that’s usually the thing…we still can keep them ’cause there’s …an RN here (Manager: 2).

Other hostels were managing residents’ advanced pain needs by using transdermal opioid patches rather than syringe drivers, although it should be noted that this could depend on the specific care needs of individual residents. At times though it was evident that using the patches was their way of adapting to the high number of personal care assistants and their restrictions in handling Schedule Eight medications. As one manager said:

...we’ve only used the [syringe] drivers...a couple of times. We haven’t used them at all for a couple of years...we normally put a [Durogesic] patch on (Manager: 1).

Clearly, the skill mix of aged care staff in some hostels impacts on their ability to provide quality care and appropriate medications for complex or severe symptoms, but the limitations on the care they can provide also results in frustration for staff.

7.1.4 Infrastructure Challenges

Another issue identified by aged care staff as a challenge to providing end-of-life care in these hostels were the challenges presented by the hostel environment itself. Often the hostels rooms were small, cluttered and carpeted. This made the use of specialised equipment in rooms difficult:

Our hostel was never designed for this so our difficulty is with their rooms...trying to set up...if we need to put lifters and things in there, the place was never designed to take this level of care (PCA: group B).

The size and inappropriate structural design of rooms also impeded on staffs’ ability to manoeuvre around the resident to provide adequate physical assistance. Although all hostel rooms had en-suites, they were not designed to facilitate hands-on care. As one personal care assistant said:
I can hardly fit myself with certain showers. I mean the way they are, I really have to squash myself in the little corner to assist the resident...with the shower. Imagine if you had to bring a lifting machine or two staff members – no way (PCA: group H).

The positioning of the residents’ rooms within the hostel could also present a dilemma, particularly when a resident entered their terminal phase and required closer monitoring. Unlike in hospitals, where critical patients are often moved nearer to the nurses’ station for closer observation, aged care staff were only rarely able to move a resident out of their room, which had been their ‘home’ for some time.

The aged care staff interviews revealed that the provision of end-of-life care was constrained by inadequate staffing numbers and skill mix and the poor structural design of the hostels, and that, in addition to these work stresses, staff felt pressure from families and acute hospitals to care for residents whose complex care needs overtaxed their resources.

7.2 Emotional Consequences of End-of-life Caring

The interviews with staff also revealed that there were emotional consequences of end-of-life caring in the hostel setting that were at once both rewarding and stressful.

Staff described the ability to provide end of life care as an honour: ‘it’s an honour to take care of somebody in their last stage of their life, I feel’ (PCA: 5). Being there with the resident at the end of their life was something they saw as important and rewarding: ‘holding their hand [resident] when they actually do pass is... fantastic because you don’t want anybody to pass away alone’ (PCA: group F). Some staff felt so strongly about being there with the resident and not leaving them to die alone that they ‘actually slept over’ (PCA: group G). To many aged care staff, being intimately involved with the resident along this journey was emotionally satisfying and relegated any constraints they experienced in providing this care to second place after the rewards they felt in providing this care.
Staff also felt emotional fulfilment from interactions with family members when providing end-of-life care in the hostel setting. The gratitude and appreciation family members showed aged care staff was reciprocated by their interest in supporting families through attending the residents’ funeral:

*Many of the staff try to attend the funerals and that’s in appreciation to the family…to show that…we also miss them (PCA: group H).*

Staff described feeling a strong sense of satisfaction at being able to care for residents until the very last, and being deprived of this opportunity was often highly upsetting. When the high care needs of a resident were unable to be met in the hostel and a collaborative decision was made to transfer the resident, aged care staff experienced negative emotional consequences. It wrenched at the emotions of everyone within the community of care. As one manager said:

*...people transitioning from here [hostel] down to there [nursing home] is very difficult for us, it’s very difficult thing for them, because we don’t actually want to see them go down there. We’d rather keep them here and it can be emotional for everyone really…it’s emotional for the staff, it’s emotional for the family. The family don’t want them to go, they like the bond, they like…the relationships that have been made…it can get quite emotional (Manager: 1).*

Staff reported feeling uncomfortable transferring residents and empathised with the resident and family. They interpreted this move as breaking the relationship bonds that they had invested so much effort in creating. They described the transfer of a resident as disruptive to the dignity of their end-of-life experience:

*It’s the last time in their life, they’re been living here for so many years and we’re going to shove them down there for a week just till they die. No I don’t feel that’s…can’t say civilised but…it’s not a comfortable way for them to go, so it’d be nice if they could stay…in the room they’re used to (PCA: 5).*

Staff also voiced concern that the resident and family would have to start over, developing new relationships in the last week(s) of their life in this new environment:
You build a rapport, like, these people, they get to know you as much as you get to know them and I think...like the...power [of thought] ‘I’m moving out of here. I’m going there’ that is like... moving them out of their comfort zone...out of their home that they’ve made for a really long time and they’re thrown over there and they’ve got to start again (PCA: group G).

Staff were also very aware that residents and families held fears about transferring to the nursing home. They mentioned that residents saw this transfer as confirmation that they were going to die. For them it was ‘...a terrifying thing...going to the nursing home and I suppose...that’s an old culture ’cause they see that as the last call...it isn’t the most uplifting thing’ (PCA: 4).

As another personal care assistant said:

...they don’t want to go down there [nursing home] and that’s their fear, they have a big fear of it. It’s known as...[nursing home] stairway to the stars...the giggle house...’cause they feel once they’re there, that’s it, they’re gone. Even their family thinks that way (PCA: group G).

In some instances, staff felt that the resident’s fear of being moved resulted in their downplaying symptoms so that they would not be transferred. When a resident masks their symptoms, it makes it difficult for staff to accurately assess and manage their symptoms. As one manager said:

...the residents are scared of going down to the nursing home and ...so that’s why they ...won’t tell us some things...because their scared...they’re in pain or can’t get around as good...we’re got one gentleman that actually went down there and he’s come back to us ...but when he first came back...he wanted to do everything for himself because in the back of his mind if he doesn’t, we’ll ship him back down to the nursing home (Manager: 4).

Understanding how frightening being transferred was for residents made the event additionally stressful and upsetting for staff.
While moving a resident to the nursing home or another higher-level hostel had emotional consequences for the staff, a resident’s death within the hostel also had an emotional impact on staff and other residents. For many staff the resident’s death engendered both sadness and a sense of relief:

...we go into a little corner, have a cry...and we laugh about the good things we remember about her but it does, it does affect us...But then sometimes they are so ill...it is such a blessing...that they go...it’s a relief...and I think it’s actually quite comforting that when they do pass, generally, you know, probably 80 - 90% pass well (PCA: 1).

Many staff were philosophical about death and dying being a part of their work experience. Often they felt a sense of achievement that they had been able to provide quality care:

...[when a resident dies] you don’t feel down, you feel you’ve done your job as best you could and they appreciated the fact that you did your best you could for them...Oh, you feel sad, but you don’t feel bad about it...that’s part of living, death’s part of living’ (PCA: group A).

It appeared that staff who had worked in the hostel for many years had learnt how to cope effectively with death and dying. As one manager stated: ‘...they’re [staff] often very philosophical about it [resident’s death]...It’s like...they’re pleased sometimes...that's happened and it’s happened quickly’ (Manager: 6).

As revealed in Chapter 4, there were variations in the number of high-level residents in each hostel. Hostels with low numbers of high-level care residents were less likely to experience a resident’s death in the hostel. Staff who had limited exposure to residents dying in their hostel seemed to have greater difficulty dealing with the death. As one manager said:

...[a resident’s death] has more impact in these areas because they’re so closely knit and I think where death is more common, in a high-care area, they see the process of where they’re bedridden and they’re more accepting to end of life.
Whereas the residents traditionally in the low-care facilities are still quite active, and I think...that does impact and because we have quite a lot of staff that haven’t dealt with death yet...So...we implemented through one of our staff meetings that when that occurs that we use our staff meeting time as a time for anybody to be able to express (Manager: 2).

Generally, the way in which aged care staff dealt with a resident’s death was by informally talking about the death at the time, either in the corridor or ‘over a cup of tea’ (PCA: group E) in the staff room where ‘we just chat between ourselves’ (PCA: 1). A more formal discussion about a resident’s death took place at handovers, and/or monthly staff meetings. While formal counselling services were available, staff rarely pursued this option.

Staff were very aware of the emotional impact a resident’s death had on their family. As a result, they sought to maintain collaboration with the family within the community of care they had created even beyond the resident’s death. One manager explained that allowing the family to participate in the preparation of the body could help them accept their loved one’s death:

*I actually went to the family members and said ‘this is what we have to do now...do you want to stay and be part of the process’. The family members actually accepted and stayed with the nurses, helped picking clothing, helped dress and be part of grooming...their loved one. At the end of that whole process they came and thanked us for allowing them to do that (Manager: 2).*

When a resident died, staff were also attuned to the emotional impact it had on other residents, particularly those whose communities of care had intersected overtime. While opportunities to reminisce and mourn a resident were available for other residents, families and staff in the form of bereavement remembrance services and one-on-one conversations, remembering those who had died at the resident meetings was especially important because:
It gets them [the residents] involved ’cause even if somebody leaves, they want to know where that person’s gone, is that person alive, has that person died… Often we get feedback from the nursing home if that person’s died, so it just goes into the minutes and they’re given an opportunity to remember anybody (Manager: 3).

As illustrated in Chapter Five, many residents felt a connection with particular residents within the hostel. Residents were very aware when a death occurred and staff indicated that in the event of a death, they approached the remaining residents individually offering gentle support and opportunities to express their feelings. As one supervisor said:

...if someone had died in the morning, generally most residents would know by that evening. Word travels fast... they’ll say, ‘I heard Mrs so and so had died’ – ‘yes, she did this morning at such and such a time, yeah’ – ‘oh, oh she was a lovely person’– ‘yeah she was...we are going to miss her’– ‘yes, we are’ – ‘and how are you feeling?’ – ‘oh, yes, I’m good, yes, I’m going back to my room’– ‘oh, well...do you want to sit and have a chat about it’, you know...softly-softly approach (Manager: 3).

A personal care assistant at the rural site believed that residents for the most part perceived another resident’s death as part of life and that had little impact on how they felt:

It’s nothing to them [residents] ... I didn’t see any trauma. I don’t if they’re been here a long, long period of time, possibly one or two residents might even consider going to their funerals but...most [are] not interested. Yeah, it’s part...of life ...these people have lived on farms, we’re in a country town and they’re lived on farms, lived with animals....they’re quite more accepting than I thought...I’m a city girl...so I find that very strange but now I’ve lived here for a while and I can see how they just put animals down... for feed and so on...I think it’s all part and parcel to them a part of life, nothing to be too concerned [about] (PCA: group H).
This was not the perception of a manager at another hostel, who described how the remaining residents wanted to honour the passing of an individual they had clearly formed a strong bond with:

The residents traditionally are told ‘can you please wait in your room’...when we transport the body out. We had...three residents who...came out into the corridor...lined the corridor...[as] we were bringing the trolley out...So I went over and said ‘look ...we need to take the resident, blah, blah, blah’, and they’re going, ‘no, we’re not going ...we want to pay our respects.’ One of [these] residents...came to the trolley and thought that the bag was a sheet and went to lift it, to actually gave him a pat on the cheek and say goodbye, and I said ‘no, darling’, I said ‘it’s a bag’. He said, ‘well, undo it!’ and we did and he tapped him on the face and he said, ‘I’m glad to see you’ve got your glasses on so you can see where you’re going’ (Manager: 3).

This again reveals how a network of interconnected communities existed within this hostel.

Despite the many challenges to providing end-of-life care in hostel settings, staff really wanted to provide this care until death. Some felt that being able to provide this level of care would be beneficial to age care staff in that they would see the bigger picture of ageing and aged care, rather than the more fractured experience of seeing residents transferred at this crucial time. They imagined a future in which residents could enter a hostel as the final place where all their needs could be addressed:

We are going to see a lot of high care residents come through ...because they’re able to stay in their homes a little bit longer with community care and that sort of thing...gone are the days when you see the resident come into the hostel and probably stay four, five, six, seven years, they’ll probably be in their homes a little bit longer and maybe shorter stay here...I think that’s the way we are moving ...it will be a one stop...they’ll be able to come into the hostel and have their full palliative approach here in the hostel. It’s certainly what we are seeing and that’s what residents are asking for and...if they want it, they’ll get it (PCA: group G).
Clearly, while variations existed in the staff experiences of dealing with death in a hostel, it was something that many experienced as rewarding and fulfilling. Staff had developed several strategies to assist them in dealing with a death of a resident and could envisage being able to provide ‘a full palliative approach’ (PCA: 4) in the future.

7.3 Conclusion

This chapter has shown that aged care staff do experience several constraints to being able to provide end-of-life care in the hostel setting. In particular, problems arose from the hostels’ limited staffing resources where the low number of staff and the skill mix of staff rostered on duty at any one time was mostly inadequate to manage high-care residents who were dying and to provide appropriate care to meet their complex needs. The outdated, structural design of hostels not originally conceived of for end-of-life care also creates challenges for staff. Nevertheless, where possible, staff would choose to provide end-of-life care. When they did, the emotions they experienced varied. Staff developed their own particular ways of dealing with death and were keen to support the members of each community. In addition, this study reveals that interconnected networks of communities of care existed linking different people within a hostel. It was clear that staff wanted to enable residents to not only age in place but also to die in place.

In the following chapter, the quantitative and qualitative data are linked with the intention of presenting a very broad and also deep discussion that seamlessly integrates quantitative and qualitative findings and connects these with pertinent extant literature.
CHAPTER EIGHT:

Creating a community of care: more than providing a palliative approach.

This research set out to explore aged care staff understandings of a palliative approach, how this was being implemented in hostel settings among high-level care residents and to explore what organisational and managerial support is in place for such an approach. In addition, the study sought to describe high-level care residents living in hostels in relation to demographic information, medical illnesses, co-morbidities, physical functioning, and individual symptoms and/or symptom clusters and to explore health issues for this group of residents, and their understandings of how these are being managed, and will be managed in the future.

The findings from this research have provided insight into how aged care staff generally approach providing care to residents with chronic and complex conditions. In particular, this research has identified the concept of a community of care in which a palliative approach is one of a number of elements of care provided. Interestingly, the term ‘palliative approach’ was not explicitly used by aged care staff in their interactions with residents in these hostel settings, or among each other in planning residents’ care. This finding led me to question the degree to which a ‘palliative approach’ is understood and operationalised by aged care staff.

This study demonstrates that there is a lack of clarity about the use of a palliative approach in hostel settings. Among aged care staff there are a number of contradictions related to the meaning of a palliative approach, and how and when it might be implemented, and the degree to which it is implemented within their facility. What is clear is that staff demonstrated they incorporated the principles of this approach into the care of their residents, yet rarely engaged with the discourse of a
palliative approach. A barrier to introducing a palliative approach is the absence of clear agreed indicators of when to introduce this approach to care. It may be the case that the nature of residents’ health problems - tending to be chronic rather than acute and imminently life-threatening - are such, that staff do not associate them with the need for palliation, as they would in the case of cancer diagnoses for example.

As noted earlier, a palliative approach takes the principles of palliative care and applies them to the care of any person with a life-limiting disease, regardless of where they are in the course of that illness. This means it can be initiated well before the terminal stage of illness (Kristjansen, Watson & Toye, 2005). A palliative approach aims to achieve the highest possible quality of life for both patient and family by maintaining dignity and controlling symptoms (Davies & Higginson, 2005). The findings of this study clearly indicate that aged care staff wanted to maintain the resident’s dignity and promote quality of life, and demonstrated respect for each resident’s needs through the provision of individualised, person-centred care. When questioned, some staff identified this as taking a palliative approach.

In addition to exploring aged care staff understandings of a palliative approach and how it was being implemented, this research set out to describe the care of residents categorised as high-level currently residing in hostel settings. Interestingly, residents (and the person responsible who spoke on behalf of the resident) did not relate their current health status to the presence of one or more medical conditions, with significant consequences. While many residents and the person responsible acknowledged that they were transitioning towards end of life, and often experienced multiple co-morbidities, this decline was perceived as a normal part of ageing rather than as a life threatening illness. Residents expected their physical condition would deteriorate and anticipated these changes. Since they did not see themselves as having a potentially life-threatening medical condition, there was no real imperative for considering or planning their transition towards end-of-life care. It was difficult, therefore, for residents to understand the need for a ‘palliative’ approach to their care and for staff to implement or initiate discussions around such an approach. Nevertheless, aged care staff were able to build a community of care around each
resident, one in which a palliative approach was an integral, but not explicit, component of that care.

The question arising from this research is that, if the language of a palliative approach is not meaningful for staff and residents, and they are not able to engage with the language of a ‘palliative approach’, do we need to re-think this for aged care? Do we need to be cautious in creating a palliative approach discourse which may be inaccessible to the very people we are trying to benefit? While the principles and goals of a palliative approach are relevant, a model needs to be created that incorporates appropriate language for dealing with progressive incurable chronic diseases in a setting where increasing illness complexity and death are seen as part of a natural process. This study presents an alternative way of conceptualising care for people who are transitioning towards the end of life in the hostel setting. What is argued here is that a community of care involves the collaboration of all parties concerned - high-level care resident, their involved family, and the staff caring for them – and that this concept is a more appropriate framework for aged care settings than the concept of a palliative approach.

8.1 Conceptual Framework for a Community of Care

8.1.1 Concepts of Community

While the term ‘community’ has been widely used in the disciplines of social philosophy, psychology, sociology and theology, there is no universally recognised definition. A community is a descriptive category or set of variables such as a place or geographical area, an area of common interest or common life (Crow & Allen, 1994; Smith, 2001) or a shared value which can engender solidarity, commitment, mutuality, and trust (Frazer, 1999). Community relationships are characterised by their intimacy and durability, and they are created over time and where relationships within a shared territory are made meaningful through shared culture (Jary & Jary, 2000).
Cohen explores communities as a cultural phenomenon, arguing that they are best understood as ‘communities of meaning’, where there is a shared sense of belonging and attachment, and where what the members have in common significantly distinguishes them from the members of other groups (Cohen, 1985, p. 12). When considering the elements of a community, the geographical aspect alone may be insufficient to define its meaning. Lee and Newby (1983) suggest that the nature of the relationship between people and the social networks of which they are a part, is a more significant aspect of ‘community’.

McMillan and Chavis (1986) reinforce this point, arguing that a ‘sense of community’ is a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together’ (p. 9). The authors’ theoretical framework identifies four elements of a sense of community: membership, influence, integration and fulfilment needs, and emotional connections. Membership refers to the feeling of belonging, and there are always inherent boundaries which provide people with emotional safety (Ehrlich & Graven, 1971). Influence refers to a sense of mattering, of making a difference to a group and of the group mattering to its members. Influence is a two-way relationship between the community and its members, where both are operating simultaneously in a tight-knit community (McMillan & Chavis, 1986). Integration and fulfilment refers to the positive continual reinforcement that members receive from the community. For any community group to maintain a positive sense of togetherness, the individual-group association must be rewarding for its members. Shared emotional connection refers to the commitment that develops for members who have shared experiences of places, time together and, events. Within the framework proposed by McMillan and Chavis, communities tend to grow from a common membership, to support integration, and to facilitate important emotional connections. This framework resonates deeply with the findings of this research and is thus used as the foundation for the concept of a community of care which forms the centre of the discussion here.
8.1.2 Model for a Community of Care

While the aim of this study was to explore a palliative approach in hostel settings, it was found that the overall concept of care, in which staff were implicitly incorporating the principles of a palliative approach, was much broader than this. I have conceptualised this approach as a community of care.

In developing the community of care framework, two important factors were evident: firstly, the way in which the community comes together to provide care; and, secondly, the meanings attributed to the care provided within the community itself. Clearly, a community of care in this context is always embedded in a specific physical setting – in this instance, an aged care hostel. However, it is the significance of the cultural aspects of the community of care that is of particular interest here. McMillan and Chavis’ (1986) model of a sense of community has been helpful in developing an understanding of a community of care within hostel settings, and I have incorporated their framework of membership, influence, integration and fulfilment of needs and emotional connections here as categories which help to explain the complexities involved in the communities of care within hostel settings. The following sections elaborate on these elements.

8.1.2.1 Membership in a Community of Care

In the context of this study, the members of the community of care include the high-level care resident, their involved family and the staff who provide their care in the hostel environment. Membership implies a willingness to invest part of one’s self to become a member, to develop a sense of belonging and identification within a group (McMillan & Chavis, 1986). It is important to note here, however, that many residents in this study were initially not ‘willing’ new members in the community. Often the basis for admission to the hostel was prompted by a medical decision following an acute hospital admission, which left residents feeling they had been given little choice in the decision-making process. Other residents rejected the possibility of living with their children because they did not want ‘to be a burden’ to them and thus saw no alternative but to move to a residential aged care facility. Some residents had
reconciled themselves to the fact that they needed to be in the hostel because of their chronic health problems associated with old age.

Despite their perceived lack of choice, most residents attempted to make the best of their situation, and in time began to develop a sense of membership and belonging. As one resident stated, ‘I’ve got used to it, accustomed to the place…I can’t do anything else. I don’t see that I can’ (Chapter Five, p. 150). ‘Making the best of it’ reflected the residents’ ambivalence about their living situation. On the one hand, living in the hostel symbolised losses and a degree of powerlessness; on the other, the hostel provided a sense of security, a safe environment and a guarantee of care. McMillan and Chavis argue that the boundaries that define membership and group belonging ‘...provide members with the emotional safety necessary for needs and feelings to be exposed and for intimacy to develop...’ (1986, p. 9). In the hostel context, residents and their families are often very vulnerable emotionally, and so the security that develops as their sense of membership and belonging strengthens is particularly important.

McMillan and Chavis (1986, p. 10) point out that group members have to ‘work’ for their membership, that considerable personal investment is involved, and this certainly appears to be the case for community of care members in this study. It takes time for group members to feel at home both within the physical environment of the hostel and within the group. However, the findings demonstrate that, in time, residents, family members and staff identify with the group, feel emotionally safe and secure, and that their sense of membership and belonging underpins and facilitates subsequent interactions and decisions.

8.1.2.2 Influence

Members have some influence over what occurs in their community, and, according to McMillan and Chavis (1986), this influence is bi-directional. Thus individuals as well as groups can influence and change what occurs in a community because they ‘matter’. All members have some influence. Individual members can exert influence
on what the group does, but the group can also exert influence over individual members. In this study, individual members included the resident, their involved family and the staff caring for that resident; together these individuals are considered the group. Each resident is at the centre of a community of care, i.e. it is their care needs that are of central concern. Given that staff and family are concerned about meeting the resident’s needs, the resident can exert influence by reporting any concerns or worries. The involved family have influence through their emotional connection to the resident. They can exert influence by making the resident’s distress or unhappiness about a particular situation known to staff or by encouraging the resident towards a particular course of action. Aged care staff have the professional skills and knowledge required to monitor, assess and address unmet needs which forms the basis of their influence. Their actions are also underpinned by their professional values.

The group in turn has influence with each of the members. The staff and family (group) have influence over the resident whereby working together they can effect changes aimed at improving the residents health and ensuring their comfort. The staff and resident together influence the family by providing emotional support. Residents in this study often provided emotional support to their family, for example by minimising their own concerns so as not to worry family members. As noted in Chapter Six, one manager was able to influence the family not to accept unnecessary surgical treatment that would have compromised the resident’s quality of life. Together, the resident and family influence staff to care in a manner that ensures that care is individualised. Hostel staff perceived they could make a difference to the resident’s outcome by individualising care which was collaborative and relationship-focused, involving shared decision-making between the resident, family, and staff. Staff also exhibited sensitivity to each individual’s needs and focused on addressing multidimensional aspects of care.

It could be argued that in most situations staff are the most influential community members. McMillan and Chavis suggest that the people who ‘acknowledge that others’ needs, values, and opinions matter to them are often the most influential members’ (1986, p. 11), and that communities look to leadership to ensure that
important problems are addressed and the interests of the community are fostered. Brown-Wilson (2008) observes that leadership is a significant factor in the development of a sense of community within care homes. In my study, it was clear that staff members assumed a leadership role within each community of care, but that they applied their leadership in a collaborative manner that facilitated cohesiveness and cooperation.

8.1.2.3 Emotional Connection

A community of care is built on a network of relationships. McMillan and Chavis (1986) suggest that shared emotional connections are often based on shared history; although not all members have to have been part of that history, they do need to understand and identify with the history. It is also important for interactions to be ‘positive’ so as to facilitate ‘connection’ (McMillan and Chavis, 1986, p. 15).

The network of relationships within the communities of care in this study, were based on the connections and bonds between staff, the resident, and their family members. The building of these relationships was led by staff and embedded within the culture of each hostel. Shared emotional connections were evident between staff, residents, and family members. Many residents spoke of their close relationship and a sense of ease they had with staff and how they were able to share stories, confidences and jokes, which made them feel special. This attachment was seen by residents to be a two-way relationship. Not only did residents become attached to personal care assistants, they also perceived that personal care assistants became attached to them. Staff spoke about being a confidant to residents such that a resident would often openly speak up about topics they would not discuss with their family. Family members perceived that staff had a genuine sense of concern for their relatives and that this was often reflected in the personalised attention the resident received.

The close connections between staff, residents, and family members were conceptualised by all members within a community of care as being ‘like family’ and ‘homelike’. Becoming a ‘family’ involved a sense of unity, being part of a group that
cared for one another. The ways in which staff in these hostels engaged with residents and family members resembled social interactions likely within a ‘family’ environment. Linked to the notion of being ‘like family’ was the sense of an emotional connection to the hostel as their ‘home’. While Brown-Wilson (2008) points out that it may be difficult to replicate a homelike atmosphere within an aged care home, many of the residents and persons responsible in this study indicated that they had come to think of the hostel as their ‘home’, and that they associated this with the ambience and the meaningful relationships that had developed within their hostel.

8.1.2.4 Integration and Fulfilment

Integration and fulfilment refers to the continual ‘positive’ reinforcement members receive from their community (McMillan & Chavis, 1986). In the context of this study, the success of the community depends on whether the community is meeting the needs of the resident, how families recognise this success, and whether staff are able to meet the resident and family needs.

Successful integration within the community reinforces the value of the community. This involves engaging all members in the decision-making related to a wide range of issues, from what treatment the resident will accept (or refuse) to where they choose to die, although in this study, clearly residents did not always have a choice in this matter. At all points along this decision-making chain the provision of useful information and the facilitation of effective communication are essential to creating satisfying outcomes (McGrath, Yates, Clinton & Hart, 1999).

Within each community of care, communication was an essential part of the collaborative processes. An open and direct style of communication with family was part of the community-orientated care provided to residents. Not only was there a transfer of information regarding the residents’ health-related changes but the community context also provided an opportunity for staff to educate families about the likely pathway of a particular disease, as illustrated by one manager (Chapter Six, p. 190).
From the moment a resident required hostel care, families were made aware that they were being included in the decisions regarding their care. Initially, staff worked with families to build a cohesive community around the resident. As time progressed, the relationship with families strengthened and a level of trust was established. Staff were then able to determine the right time to begin developing a plan about current and future care needs.

This collaborative process strengthened relationships and bonds within the community of care. As end of life drew nearer, staff worked sensitively towards engaging the resident and their family in developing a fuller awareness of, and adjustment to, a terminal prognosis. Clearly, in this way staff were implementing a palliative approach to the care of their residents. Staff recognised that keeping the community functioning as an entity at times required additional resources. To this end, they would seek collaboration with external specialist palliative care services brought in to service the community; this too strengthened the bond within the community.

For any group to maintain a positive sense of fulfilment, the individual-group association must be rewarding for its members. In this study, many residents and persons responsible described the care in relation to staff attitudes, knowledge, and behaviour, such as respect and being attentive to each resident’s needs, as ‘good’. It was evident that many of the residents and persons responsible felt ‘cared for’, which in turn led residents and family members to feel they were being provided with quality care. However, differences in the standard of care were noted among residents when there were staff shortages (Chapter Five, p. 157).

McMillan and Chavis’s theory of community provides a framework for understanding the ‘...dynamics of the sense-of-community force...’ (1986, p. 6). This doctoral study has identified that a community of care is a very significant feature of the experiences of high-level care residents, their families and aged care staff in the participating hostels. The following section draws links between aged care, palliative care and relevant interpretations of person-centred care.
8.2 Person-centredness in Aged Care and Palliative Care

The literature is consistent in demonstrating that being person-centred requires the development of therapeutic relationships between professionals, patients and their significant others, and that these relationships are built on mutual trust, understanding and sharing knowledge (McCormack, 2001; McCormack, 2004; Nolan et al, 2004). It is evident from this doctoral study that parallels exist between the values and practices of gerontology and those of palliative care. Practitioners of palliative and geriatric care aim to provide person-centred ‘holistic’ care to enhance quality of life, while maintaining dignity and individuality.

The concept of ‘person-centredness’ has become established as an approach to the delivery of health care (Mead & Bower, 2000; Carr & Higginson, 2001, McCormack, 2004) and Binnie and Titchen (1999) suggest that adopting this approach within nursing will ensure ‘holistic’ care. However, the concept of person-centredness is often ill-defined and the term is frequently used interchangeably with ‘patient-centred’ and ‘client-centred’ (Lepledge, Gzail, Cammelli, Lefeve, Pachoud & Ville, 2007). McCormack, McCance, Slater, McCormack, McArdle and Dewing (2008) define person-centredness in nursing as:

... an approach to practice established through the formation and fostering of therapeutic relationships between all care providers,...and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self determination, mutual respect and understanding... (p. 1)

McCormack and McCance (2006) state that their person-centred framework involves four constructs; prerequisites, the care environment, person-centred processes and expected outcomes. Prerequisites includes the attributes of a nurse that are considered essential ‘...building blocks to the delivery of person-centred’ nursing (McCormack & McCance, 2011, p. 41). There are five pre-requisites for working in a person-centred way. These include being professionally competent, developing interpersonal skills, being committed to the job, clarity of beliefs and values and knowing self (ibid).
Professional competence requires ‘...the knowledge and skills...to make decisions and prioritise care, and includes competence in relation to physical or technical aspects of care...’ (McCormack & McCance, 2006, p. 475). A variety of interpersonal skills, both verbal and non-verbal, is required to communicate at multiple levels. (McCormack & McCance, 2011). ‘Being committed to the job’ means the nurse will endeavour to provide the best care possible for the patient, not because they are expected to, but because they want to (ibid). Clarity of beliefs and values allows the practitioner to work with the care environment. These beliefs & values determine ‘...what people think ought to be done...’ (Manley, 2004, p. 55) and they are linked to moral and ethical codes (McCormack & McCance, 2011).

The characteristics of the care environment, such as workplace culture, skill mix and shared decision making systems, have the greatest potential to enhance or hinder person-centred nursing (McCormack & McCance, 2007). Person-centred processes reflect key elements of the interactions between patients and nurses. It is important to gain an understanding of the individual’s values and, where possible, to work within their beliefs and values to facilitate shared decision-making. A key element of shared decision-making is engagement, which reflects the connectedness of the nurse and the patient (ibid).

Therefore, person-centred care can be considered as an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships between patients, families and health care practitioners (McCormack 2004; Kovacs, Bellin, & Fuauri, 2006; McCormack & McCance, 2010). This approach requires that individual beliefs, values, and needs are respected and that caregivers adopt approaches that ensure flexibility and respect for the people at the centre of care (Nolan, Davies, Brown, Keady & Nolin, 2002; McCormack & McCance, 2010). A person-centred approach is based on consultation, patient/client autonomy, choice, individual care and resident involvement in decision-making (Davies, Nolan, Brown & Wilson, 1999; Clarke, Hanson & Ross, 2003; McCormack 2004; McCormack & McCance, 2010).
Both palliative and geriatric specialties take a person-centred rather than an organ-based approach to choosing restorative measures and weighing the benefits and burdens of intervention and treatment in older people with advanced disease (Hockley, 1993; Ahmedzai et al., 2004, Olson & Cristian, 2005). Each specialty strives for symptom control and relief through the incorporation of the least invasive treatments (Ford & McCormick, 2000).

Palliative care focuses on the provision of comfort, quality of life and a dignified death, preferably in a place of the patient’s and their family’s choosing (Pemberton, Storey & Howard, 2003; Chochinov, Hack, McClement, Kristjansen and Harlos, 2002). This is achieved through palliation of physical symptoms, alleviation of isolation, anxiety and fears associated with advancing disease, maintenance of independence as long and as comfortably as possible, and through support of the bereaved. Palliative care is thus person-centred, integrating the psychological and spiritual aspects of patient care and offering a support system to assist patients live as actively as possible until death (Ahmedzai, Costa, Blengini, Bosch & Sanz-Ortiz, 2004). It also offers a support system to help the family cope during the patient’s illness and in their bereavement.

Aged care has a strong focus on ‘ageing well’, with an emphasis on optimising the person’s level of function and promoting independence (Department of Human Services, 2003). Age related functional decline of physiologic systems means older people are less able to prevent and recover from illness. Functional decline has been identified as a leading complication of hospitalisation and adverse events (ibid). Providing quality care for older people is based on the principles of providing a person-centred approach, therefore gaining a better understanding of the complexities of their health care needs and involving older people in their own care. While ageing well and optimising function are important, there is an imperative to consider and accommodate the possibility that death may occur (Olson & Cristian, 2005). This requires a shift in focus from a ‘restorative’ approach, to maximising quality of life when death is inevitable, and facilitating the process of adapting to the changes that are occurring for patients across a range of different illnesses (Duke, 1997; Olson & Cristian, 2005).
In this study, when a hostel resident’s condition begins to significantly deteriorate, staff responded by intensifying the care that they were already providing, rather than by explicitly considering implementing a palliative approach. This means staff were more attentive to the fluctuating needs of the resident and more focused on current and future care planning. Aged care staff in this study described this type of care as providing something ‘special’ in addition to their routine work.

As noted earlier, staff did not introduce the discourse of a ‘palliative approach’ to describe or inform this routine work, nor to discuss it with residents and their family. Although aged care staff seemed less uncomfortable using the language of palliative approach when a resident required end-of-life care (i.e. when the resident’s death was clearly imminent) it appeared that they did not find the language of a ‘palliative approach’ helpful. As a result, this language was not explicitly used in the everyday world of hostel settings. Thinking about death in the future seemed to be challenging for staff, residents and family. Aged care staff seemed uncomfortable using the term ‘a palliative approach’ when residents were not identified as imminently dying, perhaps because of the social connotations of death itself. Societal reluctance to talk about death and dying is compounded by the lack of a shared and common language to describe needs and service provision as people transition towards the end of their life (Seymour, 2010). Perhaps this has something to do with the subtle differences implied between the terms ‘palliative approach’ and the term ‘palliative’ which is synonymous with end of life (Jerant et al., 2006).

While aged care staff were specifically asked to describe their understandings of a palliative approach and when would be the appropriate time to introduce this approach, the subtle differences between ‘palliative care’ and a ‘palliative approach’ were lost. Many staff described the care they provided and flagged indicators that were congruent with a resident being at end of life. One of the difficulties of implementing a palliative approach is that there is no clearly identifiable reference point as to when this approach should be commenced. Consequently, without this clarity, the way aged care staff in this study tried to meet the goals and needs of their high-level care residents with chronic and complex health conditions, was to use
clinical markers that indicate end of life was close. The fact that aged care staff do provide end of life care to residents, despite their lack of resources and skill mix, is a reflection of their person-centred approach to practice.

These findings have significant implications for the provision of a palliative approach in hostel settings. They emphasise the need to re-evaluate how this care can effectively be implemented within hostel settings. It is evident that, because of their understanding of the sensitivities of residents and their families in relation to adjusting to a new phase in the resident’s life, the language of a ‘palliative approach’ is not being operationalised by these staff. Nevertheless, these aged care staff demonstrated a shared commitment to providing high quality care that is sensitive to the changing needs of the resident, and focused on building a supportive circle of care around each hostel resident and their family.

The next section elaborates in more detail on the way in which the communities of care develop over time around each resident, and on the dimensions of care that are incorporated into each community. Table 8.1 provides a summary of the links between McMillan and Chavis’s (1986) theory of community, McCormack and McCance’s (2011) notion of person-centred care and the concept of a community of care as presented here.
Table 8.1: A summary of the links between McMillan and Chavis’s theory of community, McCormack and McCance’s person-centred care and a community of care.

<table>
<thead>
<tr>
<th>Community of Care</th>
<th>Community (McMillan &amp; Chavis, 1986)</th>
<th>Person-centred Care (McCormack &amp; McCance, 2011)</th>
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<tbody>
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<td>Prerequisites</td>
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<td>• Developing a sense of belonging</td>
<td>• Developed interpersonal skills</td>
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<td>- Developing relationships</td>
<td>• Exerting influence over situations</td>
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<td>- Becoming a family</td>
<td>• Meeting the needs of the community</td>
<td>• Gaining an understanding of the individual’s value base</td>
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<td>- Interconnected networks</td>
<td><strong>Emotional Connections</strong></td>
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<td><strong>Membership</strong></td>
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<td><strong>Influence</strong></td>
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8.3 Building a Community of Care

The development of a community of care takes time and effort on the part of all involved and tends to happen in stages. Initially, there may be awkwardness and resistance, however, given that the stakes are always high, all interested parties work together as best they can to achieve the best possible outcomes. The first stage is conceptualised here as building a community.

Before examining how the community is built, it is relevant to review some of the common characteristics of the residents who form the centre of their respective communities of care.

As outlined in Chapter Four, the majority of high-level care residents (96%, n=89) had a non-malignant chronic illness. These included cardiac and neurological disorders such as dementia, a disorder affecting some 31% of residents. More than half of the residents (53%, n=49) had three or more concurrent health problems, which for many included dementia.

Despite these considerable health issues, residents perceived their own health status as ‘good’ and did not consider themselves to have ‘ill health’. Instead, they saw themselves as transitioning towards end of life, not because of a medical condition but due to ageing. Residents accepted their condition with a sense of inevitability that it was part of the ageing process. A similar finding was made by Hall, Longhurst and Higginson (2009) in their study of eighteen nursing home residents who perceived their symptoms and loss of function as due to old age rather than illness. Pincock and colleagues qualitative study exploring the perspectives of people with severe chronic obstructive airways disease (COPD) as their illness progressed, revealed that exacerbations that caused severe symptoms and disrupted their lives were described as a ‘...way of life rather than illness’ (Pincock, Kendall, Murray, Worth, Levack, Porter, MacNee, and Sheilík’s 2011, p. 1). Similarly, many people in this study were able to adapt to and accept their lifelong condition.
Although residents in my study acknowledged that they would end their life in a residential care facility, most saw death as something in the more distant future, something they were not yet considering. This situation seemed to create a dilemma for aged care staff attempting to implement a palliative approach. Their solution was to build what I have described as a ‘Community of Care’, to develop the important relationships and safe contexts that would facilitate difficult conversations in the future. Similarly, Pincock and colleagues’ (2011) study found participants with severe COPD did not consider death as an imminent threat, and end of life wishes were generally not discussed with professional carers, friends, or family.

Interestingly, it was the residents’ peers who had the greatest influence on residents’ perception of their own health status. Surrounded by such a high proportion of high-level care residents whose condition was deteriorating or changing, residents were continually monitoring their health and function against others. Some residents in better health felt the need to differentiate themselves, and also to separate themselves physically, from those with visible signs of disability. Similar findings regarding building and maintaining peer relationships within residential aged care facilities have been identified in other research (Anderson, Petterson & Sidenvall, 2007; Hauge & Heggen, 2008; Bergland & Kirkevold, 2008). Anderson and colleagues (2007) found that living with ‘disabled people’ was a major source of dissatisfaction for residents living in care homes. Similarly, Hauge and Heggen (2008) found residents avoided enforced relationships with other frail residents, as they wanted to avoid being classified as old and dependent. Many residents in my study hoped they would reach the ‘end of life’ without ‘serious’ health problems that would limit their functional capacity. It is possible that this mind set delayed or inhibited the development of a sense of group membership for some residents. Over time, however, the feeling of membership and a sense of belonging to a community of care developed among residents.

Before membership of the community could occur, though, residents had to adjust to their new environment. The move into a hostel was a major life change for them and their family. Both the institutional atmosphere and the operational structure of rules and regulations and living to a fixed timetable made it difficult at first for many
residents to develop a sense of membership. Many residents felt restricted by the rules and felt they had lost their independence and control. For the majority of residents, the food in the hostel was a major concern and represented a loss in their lives. They disliked the food and the lack of choice. Within the organisational structure of hostels there is a need to ensure cost effectiveness, thus individual food preferences and choices have to be largely overlooked. Food-related issues within RACFs have been identified in the literature as negatively impacting on the resident’s quality of life (Crogan, Evans, Severtsen Evans & Shultz, 2004; Chan & Pang, 2007), and this study highlights the need for further research in this area.

The loss of autonomy and control many residents experienced in the transition from their own home to an institution is also well documented in the literature (Kahn, 1999; Lee, 1999; Lee, Woo & MacKenzie, 2002; Sacco-Peterson & Bordell, 2004). However, faced with deteriorating functional health and limited alternatives, most residents seemed to make the best of this situation within the inevitable organisational constraints. The challenges residents experienced in adapting to life within the hostel were recognised by aged care staff, who, from the moment they entered the hostel, began to develop relationships to facilitate their transition and to develop a community of care around each resident.

The importance of relationships has been emphasised in relation to discussions of the philosophical underpinnings of various models of nursing (Peplau, 1952; Watson, 1985; Boykin & Schoenhofer, 1993). In the aged care literature, a close relationship between nurses and the older person is recognised as the key to successful care outcomes for the patient (Nolan et al., 2002; McCormack, 2004) and to job satisfaction for the nurses, which also influences staff retention (Ball, Lepore, Perkins, Hollingsworth & Sweatman, 2009). The relationships between staff, residents, and their families have emerged as fundamental to the experience of life within the community of a ‘care home’ (Davies & Brown-Wilson, 2007). Brown-Wilson (2008) suggests that one of the key processes in creating communities in care homes is understanding and respecting the significance of relationships.
In this study, supportive relationships between staff members were evident in the way they were attuned to the needs of other staff members and often shared their workload. New staff were allocated to the same residents for a period of time so that they could get to know the residents better and begin to establish a relationship with them. Aged care staff felt part of a team, and that their contribution to the community of care was valued and recognised by all stakeholders. Other gerontology nursing research in long-term facilities has recognised the concept of a ‘team effort’ (Brown-Wilson, 2009; Hunter & Levett-Jones, 2010), and the present research demonstrates that it is the shared philosophy of preserving dignity and quality of life for the resident that underpins staff team values.

Residents felt that ‘good’ relationships with staff positively influenced how they perceived life in the hostel and the care provided. This is not surprising in that connectedness is a fundamental human need (Townsend & McWhirter, 2005) and a lack of connectedness can impact negatively on health, adjustment and wellbeing (Baumeister & Leary, 1995). In the present study, the special bond Henrietta had developed with a particular personal care assistant, and the honour she felt in sharing special private moments with her, contributed to Henrietta’s satisfaction with the care she was receiving (Chapter Five, p. 164). Another example of how the resident’s good relationship with staff could influence not only their perception of care but the actual meeting of needs is in the case of the personal care assistant who would bring one resident fresh prawns every so often as she knew this to be one of his favourite foods. These findings are similar to other nursing research on residential aged care facilities where it has been identified that personal relationships influence residents’ and family members’ perceptions and satisfaction with care and staff members’ feelings of job satisfaction (Grau, Chandler & Saunders 1995; Kellet 1999; Bowers, Fibich & Jacobson 2000; Moyle, Skinner, Rowe & Gork, 2002; Ball at al, 2009).

Staff, residents, and family members often used the words ‘like family’, not to identify a biological connection, but as a term describing their emotional connection to the community, and those within the community, their sense of belonging. It seems that in many ways a major component of becoming a ‘family’ in this environment was the nature of the relationship and interaction between residents, staff and family members.
Similar to findings by McClement, Wowchuk and Klaasen (2009), health care assistants indicated they had developed long-standing, close relationships with many of the residents they cared for and consistently described these residents as being ‘just like family’. Such long-term relationships allowed health care assistants to learn about the life experiences of the person and family, and assist in deciphering the residents’ emotional responses and detecting early changes in their physical condition.

Families felt supported by the staff and included in this ‘like family’ atmosphere, as illustrated by Sue, a participating person responsible, who was emotionally struggling with her husband’s cognitive changes (Chapter Five, p. 160). Often she felt upset during her hostel visit and would be close to tears when it was time to leave. If staff saw her ‘getting upset’, they would ‘race over, give me a cuddle’.

The literature suggests that the length of time a resident lives in a facility is an important aspect in feeling connected to, and establishing a view of the facility as home (Dobbs, 2004). Being able to remain in the same facility as their health deteriorates can thus strengthen the sense of belonging or membership that residents, families and staff feel within the community of care. The quantitative findings showed that the median length of stay for high-care residents was just over a year and half, which may have contributed to this perception of the facility as being ‘homelike’. Supporting residents with complex care needs and their families involves detailed work over extended periods of time and with considerable personal investment. Having this time to engage, often quite intimately, enabled strong relationships to develop between staff, residents and families. This finding resonates with those from Gubrium’s study (1993), which identified that ‘meaningful relationships with friends and family and personal possessions constitute a considerable amount of what home means to people’ (p. 55-56). The concept of a residential aged care environment being likened to a family has also been well documented in other studies (Wilson & Daley, 1998; Bowers et al., 2000; Touhy, Brown, & Smith, 2005; Secrest, Irorio & Martz, 2005; Phillips, Davidson, Jackson, Kristjanson, Daly & Curran, 2006). Of course, not all residents perceived the hostel as their ‘home’. A minority continued to perceive the hostel as an ‘institution’ where they were trapped and in which they had lost control.
over everyday decisions. But, for most, over time a sense of belonging and of being cared for, and about, developed.

It was evident that staff not only built a community of care around each resident and their involved family, but that these circles of care form interconnected networks of communities of care. This interconnectedness existed not only between staff throughout the hostel, but also amongst the residents and their families who were connected to other residents and their family members.

As noted in Chapter Five, some residents who considered themselves to be in better health than other residents in the hostel took on a ‘surrogate’ carer role. Staff contributed to the development of these interconnected communities by linking family members with other family members. Chapter Six highlighted the connections staff had with the families of their residents by sharing jokes, stories about their life and shared photographs from holidays. In Chapter Seven, one manager highlighted that the relationships and respect between residents was also evident after a death where fellow residents collectively insisted on paying their final respects to the deceased.

These examples demonstrate the networks that develop and that communities of care are interconnected with a hostel.

8.4 Committed Engagement

Once a community reaches a certain stage of development, committed engagement by all the members ensues. A sense of belonging, integration and fulfilment within this community of care is evident whereby the members demonstrate respect for each other, share the responsibilities of caring, and strive towards ensuring that they are meeting the needs of all members.

The central focus within a community of care in aged care facilities is meeting the increasing needs of the resident. Within the communities participating in this study,
‘care’ was the central element. There was an ethos of providing best possible care which influenced and held the community together and provided direction for care delivery. This valued philosophy was shared among all staff in that they demonstrated a commitment to improving the quality of life and a sense of dignity for residents by striving to provide appropriate, sensitive care. This was characterised by staffs’ efforts to individualise care, to build relationships with residents and their family, to develop trust, to show respect, to act as advocates, to monitor and treat symptoms, to listen sensitively and ‘stay with them’ as the resident’s condition deteriorated.

This ethos of care was underpinned by a belief that staff could make a difference to the resident’s transition towards the end of life by providing individualised care that was relationship-focused and involved collaboration and shared decision-making between the resident, family and staff. Aged care staff were sensitive to each individual’s needs and focused on a ‘holistic’ approach of identifying and addressing any unmet physical, cultural, spiritual, or emotional needs of the resident.

### 8.4.1 Committed Engagement of Staff

Staff recognised the vulnerability of their high-level care residents who were often frail, weak and had complex care issues, even if the residents did not always acknowledge these themselves. As noted in Chapter Four (section 4.1.6 & 4.1.7), residents had multiple primary health conditions with multiple co-morbidities. Close monitoring and multidimensional assessments were required to ensure each resident’s unmet needs were identified and a plan of action was put in place. The capacity of staff to understand each resident’s needs developed from their extended personal contact and the provision of intimate care. According to McCormack and McCance (2010), ‘full engagement is present when the patient and nurse are connected in the relationship and a care partnership exits’ (p. 48).

While there were registered nurses, endorsed enrolled nurses or enrolled nurses working within each hostel (Chapter Four, section 4.2.1), these staff members were all mostly involved in managing the facility, overseeing care responsibilities, dispensing
medications and attending to wound management. Thus it was personal care assistants who were primarily responsible for initially identifying residents’ unmet needs and responding in a timely way to subtle changes in their conditions. Over time these personal care assistants gained an in-depth, intimate knowledge of each resident. While the need to assess the resident’s physical pain was often highlighted, the provision of support and emotional care was very prominent in the views of the personal care assistants. They described spending time listening to residents, encouraging them to talk freely about their feelings, something the resident did not always do with their own family. By focusing on providing psychosocial support to the individual resident, personal care assistants perceived they were able to make a difference to their wellbeing. The ability and preparedness of personal care assistants to focus on various aspects of care, particularly emotional aspects, demonstrated they possess a commitment to engaging as members of each resident’s community of care.

In other institutionalised settings, such as acute hospitals, length of stay is short and care interactions are therefore time-limited. In aged care facilities personal care assistants provide care to the same residents day after day and develop a sense of ‘knowing each resident’. According to Luker and colleagues (Luker Austin, Caress and Hallett, 2000), there is a general consensus in the literature that knowledge about the patient and their perceptions of a situation assists the nurse to effectively interpret concerns and anticipate needs. This study suggests this extends to other groups engaged in more long term care, such as personal care assistants.

While the qualitative aspects of this study demonstrated that staff felt a strong commitment towards meeting the needs of residents and their families, the quantitative results revealed that residents had significant unmet psychosocial needs. It was identified that nearly two-thirds (65%, n=60) of resident participants experienced moderate to severe negative feelings of wellbeing and nearly half of the residents (47%, n=43), experienced moderate to severe psychological issues when depression and anxiety scores were combined. In addition, nearly a third of residents suffered severe to overwhelmingly low self worth (28%, n=26). These findings may have been related to the residents’ poor physical functioning abilities, their loss and adjustment problems at being institutionalised, rather than inability to meet their needs on the part of aged care staff. Garatachea and colleagues (2009), investigating whether
a relationship exists between physical activity, physical functioning and feelings of wellbeing, found a significant difference between the wellbeing of less active dependent and independent older individuals (Garatachea, Molinero, Martinez-Garcia, Jimenez, 2009). Chan and Pang (2007) found existential distress to be common among residents who were unable to adapt to the transition of being in a long-term care facility. Other researchers have identified that living in a long-term facility is often regarded as degrading because of changes in lifestyle, and losses associated with reduced autonomy, privacy and social networks (Lee, 1999; Lee et al., 2002; Franklin, Ternestedt & Nordenfelt, 2006). While it was evident in the present study that aged care staff were fully aware of the adjustment difficulties of residents and family members and they created a supportive community of care around them from the outset, additional psychological support for residents in these aged care settings is needed.

As noted in Chapter Four (p. 130), personal care assistants provided the majority of hands on care; therefore the quality of care was largely dependent on their skills. The role of the personal care assistant/worker has been described in the literature as one that is task-orientated (Cartwright & Kasyser-Jones, 2003; McCormack, 2003; Tuckett, 2006). A role that provides physical rather than affective (socio-emotional) or communicative aspects of care (Ong, de Haes, Hoos & Lammes, 1995). Although one hostel manager in this study saw personal care assistants as tending to be task-orientated, the remaining six managers held a different view. They argued that care was provided through a collaborative ‘team’ approach in which the input from personal care assistants was highly valued. The perception that personal care assistants are task-orientated and lack awareness or skills to address other needs perhaps stems from the context prior to the 1997 aged care funding changes in Australia (Riggs and Rantz, 2001). At that time, the majority of high-level care residents resided in nursing home settings and a higher percentage of registered nurses were responsible for their daily care (ibid). Since then, the role of the personal care assistant has changed, alongside the increasing complexity of health issues for residents now residing in these hostels. This raises important questions about the education and training preparation of this group of staff, and the level of continuing support they might need in order to provide competent, appropriate care to high-level care residents. It also
raises questions about the effectiveness of the assessment tools routinely used by aged care staff to capture the psychosocial health status of residents. This issue becomes particularly relevant in light of the finding in this study that significant numbers of high level care residents experience moderate to severe negative wellbeing and other psychological symptoms.

Skill mix and staffing numbers were shown to have an impact on the ways in which care could be provided. These factors affected the capacity of staff to fully commit to, and engage with, a community of care, particularly if the resident had very high-level care needs. When necessary, the resident was transferred to another facility. As noted in Chapter Four, the ratio of personal care assistant to resident varied among the eight hostels. In hostels with a higher percentage of high-level care residents the ratio of personal care assistants to residents ranged from 1:6 to 1:9. The lowest staffing ratio of PCA to resident (1:18) was in Hostel Eight, which had the smallest percentage of high-level care residents (23%). For the majority of hostels, only one personal care assistant was rostered on duty for the night shift.

Staffing shortages were most pronounced at the metropolitan site. As highlighted in Chapter Four, the metropolitan site used a large percentage of agency staff, whereas the rural site had a pool of casual staff and rarely used agency staff. Some residents noted that agency staff were not always in a position to ‘care’ in the same way as permanent staff. Each community of care takes time to develop, time for the staff to get to know the resident well and for the relationships between them and the residents’ families to form. Therefore, the casual nature of their involvement prevented these staff from engaging in communities of care.

8.4.2 Communication within a Community

A committed engagement by all the members required the use of collaboration and communication strategies within each community of care and demonstrated the commitment of members to maintain a successful community. It was evident that a level of trust developed between aged care staff and families, and that families’
confidence in staff knowledge and ability to provide quality care grew. This enabled staff to guide families through care decision-making processes and difficult conversations about the future. This trust also saw families seek further comfort and explanations from aged care staff regarding the resident’s status. Communication was a key to the success of this approach to care as it enabled staff to ‘walk the walk’ (PCA; group H) with them, to be part of the journey with the resident and their family. When a resident began to exhibit signs of deterioration in their condition and needed additional care, consultation at all levels of staff took place regarding the ongoing care needs of the resident. Communication with families about these changes was also a high priority and usually occurred via telephone or face-to-face. Staff explained that open and honest communication was the best way to keep families aware of changes, and to reinforce the collaborative processes between the staff and family.

External collaboration and communication with specialist palliative care services is important when additional support and advice is needed (PCA, 2010b). However, the extent of this collaboration varied between sites. At the rural facility, external collaboration with the local specialist palliative care service was only available via telephone, a situation that related to discrepancies between state and federal funding. To fill this gap in service delivery and to ensure on-going competencies of aged care staff to meet the demands of residents requiring end-of-life care, the rural residential aged care facility employed a clinical nurse specialist in palliative care. The metropolitan site had access to specialist palliative care services and consultation from the local palliative care community nurse specialist, but consultation with them required a medical referral. However, referrals are reliant on the primary health professional being able to identify palliative care needs or recognise that a change of focus is required. At the rural site all levels of staff were aware of the referral system in place, which was to notify the on-site clinical nurse consultant. At the metropolitan site, referrals were processed through the manager. Multiple studies have identified age care staff challenges in recognising the need for end of life care in residents and consequently the ability to identify the appropriate time to refer to specialist palliative care services (Avis et al. 1999; Komaromy et al. 2000; Froggatt & Hoult 2002, Hanson et al. 2002; Kayser-Jones 2002, Travis et al. 2002, Giles et al 2003; O’Connor & Pearson 2004; Brazil, Krueger, Bedard, Kelley, McAiney, Justice & Taniguchi,

8.5 Acceptable Transition Experiences

The success of a community of care is demonstrated by a transition towards end of life experience that is acceptable to all members of the community, that is, the resident, the staff and the family members involved. The Australian Government’s, ‘ageing in place’ policy requires a facility to adjust the provision of services and level of care criteria to meet residents’ changing needs, and, where possible, to avoid discharging people to a different facility for end-of-life care. This study clearly demonstrates that staff wanted to provide end-of-life care ‘in place’, and that residents and families keenly wanted to remain ‘in place’ too. In other words, an acceptable transition towards end of life involves ‘ageing and dying in place’. However, the capacity of a hostel facility to uphold the ageing in place philosophy through to the resident’s end of life is not without challenges; challenges that sometimes cannot be overcome. As noted in Chapter Seven, aged care staff identified a number of instances where they were not in a position to provide optimal care required at end-of-life and the resident had to be transferred to another setting. It was also identified by staff that residents would mask or underplay their symptoms to avoid being identified as needing higher care requirements, resulting in possibly being transferred to a nursing home. Clearly, residents in this study feared transfer to a nursing home. Fear of nursing home admission among older persons has been identified in other research (Salkfield, Cameron, Cumming, Easter, Seymour, Kurrle and Quine, 2000; Quine and Morrell, 2007).

Although residents, their families and staff in this study expressed an overwhelming preference for the resident to remain in the hostel until death, this was not possible for most residents. A total of 72 resident separations occurred across the eight participating hostels during a six-month period in 2008, and only a small percentage of residents (19%, n=14) died in their hostel. This figure is slightly lower than Grbich
and colleagues’ finding of 22% of deaths over a one-year period in hostel facilities that provided high and low-level care (Grbich, Maddocks, Parker, Brown, Willis & Hofmeyer, 2005). These findings strongly suggest that, at this point in time in Australia, ageing in place does not include dying in place.

The cornerstone of managing ageing in place is managing the resident’s declining health and declining functionality. Most residents entered the hostel because of declining functionality related to advancing chronic disease. Staying in this setting hinged on the capacity of each community of care to manage the inevitable changes in condition and functionality, and to implement end-of-life care. A major constraint to providing this care was availability of staffing resources. As identified in Chapter Six, the point at which it became necessary to transfer the resident was when it required two staff members to assist in meeting their needs. In such instances, the decision to transfer a resident was not taken in the spirit of palliative care, where the dying person can express a preference. The decision was taken based on the hostel’s incapacity to provide sufficient staff to sustain the care needs of the dying resident. This finding is congruent with those of a US study by Ball and colleagues (2004) who found that responding to a resident’s decline included balancing their needs with resources, overextending resources to meet needs, and accepting the fact that some residents’ needs cannot be met, except by transfer to a another facility. The constraints of resources and staffing have been identified as significant barriers to end-of-life care in a number of previous studies (Kayser-Jones, 2002; Brazil, McAiney, Caron-O’Brien, Kelley, O’Krafka, Sturdy-Smith, 2004; Brazil et al., 2006; Phillips, Davidson & Willcock, 2009).

When a resident is transferred out of the hostel, the community of care breaks down. This breakdown means that each member of the community is left to deal with both the change itself and the resident’s eventual death somewhere else without the support of the group members they had come to rely on. Having already experienced the trauma associated with moving out of their home and into a residential aged care facility, residents who are transferred face another move, one they have been shown to be extremely fearful of, at the most vulnerable time of their life. Fear and uncertainty about the future was clearly identified among both residents and their families in this
study. Staff perceived this move as preventing them from being able to preserve the resident’s sense of dignity and quality of life. While ageing in place is a major Australian Government policy, there is clearly a long way to go to achieve dying in place for people with high level care needs in hostel settings.

While staffing resources were identified as the major factor contributing to the transfer of a resident, at times end-of-life care was possible in the hostel setting. When it was clear that the resident was going to die within weeks or even less, aged care staff, if they were able, made a decision to keep the resident within the community of care and implement end-of-life care. Thus, hostel-based community of care can incorporate end-of-life care in some circumstances. One of the challenges in the decision-making processes was anticipating a timeframe for the remainder of the resident’s life. The disease trajectory of individuals with a chronic illness and frailty is often prolonged and it can be difficult to determine the end of life phase due to cycles of wellness and subsequent decline (Lynn, 2001; Lunney et al., 2003).

The strength of the emotional connection staff held for a particular resident could influence the decision process. However, overall, it was only possible to avoid transfer if staff agreed to stretch their resources, something that had both positive and negative consequences for staff. Often staff were emotionally torn between wanting to provide the best quality of care for a dying resident and not wanting to neglect the ‘less acute’ needs of other residents. This demonstrates the social connectedness that existed between the members of this community of care, but also highlights the emotional consequences experienced by the group members.

Although actual staff numbers were a significant factor in being able to provide end-of-life care in the hostel, the skill mix of staff was also relevant. For example, skill mix appeared to influence the practice of using transdermal opioid patches rather than syringe drivers to manage pain and thereby also to influence the ability of hostels to effectively manage end-of-life care for residents with complex pain symptoms. An Australian qualitative study by Holloway and McConigley (2009) identified that nurse assistants often initiated and implemented pain management treatments usually considered outside the scope of their practice. This finding reinforces the importance
of developing collaborative partnerships with specialist palliative care services, and the need for appropriate skill mix in staffing residential aged care services.

Where staff were able to provide end-of-life care, they perceived it as rewarding and satisfying. Staff saw it as ‘an honour’ to be there with the resident as they died and would often extend themselves to ensure that the resident did not die alone. This finding is confirmed by previous research which has demonstrated that aged care staff found caring at the end of life professionally rewarding (Wilson & Daley, 1998; Moyle et al. 2003; Touhy et al., 2005; McClement et al., 2009).

8.6 Conclusion

This chapter has drawn together the major findings of the quantitative and qualitative approaches within this mixed method design and puts forward a new way of conceptualising care for people who are transitioning towards the end of life in hostel settings. What has been argued here is that the concept of a community of care encapsulates the way this community comes together to operationalise care and the way in which care is delivered to high-level care residents and their families in hostel settings. This research has found evidence that a palliative approach in this context is associated by staff with end of life care. The most appropriate way to think about what aged care staff do in these hostels is through the concept of a community of care which encapsulates a combination of end of life care, rehabilitation care and acute care.

McMillan and Chavis’ (1986) elements of a sense of community provided a helpful basis for an explanatory framework within which to understand the concept of a community of care in the hostel setting. It was evident that while most residents did not immediately feel a sense of membership, over time a sense of belonging did develop. Aged care staff enveloped the resident and family in a culture that was supportive and caring. In this context, aged care staff demonstrated a person-centred approach which reflected their professional values and beliefs, their workplace culture, and their emphasis on the importance of shared decision making. Residents,
although at least initially reluctant about being there, valued and acknowledged the supportive nature of the community of care which had them at its centre. The social connectedness demonstrated by the members of the community in this study reflected a sense of ease and comfort, a sense of belonging. Shared emotional connections were evident between staff, residents, and family members and expressed by each of them as being ‘like family’ and ‘homelike’. Residents felt their good relationships with staff positively influenced their perceptions of life in the hostel. Many of the residents and persons responsible felt ‘cared for’ which engendered satisfaction with the quality of care provided. Effective communication and the interpersonal skills of the aged care staff enhanced the interactions within this community of care, resulting in satisfaction with care. Within each community of care, staff demonstrated professional competence and worked within an ethos of care to provide the best possible high-level care to residents and their families. Aged care staff demonstrated a commitment to the job despite the many challenges. This valued and shared philosophy influenced and held the community together. This community of care framework proposes an appropriate and accessible model of care for high-level care residents with chronic and complex conditions, within which end of life care is a single, integral component. It is important to note, though, that the constraints within which each community of care has to operate, inevitably mean that some needs simply cannot be met.

The following chapter presents the conclusions of this research and details the implications for practice as well as the limitations of the study.
CHAPTER NINE:

Conclusion

This concurrent mixed method research design has effectively answered the five research questions posed. The quantitative approach using descriptive statistics has yielded a clear, detailed picture of the demographics and symptoms of the high-level care residents participants, and facilitated a review of organisational and managerial data. A qualitative approach involving semi-structured and unstructured interviews has enabled the researcher to: (i) explore these residents’ perceptions of the health care provided and their perceived future care needs, and, (ii) to explore aged care staff understandings of a palliative approach and its use within hostel settings.

The study has shown that the discourse of a palliative approach is not widely adopted or operationalised within hostel settings. While there is evidence that staff are aware of the concept of a palliative approach, they do not explicitly refer to it in their conversations with residents and their families, or in planning care for residents. Staff do envelop the resident and family into a culture that is supportive and caring, but they have a lack of clarity in relation to the appropriateness and timing of introducing the language of a palliative approach into their conversations with residents and their families. The research suggests that staff feel residents and family need to be in an appropriate frame of mind to engage with this discourse, and many simply are not.

There is evidence in this research to suggest that, reluctant though they may be about spending the rest of their lives in an aged care facility, the residents themselves acknowledge the supportive nature of the community of care that has them at its centre. Therefore, using a broader framework of a community of care presents an alternative way of conceptualising care for people who are transitioning towards the end of life, a person-centred approach that may be more acceptable to residents, and their families and also to the staff who provide the care.
This study has identified the various components that make up a community of care and the processes involved in establishing one. It is clear from this analysis that some aspects of each community of care reflect the goals and philosophical underpinnings of a palliative approach, but overall the ethos is much broader. It is argued here that the language of a ‘community of care’ is likely to be acceptable to aged care staff given that it expresses their multidimensional approach to caring for people in hostel settings. The move to a hostel and the underlying implication that this is the beginning of a transition towards end of life is indeed a challenging situation for residents and their families. Requiring residents and their family to engage with the concept of palliation at this time did not appear to have value, and staff recognised this as confronting for people and avoided it. Aged care staff are very concerned to ensure that, to extent to that it is possible, residents and their families feel ‘at home’ within the hostel, and this study demonstrates that in time many people do come to feel a sense of belonging within this environment. I argue here that experiencing a sense of belonging is core to the concept of community and that aged care staff will embrace the idea of a community of care in a way that they have not been able to do with the concept of a palliative approach.

The study has demonstrated that staff at all levels work very hard to implement and maintain a community of care around each resident. Further research is needed to more fully understand the relationship between a community of care and resident satisfaction with care. There is evidence in this research suggesting that this approach to supporting residents is beneficial. However, the most concerning aspect of this study’s findings is the high proportion of residents experiencing depression, anxiety and negative wellbeing. What is unknown, however, is the extent to which uncertainty about future care arrangements and resource constraints on staff endeavouring to provide appropriate care to people with complex care needs underpin this worrying situation.

The research has also shown that maintaining a community of care through to, and including, end of life care, is not without its challenges. Resource constraints limit the capacity of staff to provide end-of-life care, which means most residents are transferred to another facility at a critical time of their life. The study shows that this
transfer is distressing for all members of a community of care and does not reflect the spirit of an ageing in place approach to caring for the older person.

I argue here that any ‘ageing in place’ policy must also emphasise and facilitate ‘dying in place’. Given the frailty and vulnerability of older people with complex care needs, providing services that minimise the fracturing and disruption of their transition towards their end of life is critical to ensuring that people can die with dignity in their place of choice. Clearly, moving a resident during the final phase of life disrespects the wishes and choices of the resident and their family. Most resident and families in this study made it very clear that, not only did they want to stay in the hostel to their end of life, they were also extremely fearful of moving to an unfamiliar place. The uncertainty that this situation engenders for residents, family and staff severely undermines the overall effectiveness of the ageing in place agenda.

This study clearly demonstrates the desirability and importance of appropriate end of life care. Although this was not the focus of this study, the relationship between hostel staff and specialist palliative care providers is undoubtedly critical to end of life experiences. It may also be extremely useful in situations where hostel staff, because of particular skill mixes, are unable to meet certain complex care requirements, that specialist staff are closely involved much earlier than this. Despite evidence of the provision of education and organisational policies and procedures regarding a palliative approach within these hostels, it is my view that the availability of an on-site champion in palliative care, an aged care link nurse with palliative care training, is a tangible way of ensuring a support mechanism that can meet the needs of staff, residents and their families.

9.1 Implications for Practice and Policy

The findings of this study have implications for all practice and policy aimed at meeting the needs of older individuals suffering from chronic and complex health
conditions, particularly those residing in hostel settings. These implications include the following:

- This study has drawn attention to sensitivities surrounding the use of a palliative approach in this context. It is also apparent that there is a lack of clarity about how a palliative approach relates to palliative care and no clear consensus about the indicators for the timing of implementing a palliative approach. Aged care staff, though, are very clear about clinical indicators for implementing end of life care and appear very comfortable with the use of the language of palliative care in this context. It is therefore recommended that the framework of a ‘community of care’ (recognising that a palliative approach is implicit within this framework) be adopted as an appropriate and potentially acceptable model for the provision of care in hostel settings, with a continued emphasis on the importance of palliative care at the end of life.

- While the Government has moved to amalgamate hostels and nursing homes under one umbrella term, ‘residential age care’, in the clinical arena a distinction continues to exist between these two settings. Primarily because of the differing levels of staff and skill mix between the two traditional models. What this study has shown is that there is now a very high rate of residents with high care needs living in hostel settings, with no change of staffing and it is therefore important that hostels are appropriately resourced to provide the necessary care.

- The Government policy on ‘ageing in place’ does not equate to dying in place within hostel settings. Primarily, this is impeded by staffing resources but also by infrastructural shortcomings. If ‘ageing and dying in place’ is to be a real option, government funding needs to be increased to appropriately resource aged care facilities to ensure that the workforce can support residents while they are transitioning towards end-of-life and through end of life care.

- In order to ensure that staff are able to properly implement a community of care around each resident, appropriate education and training is required. In addition, education and training in providing end of life care and working with
specialist care providers is also critical. One way to do this is through the use of appropriately educated link nurses who can provide liaison between hostel staff and specialist palliative care services.

- This study has revealed that a high proportion of hostel residents experience significant levels of poor self-esteem, negative well-being, depression and anxiety. While most residents state that they are satisfied with the care provided, many indicate that the move to institutional care and on-going uncertainty about their future are major concerns. This study clearly demonstrates that there is a need for on-going support and counselling, perhaps from Aged Care Assessment Teams who conduct initial assessments and recommendations for residential aged care placements. What is also clear is that further research is urgently needed to determine whether there is a relationship between poor self esteem and negative wellbeing and the lack of resources identified in this study that impacts on the capacity of aged care staff to provide comprehensive care to high level care residents.

9.2 Limitations of the Study

There are three limitations to the findings of the present study:

1. It is not possible to generalise the findings as the data were context-specific and obtained using convenience sampling for the quantitative data collection and purposive sampling for the qualitative data collection. Convenience sampling was used to recruit the residents/persons responsible because the exact number of high-level care residents living in these hostels was unknown. However, a representative sample of over one third (39.2%, n=93) of the total population was used to describe the characteristics of the high-level care residents in this study. The findings from this study could be used to provide a springboard for further research.
2. The literature reports varying reliability of the use of proxies, therefore, proxy reports should be interpreted with caution. However, proxy assessments made by significant others are reasonably accurate concerning health status, measures of functioning, activities of daily living and some symptoms (for example, fatigue, dyspnoea and vomiting) (Neuman et al., 2000, McPherson & Addington-Hall, 2003, Brandt et al., 2005). As noted in Chapter Three, Pickard and Knight’s (2005) ‘proxy-patient perspective’ was used. However, it was noted that when interviewing person responsible that at times they began to tell their own story as opposed to strictly sticking to answering on behalf of their loved one.

3. In this study, the 95% confidence intervals (CIs) for individual symptom items and total symptom scores were checked for overlap before combining the scores. Based on these results, the 95% CIs indicated that the mean (medium) predominantly showed overlap between symptom scores, meaning residents and persons responsible scores were similar. For a small proportion, where the 95% CIs were generally wider for the person responsible than the resident participants, is more likely due to the smaller sample size.

9.3 Concluding comments

Given the global burden of ageing, it is likely that themes derived from this study will be useful in informing clinical practice, research and policy in similar settings and in other developed countries facing similar issues. Not only do the findings illuminate aged care staff personal experiences of providing care to high-level care residents, the findings also provide valuable insight into high-level care residents’ demographic characteristics, perceptions of their health, the care provided and the way in which they foresee their care being provided into the future.
It is intended that the research findings will contribute to further development and implementation of policies and funding arrangements related to residential aged care, and, specifically, assist in the development of more effective provision of end-of-life care in hostel settings.

The recommendations for future research arising out of this doctoral study are:

1. Evaluation of the appropriateness and cost effectiveness of ‘a community of care’ framework for the care of high-level care residents living in hostel settings. This would include evaluation of the extent to which this framework could increase resident and family well-being and staff satisfaction. It would also include assessment of the extent to which interconnected networks of communities of care operate with hostels.

2. Research to further understanding of the implications for residents and families of being transferred from a hostel to a nursing home for end of life care.

3. Research is also needed to ensure better integration of advance care planning and palliative care into the care of people living in hostels.

4. Full evaluation of the relationship between negative wellbeing, depression and anxiety in high level care residents and the level of resources for provision of nursing care.
POST SCRIPT

Following completion of this thesis, the preliminary report on the delivery of aged care in Australia was released. As this document will potentially shape the delivery of aged care in Australia it is important to note several of the key recommendations in the draft report, and, of interest, how these link to the findings of my research. The Australian Productivity Commission Draft Report *Caring for Older Australians* was released on 21 January 2011, including drafted recommendations for redesigning Australia’s aged care system to ensure it can meet the challenges facing it in coming decades. The Commission will present its final report to the Government by the end of June 2011. Of particular concern, the report noted, are the identified, very significant gaps in the way health professionals provide end of life care in the aged care sector.

Of note, the report also identified unmet needs of resident at the end of life and significant workforce issues in RACFs as areas of concern. These are also issues that my research has identified. A major focus of the draft report is the funding of aged care in Australia, with recommendations for broadening the funding base to ensure adequate resourcing of aged care services.

The Commission report recommends that:

- To address insufficient funding for palliative and end-of-life care:
  - residential and community care providers must receive appropriate case-mix payments for delivering palliative and end-of-life care.

- Increasing workforce shortages and willingness of health professionals to enter the aged care sector, requires:
  - payment of competitive remuneration for aged care workers to reduce the lack of parity and enhance the attractiveness of the aged care sector;
o the promotion of skill development through an expansion of courses (vocational training and others) to provide aged care workers at all levels with the skills they need;
o the development and promotion of career paths for aged care workers to improve the quality of care that those workers are able to deliver.

- To increase the publicly available data and policy relevant evidence in the area of aged care:
  o The Australian Aged Care Regulation Commission should perform the role of a national ‘clearinghouse’ for aged care data. In addition, the introduction of measures to improve the usefulness, collection and public reporting of aged care data is needed to provide a better evidence base for government policy and for decision making by providers, care recipients and their families.

It is evident that my research may be timely and opportunities to improve the delivery of end of life care in the aged care sector may exist as we move forward to meet the needs of this growing group in our community.


(2004b) Review of Pricing Arrangements in Residential Aged Care [Internet] Available from: 

(2006) Resident Classification Scale – December 2006. [Internet] Available from: 


(2008) Aged Care Access Initiative Program Guidelines. [Internet] Available from: 

(2009) National Respite for Carers Program [Internet] Available from: 


(2007b) Older Australia at a glance. (4th Ed.). (Cat. no. AGE 52.). Canberra: AIHW.


Harris, K., Li, K., Flynn, C.& Chow, E. (2007) Worst, average or current pain: Which should be used to calculate the response to palliative radiotherapy in patients with bone metastasis? *Clinical Oncology (Royal College of Radiologists)* 19, (7), 523-527.


Hockley, J. (1993) Rehabilitation in Palliative Care- Are We asking the Impossible. Palliative Medicine, 7, (Supplement 1), 277-286.


APPENDIX 1:

Copy of the University of Sydney Human Research Ethics Committee approval
25 March 2008

Dr Heather McKenzie
Faculty of Nursing and Midwifery
Mallett Street Campus – M92
The University of Sydney

Dear Dr McKenzie

I am pleased to inform you that the Human Research Ethics Committee (HREC) at its meeting on 19 February 2008 ratified your approved protocol entitled "A palliative approach for people with declining health, living in hostel accommodation: the status of play".

Details of the approval are as follows:

Ref No.: 12-2007/10644
Approval Period: December 2007 to December 2008
Authorised Personnel:
- Dr Heather McKenzie
- Ms Peta McVey
- Professor Kathryn White
- Dr Sue Ronaldson
- Associate Professor Sue Kurle

The HREC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans—March 2007 under Section A.1.29.

The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

Chief Investigator / Supervisor’s responsibilities to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC as soon as possible.

2. All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
(3) The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before commencement of the research project. These include:

- If any of the investigators change or leave the University.
- Any changes to the Participant Information Statement and/or Consent Form.

(4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contact details for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement: Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4871 (Telephonic); (02) 9351 8766 (Facsimile) or infoethics@unsw.edu.au (Email).

(5) Copies of all signed Consent Forms must be retained and made available to the HREC on request.

(6) It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

(7) The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

(8) A report and a copy of any published material should be provided at the completion of the project.

Yours sincerely,

[Signature]

Professor D I Cook
Chairman
Human Research Ethics Committee

cc: Ms Paula McVey, Clinical Nurse Consultant - Palliative Care, Nossal Hospital, P O Box 42,
Wellwong NSW 2670
APPENDIX 2:

Copy of the research project - general information for aged care staff
RESEARCH STUDY: ‘A PALLIATIVE APPROACH FOR PEOPLE WITH DECLINING HEALTH, LIVING IN HOSTEL ACCOMMODATION: THE STATE OF PLAY’
A collaboration between The Faculty of Nursing & Midwifery, University of Sydney, RSL LifeCare and McLean Memorial Retirement Village.

Your organisation has agreed to take part in a research study examining the use of a palliative approach to care among residents with high level care needs living in hostel accommodation. The research will explore the experiences of registered nurses, managers and care assistants who are caring for high-level care residents with chronic life-limiting illnesses living in hostel accommodation. The research will describe the medical illnesses, co-morbidities, demographics and symptoms experienced by high level care residents in low level residential care settings, and how these residents would like their care to be managed in the future. This study is the first of its type to map the residential group receiving high level care in low level care facilities.
The study is being conducted by Peta McVey, RN, as part of the degree of Doctor of Philosophy at the University of Sydney under the supervision of Dr Heather McKenzie, Senior Lecturer, the Faculty of Nursing and Midwifery.

The research team is keen for this project to be conducted in a collaborative model and is committed to providing the participating organization with opportunity to be actively involved in the research and to utilize the research findings in their future planning.

Your participation in this project will vary depending on your role.

For **hostel coordinators/managers** the research will involve:

- Each hostel coordinator / manager and myself working together to complete a questionnaire about organizational information (staffing levels and ratios; use of agency staff; number of high level resident transfers in the past six months and policies and procedures),
- Each hostel coordinator/ manager identifying the high-level residents in their hostels,
- Being asked to participate in an interview focusing on exploring their understanding of a palliative approach, sharing experiences of caring for a high level resident with declining health, identification of strategies used to enable the resident to die in the facility and staff educational needs. Interviews will be held at a time convenient to participants, and are estimated to take 45 minutes to one hour.

For **aged care RN / ENs** the research will involve:

- Providing information sheets to these high level residents, or, where appropriate, their guardians,
- Being asked to participate in an interview with me at time convenient to them. These interviews are estimated to take 45 minutes to one hour, and they will focus on exploring their understanding and experiences of a palliative approach for high level care residents with declining health living in hostel accommodation.

For **PCAs or carers** the research will involve:

- Being asked to participate in a focus group at time convenient to them. This activity is estimated to take 45 minutes to one hour. It will focus on exploring their
understandings of a palliative approach and experiences of caring for a high level resident with declining health.

For **hostel high-level care residents** the research will involve:

- An approach by me to those residents who have expressed an interest in being involved in the research, to explain the project in more detail and seek their consent,
- Accessing (once consent has been obtained) participant resident medical files to collect required demographic and medical data. This part of the work will be my responsibility, but I will need an appropriate staff member to provide me with access to the files.
- Assisting the resident to complete the POS (Patient Outcome Scale) and ESAS (Edmonton Symptom Assessment Scale) on one occasion only, which is estimated to take a total of 20 minutes. This is my responsibility but I will need to seek permission from the relevant coordinator / manager to approach each resident on that day.

The findings from this research will be made available to the participating organisation, and also disseminated more widely through presentations to appropriate conferences and meetings, and publication in appropriate journals.

Peta McVey
PhD Student- The University of Sydney
Contact: 0438 883 532
Email: pmcv0608@usyd.edu.au
APPENDIX 3:

Copy of the recruitment flyers for aged care staff
Care Assistants & Personal Care Workers

Do you want to talk about the care you give to high level care residents?

If you have cared for a resident who was classified as high level care in the past year, Peta McVey would welcome the opportunity to talk to you. Peta, who is a PhD student at the University of Sydney, has worked in palliative care for over twenty years. For her PhD, Peta is exploring the experiences and perceptions of a palliative approach with assistants in nursing / personal care workers for residents who are high level care in hostel settings.

To date there is no known studies in Australia about the experience or perceptions of caring for elderly people in declining health living in hostel accommodation. By discussing your experiences it is hoped we can learn more about the residents care needs and your role. Focus groups with 4 to 6 care assistants will be held at your institution at a suitable time. The focus groups will be taped, but will be kept confidential so that you cannot be identified. The focus group would take about one hour of your time. If you are interested in participating in this study please contact:

Peta McVey
Phone: 0438 883 532
or
(02) 9874 3802
Registered Nurses, Enrolled Nurses & Managers

Do you want to talk about the care you give to high level care residents?

If you have cared for a high level resident in the past year whose condition has deteriorated, Peta McVey would welcome the opportunity to talk to you. Peta, who is a PhD student at the University of Sydney, has worked in palliative care for over twenty years. For her PhD thesis, Peta is exploring the experiences and perceptions of a palliative approach with aged care staff caring for residents in hostels who are classified as “high level care”.

To date there are no known studies in Australia about the experience and perceptions of a palliative approach for residents in hostel accommodation. By discussing your experience it is hoped we can learn more about the residents care needs and your role. The interviews will be taped, but will be kept confidential so that you cannot be identified. The interview would take about one hour of your time.

If you are interested in participating in this study please contact:

Peta McVey RN
Phone: 0438 883 532
or
(02) 9874 3802

The University of Sydney
APPENDIX 4:

Copy of participant Information Sheets
RESEARCH STUDY: ‘A PALLIATIVE APPROACH FOR PEOPLE WITH DECLINING HEALTH LIVING IN HOSTEL ACCOMMODATION: THE STATE OF PLAY’

PARTICIPANT INFORMATION STATEMENT- (resident)

You are invited to take part in a research study examining the use of a palliative approach to care among residents with high level care needs. The object of the study is to describe and map the experiences of high level care residents living in low level care facilities. This information will help us learn more about the needs of residents in similar circumstances and help identify any gaps in care or education needs for aged care staff. To date, no studies of this kind have been done focusing on this group of people in hostels in Australia.

The study is being conducted by Peta McVey, RN and will form the basis for the degree of Doctor of Philosophy at the University of Sydney under the supervision of Dr Heather McKenzie, Lecturer, The Faculty of Nursing and Midwifery.

If you agree to participate in this study, you will be asked to complete two questionnaires about any symptoms you may have and your perception of your care. The researcher will read the questions to you and circle your responses on the form. At the completion of the questionnaires, the researcher will ask one question “Is there anything else you would like to tell me about your health or how you would like your care to be managed in the future?”. The researcher will also seek your permission to
collect demographic data from you medical record in relation to gender, age, current
major health problem, concurrent health problems, previous residence prior to hostel,
martial status and length of time in the hostel. This information will be de-identified at
the time of data collection.

The two questionnaires have 10-12 questions each and take approximately 10
minutes to complete. You will be free to choose the time and location within the
facility to complete these questionnaires.

Participation in this study is entirely voluntary: you are not obliged to participate and -
if you do participate - you can withdraw at any time. Whatever your decision, it will not
affect your medical treatment or your relationship with hostel staff.

All aspects of the study, including results, will be strictly confidential and only the
investigator's name above and Dr McKenzie (supervisor) will have access to
information on participants, unless required by law. A report of the study may be
submitted for publication, but individual participants will not be identifiable in such a
report.

While we intend that this research study will further medical knowledge and improve
access to optimal palliative care in the future, it may not be of direct benefit to you.

When you have read this information, Peta McVey will discuss it with you further and
answer any questions you may have. If you would like to know more at any stage,
please feel free to contact Peta McVey on 0438 883 532 or (02) 9488 2200 or Dr
Heather McKenzie on 9351 0546. This information sheet is for you to keep.

| Any person with concerns or complaints about the conduct of a research study
| can contact the Senior Ethics Officer, Ethics Administration, University of
| Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or
| qbriody@usyd.edu.au (Email). |
GUARDIAN INFORMATION STATEMENT

Title of project: A palliative approach for people with declining health, living in hostel accommodation: the state of play.

We would like to invite______________________ to participate in a study of people with declining health living in hostel accommodation. We hope to learn more about the needs of residents in similar circumstances and contribute to the identification of any gaps in resident care or education needs of aged care staff. To date, there have been no studies of this kind done focusing on this group of people living in hostels within Australia. ___________________ is selected as a possible participant in this study because he / she meets the criteria of being classified as requiring high level care.

As you are currently the legal guardian of _________________ we seek your consent to permit __________________ to participate in this study. If you decide to permit _________________ to participate, we will ask you to fill in two questionnaires about any symptoms _________________ might be experiencing and their perception of their own well-being. The questionnaires have 10-12 questions and it should take approximately 15 minutes to complete them both. At the completion of the questionnaires, the researcher will ask you a single question “Is there anything else you would lie to tell me about _________________ health or
how you think he/she would like their care to be managed in the future?” The researcher will also ask your permission to collect demographic data from _______________ medical record in relation to her / his gender, age, current major health problem, concurrent health problems, previous residence prior to hostel, martial status and length of time in the hostel.

We cannot and do not guarantee or promise that _________________ will receive any benefits from the study. However, indirectly, resident participants may experience a sense of purpose from their involvement in a study designed to contribute to the development of future education programs for nurses and possible strategies to improve care for other residents in the future.

Every effort will be made to maintain confidentiality in relation to any information that is obtained in connection with this study and that can be identified with you or ________________. We plan to publish the results of this study as part of the investigator’s PhD thesis and through appropriate health care journals. In any publication, information will be presented in such a way that you or ________________ will not be able to be identified.

Your decision whether or not to permit _______________ to participate will not prejudice you or _________________ future relations with the aged care facility. If you decide to permit _________________ to participate, you are free to withdraw your consent and to discontinue _________________ participation at any time without prejudice.

We would be pleased to answer any further questions you have about this project. For further information please contact Peta McVey on 0438 883 532 or (02) 9488 2200 or Dr Heather McKenzie on 9351 0546.

You will be given a copy of this form to keep.
Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@usyd.edu.au (Email).
RESEARCH STUDY: “A PALLIATIVE APPROACH FOR PEOPLE WITH DECLINING HEALTH, LIVING IN HOSTEL ACCOMMODATION: THE STATE OF PLAY”

PARTICIPANT INFORMATION STATEMENT- (staff)

You are invited to take part in a research study examining the use of a palliative approach to care among residents with high level care needs. The research will explore the experiences of registered nurses, managers and care assistants who are caring for residents with chronic life-limiting illnesses living in hostel accommodation.

The study is being conducted by Peta McVey, RN as part of the degree of Doctor of Philosophy at the University of Sydney under the supervision of Dr Heather McKenzie, Senior Lecturer, the Faculty of Nursing and Midwifery.

If you agree to participate in this study, you will be asked to participate in an audio-recorded interview to discuss your experience of caring for high level care residents. You will be invited to participate in an interview at a time and location of your choice for approximately one hour on a single occasion.
All aspects of the study, including results, will be kept strictly confidential and only the investigator’s name above and Dr McKenzie (supervisor) will have access to information about participants, unless required by law. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time. Whatever your decision, it will not affect your medical treatment or your relationship with medical staff.

While we intend that this research study furthers medical knowledge and improve access to optimal palliative care in the future, it may not be of direct benefit to you.

When you have read this information, Peta McVey will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Peta McVey on 0438 883 532 or (02) 9488 2200 or Dr Heather McKenzie on 9351 0546. This information sheet is for you to keep.

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gбриody@usyd.edu.au (Email).
APPENDIX 5:

Copy of participant Consent Forms
RESIDENT PARTICIPANT CONSENT FORM

Title of Study: A palliative approach for people with declining health, living in hostel accommodation: the state of play.

I, ........................................................................................................................................................................
[name]

have read and understood the information for participants on the above named research study and have discussed it with the researcher/s.

I am aware of the procedures involved in the study, including any inconvenience, risk or discomfort and of their implications.

I freely choose to participate in this study and understand that I can withdraw without compromise at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

I agree to the researcher accessing my medical record.

Signature: ................................................................................................................................................................

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

Date: ................................................................................................................................................................
GUARDIAN CONSENT FORM

Title of project: A palliative approach for people with declining health, living in hostel accommodation: the state of play.

1. I,.................................................agree to permit.................................................... to participate in the above study, the details of which are described in the Guardian Information Statement attached to this form.

2. I acknowledge that I have read the Information Statement, which explains the aims and the nature of the study and the statement has been explained to me to my satisfaction.

3. Before signing this Consent Form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm that ......................... might suffer as a result of participation and I have received satisfactory answers.

4. I understand that I can withdraw .........................from the study at any time without prejudice to my or ......................... relationship with the University and the aged care facility of which he / she resides.

5. I agree that research data gathered from the results of the study may be published provided that neither ......................... nor I can be identified.
6. I understand that if I have any questions relating to participation in this research, I may contact Peta McVey on telephone 0438 883 532 or (02) 9488 2200 or Dr Heather McKenzie on telephone (02) 9351 0546, who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Information Sheet.

..................................................
Signature of Guardian

..................................................
Please PRINT name

..................................................
Date
AGED CARE STAFF PARTICIPANT CONSENT FORM

Title of Study: A palliative approach for people with declining health, living in hostel accommodation: the state of play.

I, ...............................................................................................................................................................................
[name]

have read and understood the information for participants on the above named research study and have discussed it with the researcher/s.

I am aware of the procedures involved in the study, including any inconvenience, risk or discomfort and of their implications.

I freely choose to participate in this study and understand that I can withdraw without compromise at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

Signature: ..........................................................................................................................................................

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

Date: .............................................................................................................................................................
APPENDIX 6:

Copy of the medical record audit data sheet
MEDICAL RECORD AUDIT DATA FORM  Date ______ Site & ID ______

(High level care resident)

DEMOGRAPHIC DETAILS (obtained from medical file & completed by researcher)

1. Gender
   □ Female  □ Male

2. Age ______ yrs

3. Marital Status
   □ Never married  □ Married/Defacto  □ Widowed  □ Separated/Divorced
   □ Other

4. Country of Birth and language spoken________________________

5. Cultural Background________________________

6. Living status before admission to hostel
   □ Alone  □ Living with Partner  □ Living with child
   □ Living with other family  □ Living with friend

7. Carer / support prior to entry to hostel.
   Children ___________________________ Other family _________________________
   Friend ___________________________ Neighbour ___________________________
   Other: ___________________________

8. Previous accommodation before hostel
   □ House  □ Unit  □ Self care unit in retirement village  □ Other__________________
9. Length of time in hostel ________________ mths

10. Length of time in hostel as “high level care” resident ________________ mths

11. Current major health problem

☐ Cancer  ☐ Metastatic disease  ☐ Breast  ☐ Prostate

☐ Gastrointestinal  ☐ UPI  ☐ Lung  ☐ Gynaecological

☐ Urological  ☐ Haematological  ☐ Other______________

☐ Non-malignant disease

☐ Cardiac  ☐ Respiratory  ☐ Renal

☐ Neurological/Cognitive impairment______________  ☐ Other________

12. Concurrent health problem

☐ Cardiac  ☐ Arthritis  ☐ Cognitive impairment  ☐ Neurological condition

☐ Chronic Lung disease  ☐ Other________________________
### Functional Status (Barthel ADL Index)

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FEEDING</strong></td>
<td></td>
</tr>
<tr>
<td>0 = unable</td>
<td></td>
</tr>
<tr>
<td>5 = needs help eating, spreading butter, etc., or requires modified diet</td>
<td></td>
</tr>
<tr>
<td>10 = independent</td>
<td></td>
</tr>
<tr>
<td><strong>BATHING</strong></td>
<td></td>
</tr>
<tr>
<td>0 = dependent</td>
<td></td>
</tr>
<tr>
<td>5 = independent (or in shower)</td>
<td></td>
</tr>
<tr>
<td><strong>GROOMING</strong></td>
<td></td>
</tr>
<tr>
<td>0 = needs help with personal care</td>
<td></td>
</tr>
<tr>
<td>5 = independent (face/hair/teeth/shaving (implements provided))</td>
<td></td>
</tr>
<tr>
<td><strong>DRESSING</strong></td>
<td></td>
</tr>
<tr>
<td>0 = dependent</td>
<td></td>
</tr>
<tr>
<td>5 = needs help but can do about half unaided</td>
<td></td>
</tr>
<tr>
<td>10 = independent (including buttons, zips, laces, etc.)</td>
<td></td>
</tr>
<tr>
<td><strong>BOWELS</strong></td>
<td></td>
</tr>
<tr>
<td>0 = incontinent (or needs to be given enemas)</td>
<td></td>
</tr>
<tr>
<td>5 = occasional accident</td>
<td></td>
</tr>
<tr>
<td>10 = continent</td>
<td></td>
</tr>
<tr>
<td><strong>BLADDER</strong></td>
<td></td>
</tr>
<tr>
<td>0 = incontinent, or catheterized and unable to manage alone</td>
<td></td>
</tr>
<tr>
<td>5 = occasional accident</td>
<td></td>
</tr>
<tr>
<td>10 = continent</td>
<td></td>
</tr>
<tr>
<td><strong>TOILET USE</strong></td>
<td></td>
</tr>
<tr>
<td>0 = dependent</td>
<td></td>
</tr>
<tr>
<td>5 = needs some help, but can do something alone</td>
<td></td>
</tr>
<tr>
<td>10 = independent (on and off, dressing, wiping)</td>
<td></td>
</tr>
<tr>
<td><strong>TRANSFERS (BED TO CHAIR AND BACK)</strong></td>
<td></td>
</tr>
<tr>
<td>0 = unable, no sitting balance</td>
<td></td>
</tr>
<tr>
<td>5 = major help (one or two people, physical), can sit</td>
<td></td>
</tr>
<tr>
<td>10 = minor help (verbal or physical)</td>
<td></td>
</tr>
<tr>
<td>15 = independent</td>
<td></td>
</tr>
<tr>
<td><strong>MOBILITY (ON LEVEL SURFACES)</strong></td>
<td></td>
</tr>
<tr>
<td>0 = immobile or &lt; 50 yards</td>
<td></td>
</tr>
<tr>
<td>5 = wheelchair independent, including corners, &gt; 50 yards</td>
<td></td>
</tr>
</tbody>
</table>
MEDICAL RECORD AUDIT DATA FORM

Date __________ Site & ID __________

10 = walks with help of one person (verbal or physical) > 50 yards
15 = independent (but may use any aid; for example, sticks) > 50 yards

STAIRS
0 = unable
5 = needs help (verbal, physical, carrying aid)
10 = independent

TOTAL (0–100): __________

APPENDIX 7:

Copy of the Edmonton Symptom Assessment System (ESAS)
## Edmonton Symptom Assessment System (ESAS)

*Please circle the number that best describes:*

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Worst possible pain</td>
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<tr>
<td>No tired</td>
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<tr>
<td>Worst possible tiredness</td>
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<td></td>
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<tr>
<td>Not nauseated</td>
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<tr>
<td>Worst possible nausea</td>
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<td></td>
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<tr>
<td>Not depressed</td>
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<tr>
<td>Worst possible depression</td>
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<tr>
<td>Not anxious</td>
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<tr>
<td>Worst possible anxiety</td>
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<tr>
<td>Not drowsy</td>
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<tr>
<td>Worst possible drowsiness</td>
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<tr>
<td>Best appetite</td>
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<td>Worst possible appetite</td>
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<tr>
<td>Best feeling of wellbeing</td>
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<tr>
<td>Worst feeling of wellbeing</td>
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<tr>
<td>No shortness of breath</td>
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<tr>
<td>Worst feeling of shortness of breath</td>
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</tr>
<tr>
<td>Other problem</td>
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<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

ESAS completed by:

- [ ] Resident
- [ ] Family
- [ ] Researcher
APPENDIX 8:

Copy of the Patient Outcome Score (POS, V2)
Patient ID_________________ Date: ______________

**Patient Outcome Scale**

PATIENT QUESTIONNAIRE

Please answer the following questions by ticking the box next to the answer which is most true for you. Your answers will help us to keep improving your care and the care of others. Thank you.

**1. Over the past 7 days, have you been affected by pain?**

   -   ☐ 0 Not at all, no effect
   -   ☐ 1 Slightly - but not bothered to be rid of it
   -   ☐ 2 Moderately - pain limits some activity
   -   ☐ 3 Severely - activities or concentration markedly affected
   -   ☐ 4 Overwhelmingly - unable to think of anything else

**2. Over the past 7 days, have other symptoms e.g. feeling sick, having a cough, or constipation been affecting how you feel?**

   -   ☐ 0 No, not at all.
   -   ☐ 1 Slightly
   -   ☐ 2 Moderately
   -   ☐ 3 Severely
   -   ☐ 4 Overwhelmingly

**3. Over the past 7 days, have you been feeling anxious or worried about your illness or treatment?**

   -   ☐ 0 No, not at all.
   -   ☐ 1 Occasionally
   -   ☐ 2 Sometimes - affects my concentration
   -   ☐ 3 Most of the time – often affects my concentration
   -   ☐ 4 Can't think of anything else – completely preoccupied by worry and anxiety

**4. Over the past 7 days, have any of your family and friends been anxious or worried about you?**

   -   ☐ 0 No, not at all.
   -   ☐ 1 Slightly
   -   ☐ 2 Moderately
3. Severely
4. Overwhelmingly

5. Over the past 7 days, how much information have you or your family or friends been given?
   0. Full information – always feel free to ask what I want
   1. Information given but hard to understand
   2. Information given on request but would have liked more
   3. Very little given and some questions avoided
   4. None at all

6. Over the past 7 days, have you been able to share how you were feeling with your family or friends?
   0. Yes, as much as I wanted to
   1. Most of the time
   2. Sometimes
   3. Occasionally
   4. Not at all with anyone

7. Over the past 7 days, have you been feeling depressed?
   0. No, not at all
   1. Occasionally
   2. Sometimes
   3. Most of the time
   4. Yes, definitely

8. Over the past 7 days, have you felt good about yourself as a person?
   0. Yes, all the time
   1. Most of the time
   2. Sometimes
   3. Occasionally
   4. No, not at all
9. Over the past 7 days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for appointments or repeating tests?

☐ 0  None at all
☐ 2  Up to half a day wasted
☐ 4  More than half a day wasted

10. Over the past 7 days, have any practical matters resulting from your illness, either financial or personal, been addressed?

☐ 0  Practical problems have been addressed and my affairs are as up to date as I would like
☐ 2  Practical problems are in the process of being addressed
☐ 4  Practical problems exist which were not addressed
☐ 0  I have no practical problems

11. In any, what have been your main problems in past 7 days?

1. ........................................................................................................................................
2. ........................................................................................................................................

12. How did you complete this questionnaire?

☐ 0  On my own
☐ 1  With help of a friend or family
☐ 2  With help from the researcher

Is there anything else you would like to tell me about your health or how you would like your care to be managed in the future?

POS, Version 2 (Higginson, I. 1998)
APPENDIX 9:

Copy of the POS v2 approval letter
13 September 2007

Ms Pat McVey
134 Federal Road
West Ryde
N.S.W. 2114
AUSTRALIA

Dear Ms McVey,

Re: POS User Guide

Please find enclosed a copy of the POS User Guide as requested.

I hope you find it useful. Please do not hesitate to contact the POS Development Team if you have any queries.

Yours sincerely,

[Signature]

Sarah Beber
Executive Assistant to Professor Irene Higginson

www.kcl.ac.uk
APPENDIX 10:

Copy of the organisational and managerial data form
Organisational & Managerial Data Sheet  *(to be completed by researcher)*

1. Policies

- Palliative care
- Advance care planning
- Family conferences/ multidisciplinary
- Support/counseling for patient’s
- Support/counseling for staff
- Guidelines for death in RACF
- Medication reviews by pharmacist
- Contact details for local Pal. Care Service
- After-hours medical cover
- Symptom assessments
- Care plans / documentation
- Falls-related injuries
- Restraint free
- Use of S/C fluids
- Use of complementary therapies
- Referral to specialist services (speech pathologist, dietician)
- Bereavement support
- Cultural diversity/ issues
- Volunteer support
- Enduring Power of Attorney
- Skin integrity
- Wound management
- Use of Syringe Drivers
- Use of S/C medications

2. Guidelines (procedures) relating to:

- Bowel management / enemas
- S/C fluid administration
- Use of s/c needles
- Use of Syringe Drivers
- Mouth care/ assessments
- Safe feeding techniques
- TENs machines
- PEG feeding
- Use of alternating pressure mattresses
- Wound management
- Use of Syringe drivers
- How to refer to the local Palliative care service
3. **Resources / Education**

- Copy of Guidelines for palliative approach, where is it kept
- Relevant Books
- Palliative Care brochure
- Advance Care Planning brochures
- Internet access
- Information about local P.C. Service
- In-services re Palliative Care
- Display of upcoming conferences about palliative care topics / end of life
- Further education details re Palliative Care courses (Area Health, University, College of Nursing)

- Additional

**MANAGERIAL DATA**- (to be completed in conjunction with researcher)

**Staffing** *(numbers)*

- Number of RNs
- Number of EENs
- Number of ENs
- Number of AINs
- Number of care assistants
- Other (specify)
**Staffing Ratio (numbers)**

<table>
<thead>
<tr>
<th>Shift</th>
<th>RN</th>
<th>EEN</th>
<th>EN</th>
<th>AIN</th>
<th>Care Assistants</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Morning Shift</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td><strong>Afternoon Shift</strong></td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td><strong>Night Shift</strong></td>
<td>13</td>
<td>14</td>
<td>15</td>
<td>16</td>
<td>17</td>
<td>18</td>
</tr>
</tbody>
</table>

**Use of Agency staff**

Average number per month

**Use of casual staff**

Average per month

4. **How many high-level residents over the past six months have required a hospital admission or emergency department visits (circle)**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>&gt; 10 admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

5. **Reason for hospital / emergency visit (numbers)**

- Pneumonia
- Renal failure
- Electrolyte & fluid balance disorder (dehydration)
- Cachexia (not eating+ drinking)
- Heart failure
- Septicemia
- Stroke
- Symptom management
- Other
- Unknown

Unknown
APPENDIX 11:

Copy of the general hostel information sheet & resident profile
## RACF - Hostel Information and Resident Profile

**Site & ID**

**Date**

(to be completed by researcher)

1. **Geographical population serviced**
   
   - < 200,000
   - 201,000 - 300,000
   - 301,000 - 400,000
   - 401,000

2. **Age distribution of geographical region**
   
   - 60 years
   - 75 - 84 yrs
   - 85

3. **Number of hostels associated with RACF**

4. **Number of beds associated with hostel**

   - Hostel 1: _______ beds
   - Hostel 2: _______ beds
   - Hostel 3: _______ beds
   - Hostel 4: _______ beds
   - Hostel 5: _______ beds
   - Hostel 6: _______ beds
   - Hostel 7: _______ beds
   - Hostel 8: _______ beds

### SEPARATIONS for 2006:

5. **Total hostel separations for 2006**

   - Hostel 1: _______
   - Hostel 2: _______
   - Hostel 3: _______
   - Hostel 4: _______
   - Hostel 5: _______
   - Hostel 6: _______
   - Hostel 7: _______
   - Hostel 8: _______

6. **Number of patients who died in the hostel during 2006**

   - Hostel 1: _______
   - Hostel 2: _______
   - Hostel 3: _______
   - Hostel 4: _______
   - Hostel 5: _______
   - Hostel 6: _______
   - Hostel 7: _______
   - Hostel 8: _______
RACF - HOSTEL INFORMATION AND RESIDENT PROFILE

Site & ID ___________________ Date ___________________

7. Number of patients transferred to other settings and did not return

Hostel 1 ____________ Hostel 2 ____________ Hostel 3 ____________
Hostel 4 ____________ Hostel 5 ____________ Hostel 6 ____________
Hostel 7 ____________ Hostel 8 ____________

SPECIFIC HIGH LEVEL CARE

8. Number of residents classified as “high level” (1-4 RSCS) in hostel

Hostel 1 ____________ Hostel 2 ____________ Hostel 3 ____________
Hostel 4 ____________ Hostel 5 ____________ Hostel 6 ____________
Hostel 7 ____________ Hostel 8 ____________

9. Gender ratio of high level patients (numbers)

Hostel 1: Female ________ Male ________
Hostel 2: Female ________ Male ________
Hostel 3: Female ________ Male ________
Hostel 4: Female ________ Male ________
Hostel 5: Female ________ Male ________
Hostel 6: Female ________ Male ________
Hostel 7: Female ________ Male ________
Hostel 8: Female ________ Male ________
RACF - HOSTEL INFORMATION AND RESIDENT PROFILE

Site & ID ___________________________ Date ________________

10. Age grouping of high level residents (max 80)

Hostel 1:

<table>
<thead>
<tr>
<th>≤ 60 yrs</th>
<th>61 – 70 yrs</th>
<th>71– 80 yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Hostel 2:

<table>
<thead>
<tr>
<th>≤ 60 yrs</th>
<th>61 – 70 yrs</th>
<th>71– 80 yrs</th>
</tr>
</thead>
<tbody>
<tr>
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Hostel 3:

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Hostel 4:

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APPENDIX 12:

Copy of the participant interview questions
Personal Care Assistants –
Semi-structured interview questions

Tell me, what is your understanding of a palliative approach?

Tell me, how would you know that a resident would need / benefit from a palliative approach to their care?

What would indicate to you that a resident is deteriorating and would need / benefit from a palliative approach to their care?

How easy or difficult do you think it is to make this judgment?

In your opinion, how appropriate is it for high-level care residents to remain in low level care facilities until they die if that is their wish?

Tell me about one resident you have looked after in the final stages of their life?

What are some of the strategies you have used that have worked well?

What are some that were not so good?
Manager / Registered Nurse -

Semi-structured interview questions.

Tell me, what is your understanding of a palliative approach?

What would indicate to you that a particular resident would need / benefit from a palliative approach to their care?

How easy or difficult do you think it is to make this judgment? What are you looking for?

Tell me, how would you go about discussing this with the resident’s family / carer?

Can you think of an example of a resident who has died here and were you able to implement a palliative approach?

When a resident has died in the hostel, what strategies have been used to help the staff and other residents with the loss of that resident?

Under what circumstances would you decide to transfer a resident to hospital?

In your opinion, how appropriate is it for high level care residents to remain in low level care facilities until they die if that is their wish?

What do you consider to be the staff’s education needs?
APPENDIX 13:

Copy of the early coding process for resident / person responsible interview data
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## Development of resident / person responsible themes

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<th>Fluctuating Health</th>
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<td>• declining associated with part of ageing rather than diagnosis</td>
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<td></td>
<td>• good compared to other residents</td>
</tr>
<tr>
<td></td>
<td>• good related to past health</td>
</tr>
<tr>
<td></td>
<td>• recognition of decline or unable to manage alone at home = reason for move to hostel</td>
</tr>
<tr>
<td></td>
<td>• recognition of burden / stress on family due to decline = reason for admission</td>
</tr>
<tr>
<td></td>
<td>• unsure of need for admission = take medical advice &amp; feel relieved for the decision process is taken out of their hands</td>
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<tr>
<td></td>
<td>• previous experience as respite makes the move easier</td>
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<td></td>
<td>• recognition that admission to hostel = place where they will stay till they die</td>
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<th>- become a recipient of care</th>
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<td>• lack of choice about where care is provided and how care is provided v care needs discussed</td>
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<td></td>
<td>• ?no other options</td>
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<tr>
<td></td>
<td>• loss of control &amp; independence – try to maintain independence</td>
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<td></td>
<td>• need to learn the rules and regulations- regimented</td>
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<tr>
<td></td>
<td>• not only residents but family need to adjust</td>
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<tr>
<td></td>
<td>• indifference to care provided</td>
</tr>
<tr>
<td></td>
<td>• building relationships important to creating community – encourages belonging, purpose</td>
</tr>
<tr>
<td></td>
<td>• difficult if residents have cognition problems or “ill”</td>
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<tr>
<td></td>
<td>• residents become surrogate carers – help with feeding, monitor medications</td>
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<tr>
<td></td>
<td>• staff supportive of family – create networks for new &amp;</td>
</tr>
<tr>
<td>old family members</td>
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<td>---------------------</td>
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<td>• homelike atmosphere vs not homelike</td>
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<td>• the ability to have homelike objects in room (chair, pictures hung up) vs removal of such items for OH&amp;S reasons</td>
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<td>• freedom to roam around into the manager office</td>
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<tr>
<td>• relationships with other residents and family</td>
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<tr>
<td>• social activities and services better than home</td>
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<tr>
<td>• institutionalised – lack of control, independence &amp; choice (food)</td>
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<tr>
<td>• separation from spouse</td>
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<td>• positive relationships enhance the perception of care</td>
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<td>• individuellised care</td>
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<td>• staff know the resident well, attentive to needs</td>
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<tr>
<td>• care is compromised by staffing levels and use of agency / casual staff</td>
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<tr>
<td>• recognition that PCAs need more supervision</td>
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<td>• cultural differences noted more abrupt &amp; difficult to understand</td>
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<table>
<thead>
<tr>
<th>Moving up the chain ?? Stepping up to the next level ?Uncertainty</th>
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<tr>
<td>• stepping up to next level as deterioration occurs is commonly understood Vs can remain till you die</td>
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<tr>
<td>• reinforced by when other residents move on and missing in dining room Vs seeing frail ill residents in lounge room</td>
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<tr>
<td>• some not concerned about moving – care may be better?</td>
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<td>• unsure of what happens when you deteriorate / uncertain, something they had not yet considered</td>
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<tr>
<td>• hopeful of remaining in hostel – don’t want to be removed from familiar surroundings, familiar staff or from spouse</td>
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<td>• fear of the nursing home = end of life, surrounded by sick people, death, or would give up on life symbolised the eventual outcome of their struggle</td>
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APPENDIX 14:

Copy of final themes for resident / person responsible interview data
**Final codes for Residents/ Person Responsible**

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<td>• Why am I here?</td>
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<td>• Adjusting to life in a hostel</td>
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<td>• Being ‘cared for’</td>
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APPENDIX 15:

Copy of the early coding process of aged care staff interview data
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Developing early aged care themes

| Multidimensional Care | Above and Beyond *(Provision of care)* (extending oneself, extra care, special, lateral thinking)  
Watching over  – (Increased monitoring, regular checking)  
Knowing the resident  
Commitment to the resident (Getting involved, requires staff commitment to the resident- Sharing care between staff)  
- Relationships impact on residents who stay for EoL care  
- Staff get involved with residents & families – become a family  
Collaborating decision processes  
- Point of transfer  
- Safety issues for the resident are considered, clinical markers need to be identified  
  - Provision of Eol care influenced by staff numbers and resident & family wishes  
Communicating  
- informing others of resident changes, keeping families involved, guiding the family in decisions  
- identification of appropriate residents  
- supporting the ‘family’ after death  
Rewarding  
- Family gratitude  
- Emotional satisfaction  
| Facing Challenges | Environmental issues  
- hostel design,  
- use of specialised equipment in rooms  
Staffing levels  
- Workloads – RN & PCA pressures  
- Skill mix  
External pressures  
- Families  
- Acute hospitals  
Dealing with death |
| Recognition for the ‘need for change’ | • Recognition and acknowledgment of the impact of aged care policy  
| | • staying longer in community before entry into RACFs due to community packages  
| | • Future needs - baby boomers  
| | • Rising dependency levels  
| | • Significant increase in HLC resident numbers |
APPENDIX 16

Copy of final aged care staff interview data
## Final Codes for Aged Care Staff

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<tr>
<th>Major Theme</th>
<th>Sub- theme</th>
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<td>Creating a Community of Care</td>
<td>• Aged Care Staff’s Ethos of Care</td>
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<td>• Individualised care</td>
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<td>• Relationship centred</td>
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<tr>
<td></td>
<td>• Communication</td>
</tr>
<tr>
<td></td>
<td>• Collaboration and shared decision-making</td>
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<td></td>
<td>• Interconnected communities of care</td>
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<td>• Shared connections and values</td>
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<tr>
<td>Challenges identified by Aged Care Staff</td>
<td>• Low Staffing Numbers and Workload Issues</td>
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<td>• Pressures from Families and Acute Care Hospitals</td>
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<td>• Meeting the Resident’s A Needs with the Available Skill Mix</td>
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<td>• Infrastructure Challenges</td>
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<td>Emotional Consequences of End of Life Caring</td>
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<td>• Acknowledgement of residents/families fear of moving</td>
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APPENDIX 17:

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<td>Hypertension; osteoarthritis</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>46</td>
<td>Richard</td>
<td>89</td>
<td>M</td>
<td>CVA</td>
<td>IHD; AF; osteoarthritis; duodenal ulcer; gastric oesophageal reflux disease (GORD); gout; macular degeneration; anxiety; mild dementia</td>
<td>32</td>
<td>26</td>
</tr>
<tr>
<td>47</td>
<td>Matthew</td>
<td>87</td>
<td>M</td>
<td>Diabetes</td>
<td>Osteoarthritis; depression; anxiety; hypertension</td>
<td>25</td>
<td>12</td>
</tr>
<tr>
<td>48</td>
<td>Laura</td>
<td>87</td>
<td>F</td>
<td>CVA</td>
<td>NIDDM; Angina; aortic heart valve; macular degeneration</td>
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<tr>
<td>49</td>
<td>Christopher</td>
<td>89</td>
<td>M</td>
<td>Parkinson’s disease</td>
<td>Mild dementia; GORD; depression; Vitamin B12 deficiency; prostate cancer</td>
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<td>M</td>
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<td>51</td>
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<td>F</td>
<td>CAL</td>
<td>Osteoarthritis; hypertension; glaucoma; peripheral vascular disease; mild dementia</td>
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<tr>
<td>52</td>
<td>Brenda</td>
<td>85</td>
<td>F</td>
<td>Diabetes</td>
<td>CCF; arthritis</td>
<td>48</td>
<td>24</td>
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<tr>
<td>53</td>
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<td>F</td>
<td>Chronic renal failure</td>
<td>Arthritis; NIDDM</td>
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<tr>
<td>54</td>
<td>Charlotte</td>
<td>86</td>
<td>F</td>
<td>Cancer- unknown primary</td>
<td>Peripheral vascular disease; aortic stenosis</td>
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<tr>
<td>55</td>
<td>Jane</td>
<td>97</td>
<td>F</td>
<td>Cardiac issues</td>
<td>NIDDM; hypertension</td>
<td>9</td>
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<tr>
<td></td>
<td>Name</td>
<td>Age</td>
<td>Gender</td>
<td>Diagnosis</td>
<td>Additional Diagnoses</td>
<td>First Name</td>
<td>Last Name</td>
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<td>--------------------------------------------------------</td>
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<tr>
<td>56</td>
<td>Jack</td>
<td>92</td>
<td>M</td>
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<td>NIDDM; depression</td>
<td></td>
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<tr>
<td>57</td>
<td>Annette</td>
<td>100</td>
<td>F</td>
<td>Pagot’s disease</td>
<td>Osteoarthritis; crush fracture</td>
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<tr>
<td>58</td>
<td>George</td>
<td>81</td>
<td>M</td>
<td>Parkinson’s disease</td>
<td>Angina; osteoarthritis</td>
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</tr>
<tr>
<td>59</td>
<td>Geraldine</td>
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<td>F</td>
<td>Osteoarthritis</td>
<td>Blind; aortic aneurysm</td>
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<tr>
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<td>91</td>
<td>F</td>
<td>Osteoarthritis – chronic pain</td>
<td>Cardiac issues; diverticular disease</td>
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</tr>
<tr>
<td>61</td>
<td>Henrietta</td>
<td>78</td>
<td>F</td>
<td>CVA</td>
<td>Cardiac issues; arthritis</td>
<td></td>
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<tr>
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<td>Robert</td>
<td>89</td>
<td>M</td>
<td>Diabetes</td>
<td>Kyhosis, visual disturbances</td>
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<tr>
<td>63</td>
<td>Bettina</td>
<td>87</td>
<td>F</td>
<td>Mild dementia</td>
<td>Cardiac issues; arthritis, hypertension</td>
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<td>64</td>
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<td>85</td>
<td>M</td>
<td>Bipolar disorder</td>
<td>Cardiac issues; ETOH; Parkinson’s disease</td>
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<td>65</td>
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<td>81</td>
<td>F</td>
<td>Depression</td>
<td>Arthritis; mild dementia; CAL; Parkinson’s disease; myelodysplasia</td>
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<td>Sarah</td>
<td>95</td>
<td>F</td>
<td>Cardiac &amp; chronic renal failure</td>
<td>Arthritis; NIDDM</td>
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<td></td>
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<td>67</td>
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<td>85</td>
<td>F</td>
<td>Cardiac - NSTEMI</td>
<td>Osteoarthritis; NIDDM; Chronic constipation</td>
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<td>68</td>
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<td>CAL; osteoarthritis; Ca bowel; hypertension</td>
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<td>M</td>
<td>CVA</td>
<td>Cardiac issues</td>
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<td>F</td>
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<td>Osteoarthritis; NIDDM</td>
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<td>71</td>
<td>Sam</td>
<td>90</td>
<td>M</td>
<td>Cardiac- CCF &amp; IHD</td>
<td>CAL; depression</td>
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<td>72</td>
<td>F</td>
<td>Renal disease &amp; developmentally delayed</td>
<td>Osteoarthritis; celiac disease</td>
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<td>PR no.</td>
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<td>PR relationship to resident</td>
<td>Gender</td>
<td>Resident’s age</td>
<td>Resident’s diagnosis</td>
<td>Resident’s co-morbidities</td>
<td>Length of time in hostel (mths)</td>
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<tr>
<td>1</td>
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<td>husband</td>
<td>F</td>
<td>86</td>
<td>Dementia</td>
<td>Hypertension; reflux</td>
<td>41</td>
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<td>2</td>
<td>Jules</td>
<td>husband</td>
<td>F</td>
<td>88</td>
<td>Dementia</td>
<td>Cardiac; osteoarthritis; pain</td>
<td>18</td>
</tr>
<tr>
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<td>wife</td>
<td>M</td>
<td>87</td>
<td>Dementia</td>
<td>Paget’s disease</td>
<td>40</td>
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<tr>
<td>4</td>
<td>Pat</td>
<td>wife</td>
<td>M</td>
<td>81</td>
<td>Dementia</td>
<td>Arthritis; CAL</td>
<td>9</td>
</tr>
<tr>
<td>5</td>
<td>Pam</td>
<td>wife</td>
<td>M</td>
<td>86</td>
<td>Dementia</td>
<td>CAL</td>
<td>15</td>
</tr>
<tr>
<td>6</td>
<td>Melissa</td>
<td>daughter</td>
<td>M</td>
<td>88</td>
<td>Dementia</td>
<td>Osteoarthritis; prostate hypertrophy</td>
<td>35</td>
</tr>
<tr>
<td>7</td>
<td>David</td>
<td>husband</td>
<td>F</td>
<td>84</td>
<td>Dementia</td>
<td>Cardiac; osteoarthritis; depression</td>
<td>36</td>
</tr>
<tr>
<td>8</td>
<td>Angela</td>
<td>wife</td>
<td>M</td>
<td>80</td>
<td>Dementia</td>
<td>Detached retina; hypertension</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>Suzie</td>
<td>wife</td>
<td>M</td>
<td>86</td>
<td>Dementia</td>
<td>Post-traumatic stress syndrome; CVA</td>
<td>7</td>
</tr>
<tr>
<td>10</td>
<td>Joshua</td>
<td>nephew</td>
<td>F</td>
<td>84</td>
<td>Dementia</td>
<td>/</td>
<td>13</td>
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<tr>
<td>11</td>
<td>Raymond</td>
<td>husband</td>
<td>F</td>
<td>76</td>
<td>Dementia</td>
<td>Urinary incontinence osteoarthritis</td>
<td>3</td>
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<tr>
<td>12</td>
<td>Rose</td>
<td>wife</td>
<td>M</td>
<td>69</td>
<td>Dementia</td>
<td>Depression; anxiety disorder; NIDDM; Asthma; P.E.</td>
<td>8</td>
</tr>
<tr>
<td>13</td>
<td>Tracey</td>
<td>daughter</td>
<td>F</td>
<td>86</td>
<td>Dementia</td>
<td>Cardiac (AF, CCF, angina); hyperthyroid</td>
<td>48</td>
</tr>
<tr>
<td>14</td>
<td>Sue</td>
<td>wife</td>
<td>M</td>
<td>75</td>
<td>Dementia</td>
<td>Hypertension; CAL; cataracts</td>
<td>15</td>
</tr>
<tr>
<td>15</td>
<td>Heather</td>
<td>wife</td>
<td>M</td>
<td>78</td>
<td>Dementia</td>
<td>/</td>
<td>7</td>
</tr>
<tr>
<td>16</td>
<td>Virgina</td>
<td>wife</td>
<td>M</td>
<td>88</td>
<td>Dementia</td>
<td>CAL; deaf</td>
<td>19</td>
</tr>
<tr>
<td>17</td>
<td>Sophie</td>
<td>daughter</td>
<td>F</td>
<td>85</td>
<td>Dementia</td>
<td>Arthritis; depression</td>
<td>10</td>
</tr>
<tr>
<td>18</td>
<td>Christine</td>
<td>daughter</td>
<td>F</td>
<td>85</td>
<td>Dementia</td>
<td>Arthritis; diverticular disease</td>
<td>23</td>
</tr>
<tr>
<td>19</td>
<td>Janet</td>
<td>wife</td>
<td>M</td>
<td>79</td>
<td>Dementia</td>
<td>Cardiac; CVA</td>
<td>4</td>
</tr>
<tr>
<td>20</td>
<td>Alison</td>
<td>wife</td>
<td>M</td>
<td>82</td>
<td>Dementia</td>
<td>Cardiac; TIA; arthritis</td>
<td>17</td>
</tr>
<tr>
<td>21</td>
<td>John</td>
<td>husband</td>
<td>F</td>
<td>91</td>
<td>Dementia</td>
<td>Cardiac; diverticular disease</td>
<td>9</td>
</tr>
</tbody>
</table>
APPENDIX 18:

Table A: Resident and person responsible Patient Outcome Scores (POS) for individual items and severity of symptoms.
Table A: Individual Resident and Person Responsible Patient Outcome Scores (POS) for Individual Items and Severity of Symptoms.

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean / Median</th>
<th>SD / IQR</th>
<th>95% CI</th>
<th>Nil / moderate (n, %)</th>
<th>Severe / Overwhelming (n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RESIDENTS</strong> (n=72, <strong>n=71)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>1.18</td>
<td>1.16</td>
<td>0.91 - 1.45</td>
<td>63 (87%)</td>
<td>9 (13%)</td>
</tr>
<tr>
<td>Other symptom</td>
<td>0.94</td>
<td>1.04</td>
<td>0.70 - 1.19</td>
<td>65 (90%)</td>
<td>7 (10%)</td>
</tr>
<tr>
<td>Resident anxiety</td>
<td>0.96</td>
<td>1.22</td>
<td>0.67 - 1.25</td>
<td>59 (82%)</td>
<td>13 (18%)</td>
</tr>
<tr>
<td>Family anxiety</td>
<td>0.69</td>
<td>0.95</td>
<td>0.47 - 0.92</td>
<td>70 (90%)</td>
<td>7 (10%)</td>
</tr>
<tr>
<td>Information</td>
<td>0.00*</td>
<td>0.00 - 1.75</td>
<td>0.00 - 0.00</td>
<td>65 (90%)</td>
<td>7 (10%)</td>
</tr>
<tr>
<td>Support</td>
<td>1.63</td>
<td>1.79</td>
<td>1.21 - 2.06</td>
<td>45 (62%)</td>
<td>27 (38%)</td>
</tr>
<tr>
<td>Depressed</td>
<td>1.08</td>
<td>1.38</td>
<td>0.76 - 1.41</td>
<td>56 (78%)</td>
<td>16 (22%)</td>
</tr>
<tr>
<td>Self worth</td>
<td>1.68**</td>
<td>1.42</td>
<td>1.34 - 2.01</td>
<td>51 (71%)</td>
<td>20 (28%)</td>
</tr>
<tr>
<td>Wasted time</td>
<td>0.00*</td>
<td>0.00 - 0.00</td>
<td>0.00 - 0.00</td>
<td>70 (97%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Personal affairs</td>
<td>0.00*</td>
<td>0.00 - 0.00</td>
<td>0.00 - 0.00</td>
<td>70 (97%)</td>
<td>2 (3%)</td>
</tr>
</tbody>
</table>

| **PERSON RESPONSIBLE** (n=21) |               |           |             |                       |                             |
| Pain                   | 0.86          | 1.15      | 0.33 - 1.38 | 18 (86%)              | 3 (14%)                     |
| Other symptom          | 0.00*         | 0.00 - 2.00 | 0.00 - 2.00 | 20 (95%)              | 1 (5%)                      |
| Resident anxiety       | 0.76          | 0.94      | 0.33 - 1.19 | 20 (95%)              | 1 (5%)                      |
| Family anxiety         | 1.00*         | 0.00 - 2.00 | 0.00 - 1.00 | 20 (95%)              | 1 (5%)                      |
| Information            | 0.00*         | 0.00 - 0.00 | 0.00 - 0.00 | 21 (100%)             | 0 (0%)                      |
| Support                | 1.33          | 1.62      | 0.59 - 2.07 | 15 (71%)              | 6 (29%)                     |
| Depressed              | 1.00*         | 0.00 - 1.50 | 0.00 - 1.00 | 18 (86%)              | 3 (14%)                     |
| Self worth             | 1.67          | 1.11      | 1.16 - 2.17 | 15 (71%)              | 6 (28%)                     |
| Wasted time            | 0.00*         | 0.00 - 0.00 | 0.00 - 0.00 | 21 (100%)             | 0 (0%)                      |
| Personal affairs       | 0.00*         | 0.00 - 0.00 | 0.00 - 0.00 | 19 (91%)              | 2 (9%)                      |

*a = range of scores 0, 2, 3, 4; b = range of scores 0, 2, 4; c = range of scores 0, 2, 4.

**= median IQR = Interquartile range
Table B: Resident and person responsible Edmonton System Assessment System (ESAS) scores for individual items and severity of symptoms
Table B: Individual resident and person responsible Edmonton System Assessment System (ESAS) scores for individual items and severity of symptoms.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Mean/ Median</th>
<th>SD / IQR</th>
<th>95% CI (n, %)</th>
<th>Nil/ Mild (n,%)</th>
<th>Moderate/Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RESIDENTS (n=72)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>2.81</td>
<td>3.27</td>
<td>2.04 – 3.57</td>
<td>47 (65%)</td>
<td>25 (35%)</td>
</tr>
<tr>
<td>Tiredness</td>
<td>4.46</td>
<td>3.29</td>
<td>3.68 – 5.23</td>
<td>32 (44%)</td>
<td>40 (56%)</td>
</tr>
<tr>
<td>Nausea</td>
<td>0.00*</td>
<td>0.00-0.00</td>
<td>0.00 – 0.00</td>
<td>67 (93%)</td>
<td>5 (7%)</td>
</tr>
<tr>
<td>Depression</td>
<td>0.00*</td>
<td>0.00-4.00</td>
<td>0.00 – 4.00</td>
<td>55 (76%)</td>
<td>17 (24%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.00*</td>
<td>0.00-3.00</td>
<td>0.00 – 3.00</td>
<td>57 (79%)</td>
<td>15 (21%)</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>0.00*</td>
<td>0.00 - 4.00</td>
<td>0.00 – 3.00</td>
<td>55 (76%)</td>
<td>17 (24%)</td>
</tr>
<tr>
<td>Appetite</td>
<td>4.03</td>
<td>2.61</td>
<td>3.41 – 4.64</td>
<td>32 (44%)</td>
<td>40 (56%)</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>4.57</td>
<td>2.66</td>
<td>3.94 – 5.20</td>
<td>24 (33%)</td>
<td>48 (67%)</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>0.00*</td>
<td>0.00- 3.00</td>
<td>0.00 – 2.00</td>
<td>55 (76%)</td>
<td>17 (24%)</td>
</tr>
<tr>
<td><strong>PERSON RESPONSIBLE (n=21)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>0.00*</td>
<td>0.00 – 3.00</td>
<td>0.00 – 3.00</td>
<td>17 (81%)</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Tiredness</td>
<td>4.38</td>
<td>3.30</td>
<td>2.87 – 5.89</td>
<td>10 (48%)</td>
<td>11 (52%)</td>
</tr>
<tr>
<td>Nausea</td>
<td>**</td>
<td>**</td>
<td>**</td>
<td>21 (100%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Depression</td>
<td>2.57</td>
<td>3.24</td>
<td>1.09 – 4.05</td>
<td>16 (76%)</td>
<td>5 (24%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>3.57</td>
<td>3.18</td>
<td>2.12 – 5.02</td>
<td>15 (71%)</td>
<td>6 (29%)</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>0.00*</td>
<td>0.00 – 3.00</td>
<td>0.00 – 6.00</td>
<td>17 (81%)</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Appetite</td>
<td>1.76</td>
<td>2.27</td>
<td>0.72 – 2.80</td>
<td>17 (81%)</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>3.81</td>
<td>2.44</td>
<td>2.70 – 4.92</td>
<td>9 (43%)</td>
<td>12 (57%)</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>0.00*</td>
<td>0.00-2.00</td>
<td>0.00 – 0.00</td>
<td>18 (86%)</td>
<td>3 (14%)</td>
</tr>
</tbody>
</table>

** 100% guardians denied any nausea no mean, SD or CI could be calculated

* = median IQR = Interquartile range