Experiences, education and support needs of residential aged care staff caring for older adults with mental-palliative comorbidity

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Abstract

Australia's ageing population is contributing to an increased demand for residential aged care services (RACS). At the same time, these services are increasingly providing care for older adults with long-standing mental disorders (e.g., major depression, bipolar disorder and schizophrenia spectrum disorders) and life-limiting physical illnesses requiring palliative care. These older adults have multiple care requirements, including cognitive, behavioural and palliative care needs. However, RACS care staff are often ill-equipped to care for them. The aims of this study were to: (i) examine the experience of RACS staff caring for residents with mental-palliative comorbidity, and (ii) identify their initial and ongoing education and support needs. An interpretative phenomenological analysis approach was used, incorporating semi-structured interviews. A purposive sample of 12 RACS staff participated in semi-structured interviews. The study identified several strategies to enhance mental-palliative care in RACS. The overarching theme was conceptualised as *Adopting a person-centred approach to care*. This was supported by five main themes: *Understanding each person*, *Complexities in assessing and managing pain*, *Preventing and responding to behaviours of concern*, *Organisational provision for staff development and wellbeing promotion* and *Engaging in interdisciplinary collaboration*. These findings may contribute to a greater understanding of the experience of RACS staff caring for residents with mental-palliative comorbidity and highlight areas for improvement in the education and support of staff caring for this cohort.

Masters by Research declaration

I, Jillian Goullet, declare that the Master by Research thesis entitled Experiences, education and support needs of residential aged care staff caring for older adults with mental-palliative comorbidity is no more than 60,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work. I have conducted my research in alignment with the Australian Code for the Responsible Conduct of Research and Victoria University's Higher Degree by Research Policy and Procedures.

[redacted]

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This study is dedicated to adults with long-standing mental illness and life-limiting physical illnesses that require palliative care. May your health care experience be person-centred and evidenced based; provide comfort and care; be responsive to all your individual needs, and enhance your quality of life.

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CHAPTER 1:
Introduction

1.1 Introduction

This thesis presents a qualitative study of the experiences, education and support needs of residential aged care (RAC) staff caring for older adults with long-standing mental illness and life-limiting physical illnesses that require palliative care (hereafter, mental-palliative comorbidity). The study involved 12 participants purposively recruited from a private RAC provider in Melbourne, Australia. Data collection and analysis followed the principles of interpretative phenomenological analysis. This chapter introduces the study and explains the broader context, research question and aims, followed by the justification of the study. The key terms used in the study are then defined. Lastly, the structure of thesis is outlined.

1.2 Background

In Australia, there is an increasing need to provide palliative care to those living in RAC. This is due to the ageing population and the growing number of residents with high palliative care needs (Broad et al., 2015). Data from 2013-14 indicate that 7.8 percent of the Australian population aged 65 years and over (270,559 people) were residing in RAC (Australian Institute of Health and Welfare, 2017a). It is projected that the number of people requiring RACS in Australia will increase by 250%, with some 3.5 million people (10.3% of the population) using these services by 2050 (Australian Institute of Health and Welfare, 2017a). At the same time, the number of people with a mental illness is increasing. The World Health Organization (2017) estimates that approximately 15% of adults aged 60 years and over will experience a mental illness. Substantial evidence demonstrates that those with severe and persistent mental illness die 20 years younger than the general population, largely due to a variety of comorbid physical illnesses (Cranwell et al., 2016; Foti et al., 2005; Happell et al., 2012; Picot et al., 2015). Picot et al. (2015) suggest that the number of people with a mental illness and physical comorbidity, who will eventually require palliative care, is at a crisis point.

Palliative care involves caring for a person who has a life-limiting physical illness that can reasonably be expected to cause their death within the foreseeable future (World Health Organisation, 2014). In 2013-14, there were approximately 231,700 permanent RACS residents who required palliative care (Australian Institute of Health and Welfare, 2017b). It is unclear how many of those had an additional diagnosis of a mental illness. In the RACS setting, staff often lack the skills to care for these residents and are reportedly reluctant to undertake training in this area (Broad et al., 2015; Frey et al., 2015). In 2019 a Royal Commission into Aged Care Quality and Safety revealed significant shortcomings in the aged care sector in Australia. This inquiry pinpointed critical deficits and inconsistency in palliative and end-of-life care. In particular mental health services, doctor visits, oral and dental health care, and holistic and preventative care were all below community expectations (Royal Commission into Aged Care Quality and Safety, 2019). This research aims to improve the understanding of how RACS staff experience and deliver mental-palliative care services. These findings may provide insights and benefits to various stakeholders, including health care services, RACS clinical staff and policy makers. Subsequent understanding in this area may aid in enhancing outcomes for older adults living in RACS with mental-palliative comorbidity.

1.3 Research question and aims:

The research question for this study was:

- What are the experiences, education and support needs of residential aged care staff caring for residents with mental-palliative comorbidity?

The specific aims of this study were to:

- Examine the experience of RACS staff caring for residents with mental-palliative comorbidity, and
- Identify their initial and ongoing education and support needs in caring for this group of residents.

1.4 Justification for the study

Global population ageing and a commensurate increase in mental illness in older adults are pushing demand for RACS staff to deliver palliative care to those with multiple care requirements related to comorbid physical and mental illness (Amare et al., 2020; Kogan et al., 2016; Stargatt et al., 2017). Despite clear evidence in favour of palliative care in RAC (see, for example, Bökberg et al., 2020; Rainsford et al., 2020), gaps in policy and practice are reflected in care staff who are often ill-equipped to respond to the complex needs of their residents (McInerney et al., 2009).

One of the growing groups of residents requiring specialist care are those with a mental illness and physical comorbidity, who require palliative care (Jester et al., 2020; Picot et al., 2015). A knowledge gap exists in RACS clinical staff perspectives and experience in assessing, treating and caring for older adults with mental-palliative comorbidity (Bhar et al., 2020; Evenblij et al., 2016). Access to palliative services for people with severe mental illness has been shown to be particularly poor, while partnerships between RACS, mental health and palliative care services are often inadequate (Picot et al., 2015). Knowledge deficits and inadequate palliative care delivery have been attributed to many factors in RACS, including a lack of resources, improvements needed in knowledge development, limited supportive leadership, and poor organisational culture (Beck et al., 2014; Frey et al., 2016; Ludlow et al., 2021). There is a wide variability of skill mix in the aged care workforce, which is comprised largely of registered nurses (RNs), enrolled nurses (ENs) and personal care attendants (PCAs). These members of the multidisciplinary team also have different levels of confidence in communicating with residents, families and external services, and skills in planning and providing care (Phillips et al., 2008). Management and organisational influences are evident in the availability of specialist palliative care education and support. Education and support, in turn, influence staff confidence, capacity and stress (Frey et al., 2015).

While research in the specialised field of palliative care for people with mental and physical comorbidity is gaining traction, few studies have investigated the knowledge and practices of staff in RACS when caring for residents with mental-palliative comorbidity. More evidence is needed to improve the provision of palliative care in this cohort. This evidence requires a clear understanding of the experiences, education and support needs of RAC staff caring for residents with mental-palliative comorbidity.

1.5 Key terms, definitions and abbreviations

This thesis contains the following terms that should be explained at the outset:

- **End-of-life care** refers to the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers is higher at this time (World Health Organisation, 2014).
- **Enrolled nurses (ENs)** are nurses with appropriate educational preparation and competence for practice, who are registered under the Health Practitioner Regulation National Law. ENs practice in accordance with the Enrolled Nurse Standards for Practice. Core practice generally requires that ENs work under the direct or indirect supervision of RNs (Nursing and Midwifery Board of Australia, 2016).
- **General practitioners (GPs)** are medical doctors. In Australia, GPs are generally the first point of access to healthcare. They diagnose, treat and educate patients, and refer patients to specialists, as needed (www.racgp.org.au).
- **Interpretative phenomenological analysis (IPA)** is a qualitative research method which enables the researcher to explore the lived experience of participants and recognise their individual and social context, while appreciating their own interpretation and organisation of the data (Biggerstaff & Thompson, 2008).
- **Mental illness**, as the preferred term in the current study, refers to a diagnosable illness that significantly interferes with a person’s cognitive, emotional or social abilities. Examples of mental illness include depression, anxiety disorders, bipolar disorder, and psychotic disorders, such as schizophrenia. A person with a mental illness typically cannot cope and function as they did previously, causing considerable personal, social and financial distress (Foster et al., 2021; Wilson et al., 2016). Terms such as ‘mental health issue’ or ‘mental disorder’ are also commonly used.
- **Mental-palliative care** refers to the treatment of patients with a mental illness, who are also receiving palliative care. In palliative care for patients with a coexisting

mental illness, more attention is typically given to psychosocial and spiritual care, compared to those without this disorder (Evenblij et al., 2016).

- **Palliative care** is person- and family-centred care for a person who has an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.
- **Personal care attendants (PCAs)** (also known as ‘personal care workers) assist residents with activities of daily living, including help with personal care, grooming, dressing and eating. They also assist with activities related to residents’ independence.
- **Person-centred care (PCC)** places the person at the centre of the service. Each person is treated as an individual, with the focus on what they can do, not their condition or disability. Support and treatment are tailored to achieving the person’s unique circumstances.
- **Registered nurses (RNs)** are nurses whose practice is evidence-based and person-centred, encompassing preventative, formative, supportive, curative, restorative and palliative care. RNs engage in professional and therapeutic relationships with patients, as well as with families, groups and communities. Patients’ issues may relate to physical, psychiatric, developmental and/or intellectual conditions. RNs are regulated health professionals, accountable and responsible to the Nursing and Midwifery Board of Australia (2016).
- **Residential aged care services (RACS)** refers to facilities that offer a domestic-styled environment in which staff provide 24-hour functional care for people with complex health needs who need assistance with activities of daily living (ADLs). **Residential aged care (RAC)** may also be known as ‘nursing home’, ‘care home’ or ‘long-term care’, although the requirements and commitments of each may differ.
- **Residents** are people who live in RAC. They are often, but not always, older adults. In other healthcare settings, the terms ‘patient’, ‘consumer’ or ‘client’ may be used.

1.6 Structure of the thesis

The thesis is presented as six chapters. Following this introduction, Chapter 2 presents a review of literature on older adults with mental-palliative comorbidity, positioned within the complexity of caring for this cohort within prevailing models of care. In Chapter 3, the methods are outlined in respect to the study's design rationale, data collection and analysis processes. Chapter 4 contains the results of the study, including the overarching theme of *Adopting a person-centred approach to care* and its five related main themes. In Chapter 5, the discussion considers the research findings in conjunction with IPA and other literature in the field. Finally, Chapter 6 outlines the limitations and strengths of the study, followed by the implications for future practice and research.

CHAPTER 2:
Literature review

2.1 Introduction

This chapter will provide an overview and description of RACS and quality care for older adults with mental-palliative comorbidity, in connection with current literature and current practice considerations. It presents a historical perspective of aged care, RACS organisational structure and staffing profiles, and models of care. Close attention is given to the philosophy of PCC, particularly in relation to the complexity of mental illness, palliative care, mental and physical comorbidity. This is followed by a review of the preparedness of RACS staff to provide mental-palliative care in this cohort.

2.2 Residential aged care services and quality of care

2.2.1 Historical perspective

In Australia and internationally, there is no universal definition of RACS. The historical origin of ‘nursing homes’ dates back to the Byzantium empire, when Emperor Constantine the Great and his mother, Helena, established infirmaries (Lascaratos et al., 2004). The etymology of the names ‘gerocomeia’ or ‘gerontocomeia’ (meaning ‘nursing homes’) comes from the Greek words ‘geros’ (old aged) and ‘comein’ (care); similarly, ‘gerotropheia’ comes from the words ‘geros’ and ‘trephein’, which means ‘nourishing’ (Lascaratos et al., 2004). Often situated near monasteries with close connection to religion, these establishments frequently provided care for older adults, in terms of lodgings, food and certain hospital and medical care (Lascaratos et al., 2004). Over time, nursing home care evolved in terms of the extent and type of care made available to residents. Just as the words used to name it, there remains significant disparity in relation to the specific type of care offered in these settings (Sanford et al., 2015). Often lacking clear specification, the purpose of a ‘nursing home’ often lacks aspirational vision, rather focusing on the activities or tasks that are undertaken (Ibrahim et al., 2020). There is a prevailing view that RAC is a home of final resort, where older people go when they are unable to stay safely and independently within their own home, and await death (Schwarz et al., 2018). This negative view of RAC can promote stigma and a culture where RACS only meets minimum standards of care, instead of being aspirational and striving to provide optimum care (Ibrahim et al., 2020).

In Australia and elsewhere, the aged care context is changing in terms of aged care roles and models of care, mainly in reaction to changing consumer expectations and rising demand for improved flexibility, choice and control (Ratcliffe et al., 2010). A more modern depiction proposes that 'RACS meet the individual needs of residents and provide opportunity for residents to thrive' (Ibrahim et al., 2020, p. 148). To this end, a combination of models has emerged whereby growth of traditional biomedical-based nursing care is more adaptable and inclusive of holistic biopsychosocial elements of PCC (Fairbrother et al., 2015). The implementation of these best practice models of care are not easy to achieve, partly due to perceptions and expectations of aged care nursing staff that are vague and conflicting (Davis et al., 2016). In addition, RACS and other health care staff encounter significant challenges in meeting consumer, professional, organisational, and policy expectations along with workforce variability and resource constraints (Ludlow et al., 2021). Consequently, structural barriers and aged care policy represent significant pressures to sustaining quality nursing in aged care.

2.2.2 RACS organisational structures and staffing profile

Australia's aged care system delivers support and care to people in many diverse contexts, including hospitals, in the community and in residential settings. RAC settings vary depending on the provider (organisation) type, with some being owned by government, not-for-profit (charitable, community and religious) or private organisations (Australian Institute of Health and Welfare, 2017a). Like in many other countries, Australia is experiencing the marketisation[1] of aged care (Brennan et al., 2012; Henderson et al., 2018). Not-for-profits remained the most common providers of RACS (57 per cent in 2012); however, 92 per cent of aged care beds (formerly known as 'bed licences') purchased from the government in 2010–2015 were purchased by for-profit service providers (Grant Thornton, 2020). In 2020, there were 3,300 aged care providers in

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[1] Marketisation of aged care is part of a broader trend towards the marketisation of social services, whereby public service providers are substituted by private providers, with consumers assuming increased responsibility for service charges. Marketisation in residential aged care is linked with deregulation of ownership of aged care facilities, increased service provision by private for-profit service providers and greater financial contribution by consumers to care (Henderson & Willis, 2020).

Australia providing care across 9,500 services (Australian Institute of Health and Welfare, 2020b). There are variances in approach between for-profit and not-for-profit providers, whereby the former have a stronger focus on profit generation through competition, while the latter are motivated more by social justice and ethical services (Brennan et al., 2012; Willis et al., 2018). The Australian Government provides financial contributions towards the cost of aged care.[2]

Each RACS provider operates with a specific organisational structure that comprises an executive management team that oversees the entire service. At each individual RAC site, a manager oversees the facility, with a clinical in-charge RN supervising clinical care. Care is provided by a mix of health care staff, including RNs, ENs and PCAs, who work across shifts. RACS staff hold specific work roles and responsibilities that are specific to their training, qualifications, experience and scope of practice (Australian Institute of Health and Welfare, 2017a). In Australia in 2016, over 366,000 people were employed in residential and community aged care, including 240,000 direct care workers (Mavromaras et al., 2017). Of those, the full-time equivalent (FTE) staff comprised mainly PCAs (71.5%), RNs (14.9%) and ENs (9.3%) (Mavromaras et al., 2017). It is projected that, by 2050, a further 130,000 additional FTE staff would be needed (Royal Commission into Aged Care Quality and Safety, 2019). Notwithstanding these projections, there are already significant challenges in providing RAC in Australia, including low staffing levels, under-qualified nursing staff, and increased resident needs (Henderson & Willis, 2020). A consultation undertaken by Australia's Aged Care Workforce Strategy Taskforce (2018) reported significant gaps in the competencies of Australia's aged care workforce, highlighting the urgent need for better training and education. Specific to the current study, there is evidence that many RACS staff across all workforce levels lack knowledge and skills in providing palliative care (Frey et al., 2020).

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[2] In 2017–18, the Australian Government spent over $18 billion on aged care. Of this, 67% was on residential care and 28% was on home-based (community) care and support services (www.health.gov.au).

2.2.3 Legislation, standards and quality in aged care

In Australia, the obligations and responsibilities of aged care providers are articulated in the *Aged Care Act 1997* (www.legislation.gov.au). As the overarching legislation, the Act covers government-funded aged care, setting out rules and regulations that relate to funding, approval of providers, quality of care, and client/resident rights (that is, 'user rights'). Approved providers receive government subsidies under the Act. Since 2020, the responsibility for approving providers has been delegated to the Aged Care Quality and Safety Commissioner. The Act is operationalised through other supporting rules, regulations and standards, such as the *Aged Care Quality Safety Commission Act 2018*, the *Aged Care Quality and Safety Commission Rules 2018, Quality of Care Principles 2014* and *User Rights Principles 2014*.

Aged care is also subject to other broader laws, including those that relate to information, privacy, diversity and discrimination. Thus, it is a 'patchwork' of legislation and other instruments that set out the requirements for and expectations of approved providers, the allocation of aged care places, and the eligibility and classification of those who receive care (Royal Commission into Aged Care Quality and Safety, 2019). All approved aged care providers in Australia are required to comply with eight Aged Care Quality Standards, as set out by the Aged Care Quality and Safety Commission (www.agedcarequality.gov.au). The eight Standards are:

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

While 'quality of care' may be understood differently across countries and cultures, it is generally determined by factors such as aged care funding, regulation, health and social care policy, industry interest groups, and social or consumer movements (Garratt et al., 2021). In a study of RACS staff perspectives on quality of care, Garratt et al. (2021) reported the particular benchmark of PCC within these services. PCC and quality care were found to foster familiarity and interpersonal relationships, the provision of a home-like environment, and therapeutic communication between staff, residents, and their families (Garratt et al., 2021).

Despite the best efforts of most providers and care staff, Australia's recent Royal Commission into Aged Care Quality and Safety (2019) found substantial inadequacies.. The findings of this inquiry pointed to systemic problems concerning access to services, a lack of cultural diversity, substandard care, abuse and inappropriate use of restrictive practices, inadequate complex care and deficits in routine care. The Australian Government has considered the final report of the Royal Commission (2019), whose 148 recommendations call for wide-ranging reform of the aged care system. Its response includes a proposed $17.7 billion aged care reform package designed to deliver sustainable quality and safety in residential and home-based (community) aged care (Department of Health, 2021a). Not surprisingly, many of the Royal Commission's recommendations relate to models of care. A new consumer-focused Aged Care Act, intended to come into effect in July 2023, will serve as the foundation for 'system-wide aged care reform, with the explicit goal of supporting a system of aged care based on a universal right to high quality, safe and timely support and care' (Department of Health, 2021a, p. 1). Efforts to improve the aged care system will also consider staff-to-resident ratios, which are currently not consistently structured or regulated.

2.2.4 Models of care: Person-centred care in aged care

With the recognition of personhood as a fundamental element of care, PCC is recognised as the foundation of high-quality healthcare. It has been linked to several key concepts, including holistic or whole-of-person care, dignity, value and choice, self-determination, and purposeful living (Kogan et al., 2016). Descriptions of PCC relate to personhood (Kitwood, 1997), knowing the person (Talerico et al., 2003), promoting involvement in decision-making and autonomy (Mead & Bower, 2000), quality of care (Cohen-Mansfield et al., 2018), a nurturing therapeutic relationship (Brooker, 2003) and the provision of a supportive physical and organisational environment (Rader & Semradek, 2003). Hence, there is strong evidence in favour of PCC as a model of care that guides resident wellbeing and overall quality of life (Cohen-Mansfield et al., 2018). In addition to the benefits for residents, PCC is known to positively influence staff satisfaction (Sjögren et al., 2017). In RAC, specifically, a PCC approach has led to a shift from a task-focused, institutional and custodial model of care, to one that adapts a PCC model of care as the directing standard of practice (Oppert et al., 2018; Venturato et al., 2020). While PCC depends on a shared philosophy of care across an organisation, the concept is often based on theoretical models that do not explain the organisational and environmental facilitators for PCC (Sjögren et al., 2017). Of particular relevance to the current study, it is important for PCC to be tailored to different care recipients, including those with mental illness and neurocognitive disorders, including dementia[3] (hereafter 'dementia'). According to Edvardsson et al. (2008), the essential components of PCC for people with dementia are:

- Positive regard of personhood in people with dementia
- Personalising care and environmental surroundings
- Offering residents choice and shared decision making
- Interpreting behaviour from individual viewpoints
- Focusing on resident wellbeing before routines and care duties, and prioritising the therapeutic relationship to the same degree as care duties
- Understanding residents' history and providing opportunities for validation and reminiscence therapy
- Promoting activities that enhance quality of life.

Despite evidence in favour of the effect of PCC on people with mental illness and/or dementia, its uptake has not been consistent, nor without challenges (Smith & Williams, 2016). While frameworks exist to guide PCC in different cohorts—notably Kitwood's (1997) work in PCC in dementia care—there remains a need for practical strategies and models to support the establishment and replication of PCC in different care settings

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[3] Neurocognitive disorders (NCD) encompass disorders in cognitive function, in which impairment may occur in any or all of attention, planning, inhibition, learning, memory, language, visual perception, spatial skills, social skills or other cognitive functions. Under new diagnostic criteria, dementia is categorised as an NCD (www.dementia.org.au).

(Kogan et al., 2016). In aged care, for example, PCC is generally well known as a concept, but inconsistently applied. In an Australian study of the facilitators and barriers to providing PCC to residents with and without physical and psychological issues in RACS, it was found that aged care staff had an acceptable but incomplete understanding of PCC (Oppert et al., 2018). Additional barriers to providing PCC included time limitations and residents' dementia behaviours, while teamwork was essential for enhancing personal relationships (Oppert et al., 2018).

The challenges of providing PCC in aged care were clearly identified by the Royal Commission (2019), with multiple examples of how RACS had failed to meet the individual needs of residents and provide PCC. In a recent study, Ibrahim et al. (2020) used a three-stage method to conceptualise new models of RAC in Australia. These stages comprised initial model concept mapping, consultation with key stakeholders to test and develop the model, and a review of the model's adaptability in the event of organisational failure. The proposed model aims to provide 'PCC to older people with complex health issues, requiring end-of-life care, and/or living with dementia … supporting dignity of risk and quality of life and enabling older adults to thrive' (Ibrahim et al., 2020, p. 148).

The importance of embracing different cultures and cultural influences for residents and staff has also been identified as a way to promote individuality and a sense of belonging (Oppert et al., 2018). In a study of the organisational and environmental elements of PCC in RAC, Sjögren et al. (2017) found that PCC needed to be understood and utilised by staff at all levels and across all disciplines. In addition, PCC should be part of an organisation's central mission, with a clear shared philosophy of care. This required adequate leadership, social support from colleagues and leaders, and interdisciplinary collaboration (Sjögren et al., 2017). Other requirements included dementia-specific physical environments, smaller facilities, and adequate provision of staff time to allowing staff-resident quality time together. To take PCC from theory into practice in aged care and mental health settings, the provision of PCC also requires culture change supported by targeted education and supervision for staff (Ruddick, 2010; Sjögren et al., 2017).

2.3 Mental illness

Mental illness is a central area of healthcare focus, as there is a high prevalence of people living with this disorder in all communities. A national survey reported of the 16 million Australians aged 16-85 years surveyed, nearly 45% or 7.3 million had experienced a mental illness within their lifetime (Australian Institute of Health and Welfare, 2018). One in five (20% or 3.2 million) Australians have presented with symptoms of mental illness in the last 12-months. (Australian Institute of Health and Welfare, 2019). The most prevalent mental illness was anxiety disorders, affecting 1 in 7 (14%) of the population, followed by mood disorders (6%), and substance use disorders (5%) (Australian Institute of Health and Welfare, 2019).

There is significant evidence that people with a mental illness experience disadvantage and reduced overall health and related quality of life, in comparison to the general population (Happell et al., 2016; Satcher & Rachel, 2017). A person living with a mental illness can experience significant personal, social and economic effects (Foster et al., 2021). On a global level, the World Health Organization continues to advocate for systemic change in mental health services, including mental health promotion, and sustained efforts to reduce the numerous barriers that frequently preclude health equity by preventing individuals from accessing mental health care and treatment (World Federation for Mental Health, 2013; World Health Organization, 2017). The most significant barriers concern under-resourcing of mental health generally, and stigma. Mental health stigma and discrimination occur at individual, family, community, government levels (Corrigan, 2016). Stigma is a significant barrier to help-seeking for people with mental illness, and often delays or prevents access to support and treatment (Satcher & Rachel, 2017).

2.3.1 Structure and staffing of mental health services

Specialised mental health care is delivered in a multitude of health contexts, across all age groups. The mental health sector includes private and public psychiatric services, community mental health care services, psychiatric units located within public hospitals and government or non-government-operated residential mental health services

(Australian Institute of Health and Welfare, 2018). People with a mental illness also often present to hospital emergency departments, which have an integral function in assessing and treating people with mental illness, and are often the preliminary access point to mental health care (Cranwell et al., 2016).

The diverse mental health workforce comprises of multidisciplinary teams that include psychiatrists, psychologists, mental health nurses, GPs, social workers, occupational therapists, counsellors and peer workers and other specialised allied health professionals. In Australia, specialist mental health professionals include an estimated 3,400 psychiatrists, 26,300 registered psychologists and 22,200 mental health nurses (Australian Institute of Health and Welfare, 2019). These clinicians are required to have skills and knowledge specific to mental health therapeutic modalities (Foster et al., 2021).

Within mental health services, Aged Person Mental Health Services (APMH) provide support for people over the age of 65 who present with psychiatric or severe behavioural difficulties associated with organic disorders, such as dementia (www.health.gov.au). These services are delivered in a variety of settings including community-based APMH teams, acute inpatient services, intensive community treatment programs and residential care. Residential mental health services employ mental health professionals on-site 24 hours per day, delivering rehabilitation, treatment or extended care in a home-like environment. In Victoria in 2018-19, there were 8,045 episodes of aged residential mental health services care recorded and reported for an estimated 6,375 residents (Australian Institute of Health and Welfare, 2020c). In 2018–19, the most common diagnosis reported in these residential settings was schizophrenia (25.1% of episodes), followed by specific personality disorders (13.2%) and schizoaffective disorders (8.8%) (Australian Institute of Health and Welfare, 2020c). Between 2014–15 and 2018–19, residential mental health care episodes decreased marginally from 3.3 to 3.2 per 10,000 population (an average annual change of -0.8% over the period) (Australian Institute of Health and Welfare, 2019). Notably, from 1992-93 to 2010-11, decreases in hospital care episodes have been accompanied by changes in the mix and type of mental health inpatient services (Australian Institute of Health and Welfare, 2019). In Australia, there was a high reduction in bed numbers within older persons' mental health services between 1992-93 and 2010-11, reducing capacity by 57%, with a decrease across all available services (Department of Health and Ageing, 2013).[4] Closures and reductions of aged mental health services have seen mainstream RACS take responsibility for a growing number of older people with mental illness (Amare et al., 2020).

2.3.2 Legislation, standards and quality in mental health care

The Australian mental health care system is underpinned by legislation and standards aimed to safeguard and foster best practice care and treatment for those living with mental illness. Victoria's current *Mental Health Act 2014* (2021b) articulates the commitment to placing the person living with a mental illness at the centre of decision making about their care and treatment. The Act is supported by mental health regulations and practice standards, which form a framework for quality and safety in mental health services in private and public hospitals, and community services (Department of Health, 2021b).

Similar to Australia's aged care sector, legislation and regulations in mental health service provision have not prevented inadequate access to and provision of care. A Royal Commission into Victoria's Mental Health System (State of Victoria, 2021a) was conducted in 2019. In response to its recommendations, the Victorian Government will repeal the current Mental Health Act and enact a new Mental Health and Wellbeing Act (aimed for 2022). A new body, Mental Health Reform Victoria, has been established to deliver the Commission's 65 final and nine interim recommendations (www.mhrv.vic.gov.au). The 10-year vision for the future mental health system high lights a commitment to providing 'a responsive and integrated system with community at its heart' (State of Victoria, 2021a). This will require a revision of the structure, resourcing and staffing of models, which have failed to adequately support the diverse needs of people living with mental illness, as well as the psychological distress of families and carers (State of Victoria, 2021a). In so doing, the Commission acknowledged the growing number of older Victorians living with mental illness and an associated demand for provision of mental health services for older adults (State of Victoria, 2021b).

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[4] The process of de-institutionalisation has occurred in various countries, including Australia, and applies to mental illness, physical and intellectual disability, and multiple disability. In the mental health context, the tenets of de-institutionalisation are to prevent inappropriate admissions, discharge patients to non-institutional living and provide services in a community setting (Doessel et al., 2005). While de-institutionalisation brings many benefits to people with mental illness (Hobbs et al., 2002), many who need residential treatment cannot obtain it, often resulting in homelessness or imprisonment (Yohanna, 2013).

2.3.3 *Prevalence and treatment of mental disorders in RACS*

Diagnoses of mental illness are increasingly common in RACS. In an Australian study of the prevalence, trends and factors associated with mental illness in RACS, Amare et al. (2020) reported 57.8% of residents had at least one mental illness. The most common diagnosis was depression 46.2%, followed by phobia-anxiety 14.9% and psychosis 9.7% (Amare et al., 2020). Notwithstanding these numbers, it is not unusual for older adults to encounter difficulties obtaining a mental illness diagnosis and treatment for illnesses such as depression (Choi et al., 2016; Polacsek et al., 2018; Xiang et al., 2018).

Older adults generally, including those in RAC, face multiple challenges in obtaining a diagnosis and treatment for mental illness. In addition to the common help-seeking barriers of stigma and access (Corrigan, 2016), they must often also overcome misguided attitudes of health professionals towards mental illness in older age, inconsistent screening for mental illness in older adults, and previous negative experiences (Xiang et al., 2018). In a study of older adults' lived experience of accessing treatment for mental illness, Reynolds et al. (2020) reported participants' fear of being labelled with a mental illness, confusion about the health system, and the influence of emotional responses to psychological treatment (such as hope, fear and mistrust). There is also a common misconception—by older adults and health professionals—that symptoms such as pain, fatigue or dependency on others are normal in older age (Ouchida & Lachs, 2015).

Problems in obtaining a diagnosis and treatment once admitted to RACS include the change in service funding and availability. With residential care funded by the Australian Government, the resident loses access to mental health services via the Medicare Benefits Scheme.[5] Despite the demonstrated need for mental health services in RAC, gaps in understanding and processes around how this is managed for residents mean that mental health services are often inconsistent or absent in RACS (Radermacher, 2021).

In another Australian study, this time of the availability of psychological services in RACS, Bhar et al. (2020) also reported high rates of depression and anxiety. Despite their

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[5] Australia's national Medicare Benefits Schedule supports services under the *Better Access to Psychiatrists, Psychologists and General Practitioners* (www.health.gov.au).

prevalence, access to psychological services was poor, and it was rare for residents to be referred to psychologists or engage in psychological treatments (Bhar et al., 2020). Findings such as these confirm the need to improve evidence-based practice and best-practice interventions for meeting mental illness needs within the aged care context (Amare et al., 2020). Meeting these needs is even more challenging when residents have physical comorbidities and/or functional deficits.

2.3.4 Mental-physical comorbidity

For individuals living with chronic mental illness, there is an increased risk of developing physical co-morbidities. These medical conditions are often under-recognised, as those living with mental illness are often faced with barriers in accessing and receiving appropriate physical health care and treatment (Picot et al., 2015). The need to improve understanding of the lived experience of people with mental illness and co-existing medical comorbidity, and their carers, who are navigating through multiple health care services was highlighted in an Australian study by Cranwell et al. (2016). Interviews with 12 consumers and four main caregivers highlighted difficult and time-consuming processes in accessing of specialist services, differing experiences of health professionals level of support and engagement, lack of continuity between tertiary medical and primary care services, and the pivotal role of care transitions (Cranwell et al., 2016). These transitions are particularly important for people with mental-physical comorbidity.

In Australia, life expectancy for both males and females is one of the highest in the world (Australian Institute of Health and Welfare, 2021a). However, life expectancy for people living with mental illness is up to 20 years less than the general population, largely due to comorbid physical illnesses (Cranwell et al., 2016; Picot et al., 2015). People can experience multiple co-existing conditions, two or more at the same time (that is, multimorbidity) (Johnston et al., 2019). For people with mental illness, the prevalence of cardiovascular disease, metabolic syndrome, diabetes mellitus, and respiratory disease, surpasses that of the general public by at least two-fold, and this gap is increasing (Happell et al., 2016). This association between high mortality and poor prognosis impacts greatly on a person with a mental illness (Happell et al., 2016). In a longitudinal study of the association between older adults' physical and mental health, Luo et al.

(2020) recommended paying close attention to mental health screening in older adults with physical health problems. Confirming the reciprocal relationship between mental and physical health, they highlighted the need to closely observe and monitor different aspects of the older person's health and wellbeing (Luo et al., 2020). Overall, however, older adults with mental-physical co-morbidity are more likely to need palliative care, in addition to their higher and more complex care requirements (Picot et al., 2015).

2.4 Palliative care

The aim of palliative care is to provide 'spiritual care, relief and management of symptoms and the total care and support of the resident and their family member during the terminal phases of illness' (Scott et al., 2014, p. 397). In other words, palliative care seeks to support the best quality of life for the resident and their family when the former has a life-limiting illness. Palliative care extends beyond physical treatment, offering care that also meets the person's emotional needs. Hence, good quality palliative care encompasses family involvement, comprehensive support for the patients, clinical management, and effective pain control (Vedel et al., 2014). In a qualitative study of the views of stakeholders of the key elements of palliative care, Vedel et al. (2014) proposed a comprehensive approach to patient care, underpinned by the premise that a predominantly technical approach—which emphasises the physical needs of the patient—is insufficient, as they under-represent interpersonal and interactive approaches. In addition to treating physical distress, it was essential to support patients' psychological state (Vedel et al., 2014).

With a more specific aim of defining specialist palliative care, Forbat et al. (2020) undertook a three-phase Delphi study involving qualitative interviews and two questionnaire cycles with 31 clinicians (doctors, nurses and social workers). A consensus definition developed from this study is as follows (Forbat et al., 2020, p. 316):

> *Specialist palliative care offers empathic, compassionate and comprehensive biopsychosocial care for patients who will die from their illness, and their families. Care is focused on quality of life and dignity, enabling people to live well until they die. Specialist palliative care clinicians have evidence-based expertise in managing pain, prognostication, diagnosing dying and recognising dying as a natural part of*

> *life, and are highly skilled in communicating about death and dying. These clinicians manage conflict on decision making around benefits and burdens of treatment, complex symptom management and expert knowledge on medications and complex pharmacology while navigating the complex ethical regulatory aspects of care. Specialist palliative care clinicians support patients with high distress and complex needs and family dynamics, and are involved in complex bereavement support.*

Chronic diseases, in particular, are challenging to manage effectively, with intervention usually focusing on supportive care and treatment to avert disease progression, discomfort, reduce pain and reduction in activity (World Health Organisation, 2014). The number of people receiving palliative care services in Australia increased by 52% between 2002–03 and 2011–12 (Australian Institute of Health and Welfare, 2014). In 2018-19, older adults (those aged 75 years and older) accounted for just over half of palliative care (53.6%) hospital admissions; in RAC, almost 30% of residents required palliative care in 2018-19 (Australian Institute of Health and Welfare, 2021b). As the need for palliative care increases with age, there is a clear need for palliative care services in Australia, and in RACS in particular (Beck et al., 2014; Picot et al., 2015). In 2019-20, palliative care prevalence in aged care increased from 10% in people aged under 70 years to 50% in residents aged 85 years and over (Australian Institute of Health and Welfare, 2021b). However, there are no data available specifically for cases of mental-palliative co-morbidity.

While numerous studies have been conducted into palliative care best practice (Forbat et al., 2020; Rainsford et al., 2020; Woods et al., 2008), less is known about best practice for RACS residents with mental-palliative co-morbidity. As highlighted in a review of palliative care for persons with severe persistent mental illness, Donald and Stajduhar (2019) confirmed the complex needs of this highly vulnerable population, which were not being consistently met by the healthcare system. Findings related to complexity of care, limited access to care (both via healthcare providers and systems), autonomy and competence, and the potential for enhanced relationships between mental health and palliative care (Donald & Stajduhar, 2019). Further qualitative and quantitative research studies are required in this area, and interventions need be developed and validated based on current knowledge to inform care.

2.4.1 RACS capacity for mental-palliative care

Population ageing and increased prevalence in mental illness are resulting in a progressive increase in complex and intensive treatment interventions and care (Nay et al., 2014). Despite its complexity, RACS are increasingly responsible for providing care for older adults with mental illness and life-limiting physical illness (mental-palliative co-morbidity) (Frey et al., 2020; Picot et al., 2015).

RACS are often required to deliver complex and comprehensive care to residents, even though they may not be adequately resourced to do so. In a study of the experiences of RACS and specialist palliative care services in delivering palliative and end-of-life care, Lane and Philip (2015) highlighted the importance of managing expectations of care. Through qualitative interviews and focus groups, participants shared their experiences of low expectations of the care available in RACS, pressures in tackling complex decision-making and coexisting administrative responsibilities, and varied views between RACS and specialist palliative services staff related to their individual roles. Additional challenges in RACS are that the standard model of care delivery is premised primarily on an acute medical model of care, with minimal supervision from nursing and medical staff (Lane & Philip, 2015). Hence, these services are not well-positioned to provide the required amount of palliative care services and complex care to residents with mental-palliative co-morbidity.

While the need for education in aged care is well known, Bhar et al. (2020) suggest that it would be appropriate for RACS managers to recruit mental health specialist nurses to assess and manage agitation and behaviours of concern.[6] RAC staff and GPs report lacking the skills and knowledge required to support mental health in older adults, often underestimating the incidence and effect of mental illness in this cohort. This is made more complicated by dementia, physical illness and multiple comorbidities (Bhar et al., 2020; Davison et al., 2017).

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[6] Challenging behaviours are those that are of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others, and are likely to lead to responses that are restrictive, aversive or result in exclusion (Royal College of Psychiatrists et al, 2007).

There are several fundamental barriers to caring for persons with mental-palliative comorbidity. Exploring nurses' experiences of providing palliative care to persons living with mental illness in Dutch mental health services, Evenblij et al. (2016) highlighted the importance of care domains, multidisciplinary collaboration, nurse early involvement and support of the family. It was noted that palliative care for persons with mental illness required increased psychosocial and spiritual care approaches, compared to palliative care for persons without mental illness (Evenblij et al., 2016). Emphasising better training of mental health nurses about palliative care, and close collaboration between physical and mental health care, Evenblij et al. (2016) confirmed the holistic palliative care needs of those with mental illness. While progress has been made, the findings of an earlier systematic overview of palliative care for people with severe mental illness remain relevant (Woods et al., 2008). The main findings indicated palliative care should be centred on the specific needs of individuals living with mental illness, which required a therapeutic relationship based on dignity, respect, hope, and non-abandonment (Woods et al., 2008). Woods et al. (2008) also identified the importance of integrated care, and cross-training in palliative care and mental health.

In a recent UK study of views and expectations of palliative and end-of-life care, Jerwood et al. (2021), interviewed five persons living with severe mental illness and a co-existing incurable physical health condition, and three of their carers. Patients and carers identified four key themes related to experiences of care. First, patients experienced a high incidence of prejudice and stigma. They highlighted the importance of 'seeing me, not my diagnosis', and to consider the whole person. Second, health care staff demonstrated limited confidence, fear and/or held beliefs that persons living with mental illness were associated with limited capacity and higher risk, resulting in avoidance, hesitancy and abandonment often occurring in care. Third, it was important to recognise carers' roles and the negative impact of the caring role, emphasising the need to recognise and support carer needs. Fourth, both patients and carers described negative experiences of abandonment by services, limited connection and difficulty in accessing services. They recommended enhancing connections between services, and 'leaning in' to work together with the patient and carers (Jerwood et al., 2021).

The focus of mental-palliative care needs to be directed and self-determined by the person living with mental illness. In a study of preferences for end of-life care among persons living with serious mental illness, Foti et al. (2005) reported that individuals could elect treatment preferences in response to palliative and end-of-life situations. While emphasising the need for further research, they suggested the potential for advance care planning, the assessment of permanency of decisions made over time, and the usefulness of situational-based preferences to guide end of-life care decisions in this population (Foti et al., 2005). Benefits associated with active participation in care decisions and advance directives included individual empowerment and autonomy, increasing therapeutic alliance and improving communication between patients, family, and health care services (Foti et al., 2005). Unfortunately, end-of-life discussions are often avoided with individuals with a serious mental illness. There is an assumption of incapacity and/or a fear that such communication will be cognitively and emotionally disturbing to the individual. Where a person’s capacity to make health care decisions is compromised by physical deterioration, cognitive decline and mental illness, there may be a necessity to appoint a substitute decision-maker[7]. However, this can become complex for people living with serious mental illness, as they may not have family or friends or may not identify a family member as a substitute decision maker (Woods et al., 2008). In these instances, it may be necessary to appoint a substitute decision-maker. Under the Mental Health Act 2014 and Aged Care Act 1997 (www.legislation.gov.au), a nominated person or advocate can be appointed to assist in this process.

The environmental design of the RACS is also an important element in the provision of mental-palliative care. A literature review by Chaudhury et al. (2018) found that many different aged care models have been established in Australia and internationally to promote older adults’ independence and provision of normalised and or home-like environments. They reported that extensive evidence on the positive influence of facility size, homelike atmosphere, spatial design, sensory stimulation, and environmental features enhancing social areas can impact on residents’ behaviours and overall wellbeing

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[7] A substitute decision maker can be appointed for a person who has compromised capacity. The substitute decision-maker can be authorised to make decisions about aspects of a person's medical treatment, finances or lifestyle (www.publicadvocate.vic.gov.au).

in RAC. Incorporation of positive environmental adaptions can play an integral part in fostering optimal mental-palliative care for residents.

2.5 Summary

In Australia and internationally, the aged care sector is continually striving to improve and provide excellence in care for older individuals. However, the aged care system, services and resources often fall deficient in meeting this need, particularly as older people are at increasingly higher risk of having multiple health comorbidities, and losses related to many aspects of their lives. Older adults are also living with mental illness, which has a significant impact on their physical health, wellbeing and quality of life. There are also inadequacies and barriers to effective care and treatment of persons living with mental health illness. In addition, older persons with mental illness will at some stage require end-of-life and palliative care. There is a lack of current literature exploring the mental and palliative care needs for individuals living in RACS.

CHAPTER 3:
Design and Method

3.1 Introduction

In this chapter, the design and methods of the study are presented. The chapter commences by outlining the conceptual framework and design rationale. Following this, a summary of the participants and recruitment, and methods of data collection are considered. Finally, the ethical considerations, data analysis and rigour of the study are discussed.

3.2 Conceptual framework for the study

Application of theory to nursing practice has long been known to have gaps, and the way in which theory is conceptualised and framed can fail to communicate and or address the current practice issues (Stevenson, 2005). In practical theory development, it is expected that important contributions to theory will come from practitioners in the course of their work and that those who are primarily theorists will engage with practitioners, who will then become involved in applied work (Reed & Shearer, 2008).

In their early work on the coordinated management of meaning, Pearce and Cronen (1980) proposed a systemic, social constructionist and pragmatist systemic approach that recognised the influence of context. A social constructionist anticipates the research process as construction, rather than capture, and pragmatic, in that the value of inquiry is determined by whether it helps people to ‘go on with’ their lives (Stevenson, 2005).

The current study used a social constructionist paradigm, whereby three elements were considered. First, reality is varied, process driven, and constructed under each study’s particular conditions. Second, research processes transpire from interaction with participants. Third, it considers the researcher’s personality, along with that of the participants. (Charmaz, 2008). In conjunction with a social constructionist/pragmatist position, this study followed the fundamentals of interpretative phenomenological analysis (IPA). This framework acknowledged that we are each influenced by the worlds in which we live in and the experiences we encounter. Therefore, IPA is an interpretative process between the researcher and researched, influenced predominantly by Heidegger's interpretive phenomenology, hermeneutics and idiography. The multi-faceted use of the social constructionist, pragmatist paradigm and IPA has the potential to support the development of new nursing theories (Peat et al., 2019).

3.3 Design rationale

In the healthcare field, qualitative research is an essential approach to enhance understanding and inform health equity, research and clinical practice (Sacks, 2015; Shelton et al., 2017). It enables a thorough and detailed understanding of the factors that influence health and disease, potential interventions and opportunities for testing and developing theories (Shelton et al., 2017). Researchers using qualitative methodologies strive to understand the feelings, thoughts and experiences of research participants. In the health field, the focus is on people dealing with health problems and treatments in a particular setting. This type of research is often premised on the researcher aiming to 'understand, describe and interpret social phenomena as perceived by individuals, groups and cultures' (Holloway & Galvin, 2016, p. 3).

3.4 Qualitative research

Qualitative research is considered particularly appropriate to the health care sector, as it allows the researcher to work across disciplines, fields and subjects (Holloway & Galvin, 2016). By immersing themselves in the natural setting of the participants whose thoughts and behaviours they hope to explore, qualitative researchers take the 'emic' perspective, that is, participants' views, interpretations and perceptions, and the meanings they attribute to them (Sacks, 2015). In addition, qualitative researchers use 'thick description' to describe, interpret and analyse the data. Thick description is a comprehensive account, uncovering feelings and the meanings of participants' experience and actions (Holloway & Galvin, 2016). These detailed descriptions provide context, particularly related to emotion and social association. In this way, the association between the participant and the researcher is close, professional and personal, and founded on a view of equality as human beings. Adopting a non-judgemental stance, gaining mutual trust and rapport are crucial to this process (Sacks, 2015).

Different qualitative research methodologies include (Holloway & Galvin, 2016):

- Phenomenology, which aims to describe and explore phenomena, as described by research participants. It is sometimes referred to as ‘the lived experience’ of a situation.
- Grounded theory, which takes a systems approach, whereby the researcher collects and analyses data, then develops a theory based on and grounded in the data.
- Narrative analysis, which emphases the way participants present their accounts of themselves. Where self-narrations are both claims of identity and constructions, narrative research provides access to deep and new thoughts, perspectives and experiences.
- Ethnography, which concerns the study of human behaviour in the context of culture, to increase understanding of cultural norms, rules and routines. Driven by process, methods and strategy of research, the ethnographic account is a portrait of the group being studied and is often relayed in a written story.

The qualitative research approach used in the current study was IPA.

3.4.1 Interpretative phenomenological analysis

IPA was developed by Jonathan Smith initially as a qualitative approach in the discipline of psychology (Smith, 2017). Now used in a wide range of health and social science disciplines, the function of IPA is to explore the lived experience of participants and recognise their individual and social context, while acknowledging the researcher’s interpretation and organisation of the data (Biggerstaff & Thompson, 2008). As a participant-oriented approach, IPA encourages participants to express themselves and their lived experience in a way that enables in-depth understanding on the part of the researcher (Alase, 2017). In this way, participants provide an idiographic explanation of their experiences and what it means, within their social context, to live with a specific condition or be in a certain situation (Biggerstaff & Thompson, 2008).

IPA is based on the three main principles of phenomenology, hermeneutics and idiography. First, phenomenology, introduced by Edmund Husserl, is an eidetic method that seeks to identify the elements of an individual's experiences, which make them unique or distinguishable from others' (Smith, 2017; Terra & Passador, 2015). Thus, eidetic reduction distinguishes the essential characteristics of a given thing (Levin, 1968). Eidetic reduction occurs through the removal of any parts that are not crucial for the recognition of the phenomenon, in order to construct a rich understanding of the phenomenon as experienced by a person in the current time and place (Terra & Passador, 2015). It focuses on how a person perceives or discusses certain events and does not follow specific criteria or systems that may superimpose any preconceptions on the data (Pietkiewicz & Smith, 2014). This process supports the researcher's goal of exploring what makes one person's experience unique from another's.

Second, IPA is premised on hermeneutics, whereby researchers seek to understand people and the contexts in which they exist (Heidegger, 1953). By going beyond description to interpretation, Heidegger (1953) maintained that true understanding was only possible through human engagement. This involves the researcher interpreting the language of participants, in order to understand the meaning associated with their experiences (Pietkiewicz & Smith, 2014). Put simply, the researcher 'stands in their shoes'.

Third, IPA incorporates an idiographic approach, where the researcher explores every single case before producing any general statements. The researcher seeks to analyse each situation in fine detail. More commonly, IPA involves an in-depth analysis of the data, progressing to a search for patterns in the data. It necessitates taking a conventional iterative approach, where the researcher reads through the transcripts several times, taking note of various emerging themes, and grouping and refining them into superordinate themes and related sub-themes (Smith, 2011). The emerging themes are examined for relevant connections, and a list of resulting superordinate themes generated (Terra & Passador, 2015). This process can be a balancing act between diversity (divergence) and alignment (convergence) (Boon et al., 2014).

As a predominantly qualitative approach, IPA is particularly suited to the current study of RACS staff caring for residents with mental-palliative comorbidity, because of the focus on the lived experience of and the rich detailed information that is collected, which is not easily translated into numerical codes. IPA is especially suitable for the study of under-researched, complex or new phenomena, and enables researchers to better understand process and change in a phenomenon (Smith, 2017).

3.5 Methods of study

3.5.1 Setting for the study

The study took place in a large private RAC provider in Melbourne, Australia. The RACS had 26 independent residential services, while also providing community-based support services. Each of these services offer a range of aged care services to promote health and wellbeing whilst supporting residents' social, physical, emotional, mental and spiritual needs. Health care staff provide supportive care, including attending and supporting activities of daily living, medication administration, specialised care and leisure and lifestyle needs. Some residents also require palliative and mental health care. Recruitment took place at three of these residential services (Unit One, Unit Two and Unit Three), which are located in separate geographical locations across Melbourne. Each unit has approximately 100 residents and 60 staff, consisting of RNs, ENs, PCAs, a lifestyle coordinator, and catering and cleaning staff. All units have individual rooms with *en suite* bathrooms, and multiple dining and recreational spaces. Of the units selected for the study, two had a 10-bed section for residents with neurocognitive disorders.

3.5.2 Selection and recruitment of participants

The researcher obtained approval to recruit participants from the organisation's chief executive officer. The researcher then approached individual RACS homes from the organisation, first by email and then in individual discussions with each manager. At this time, RACS managers were informed about the aims, processes and timing of the study. Recruitment then commenced, using the following inclusion criteria for RACS staff:

- Currently employed as a RN, EN or PCA;

- Worked in RACS for at least two years; and
- Aged 18 years or over.

No exclusion criteria were applied. Potential participants were approached and informed briefly about the study by the RACS site manager. If interested in participating, and agreeable, a time was made by the researcher to meet with the RACS staff member individually at the home to discuss the purpose, procedures, and significance of the study, confidentiality and consent. Participants were encouraged to ask questions about the study and were given a copy of the participant information (Appendix 1) and consent form (Appendix 2). They were also advised that they could withdraw from the study at any time and were not required to provide an explanation to the researcher for withdrawing. Participants were reimbursed with a $30 gift card at the end of the interviewing stage.

A sample size of 12 participants were purposively recruited. There were no difficulties encountered in the recruitment of this sample size. A sample size of 12 was determined as appropriate in size, for a qualitative: IPA study, allowing the emphasis to be on the participants lived experience and expression of rich, in-depth and detailed information (Smith, 2017). In addition, this sample size met the requirements for a master's research study.

3.6 Data collection

3.6.1 Interviews

Twelve staff members were recruited purposively from the three RACS homes, four from each facility. Individual, semi-structured audio-recorded interviews were used to collect data. Interviews were conducted in a private quiet room, specifically arranged for the purpose of the interviews. The interview rooms were situated in a non-clinical area limiting distractions and interruptions. Participants were agreeable to use the RACS interview room. All participants agreed to conduct the interviews at the workplace during their shift as this was more convenient. The interviews were guided by an interview guide (Appendix 3). In IPA, interview questions are used to guide a natural flow of conversation

(Pietkiewicz & Smith, 2014). An important approach is to use predominantly open-ended questions, and to ask questions that were not leading and did not reflect the researcher's values and/or assumptions (Smith, 2011).

In line with the study aims, the interviews sought to gain understanding of participants':

- Experience in caring for residents with mental-palliative comorbidity
- Role in managing mental-palliative care for residents in RAC
- Type of pre-qualification and/or in-service training in relation to caring for residents with mental-palliative comorbidity
- Decision-making about when to engage external services for assistance in providing mental-palliative care
- Access to health and wellbeing services at work, to support them in their role in providing mental/palliative care
- Other training and/or support needs that would help in the role of caring for residents with mental-palliative comorbidity.

The interview process allowed the researcher to stimulate discussion, while allowing time for participants to add detail freely.

3.6.2 Socio-demographic questionnaire

Sociodemographic information was collected to obtain a deeper understanding of participants' backgrounds. At the beginning of each interview, participants completed a short socio-demographic questionnaire (Appendix 4) focusing on their age, gender, education, position(s) held at the RACS home, years of employment, and prior experience in providing health care.

3.7 Assumptions and expectations

In qualitative research, the researcher is the device for collecting data and, unconsciously or consciously, impacts on how data are collected and analysed (Charmaz, 2008). Hence, it is essential that they adopt a reflexive approach in managing the 'human as instrument' in qualitative research (Holloway & Galvin, 2016). Reflexivity is defined as a process by means of critical reflection of oneself as a researcher (Denzin & Lincoln, 2011). This necessitates qualitative researchers developing self-awareness, through monitoring and analysis, to acknowledge their position and function within a study. Reflexivity also incorporates the interaction between the researcher, participants and the research itself, and takes into consideration how the research process can affect the results and outcomes of the study (Holloway & Galvin, 2016). Hence, it is imperative for the researcher to be reflexive, be open about their weaknesses and strengths, and analyse their influence on the research setting, and to take notice of others' responses to them (Tracy, 2010).

The student researcher has practised as an RN for over 20 years, predominantly in RAC. This experience underpins her beliefs, values and expectations about legislated practice standards and best practice knowledge. During the data collection phase, she was acutely aware of the need to maintain an unbiased view. Awareness of personal bias is essential in relation to issues of research credibility (Biggerstaff & Thompson, 2008). It is essential that qualitative researchers engage in self-reflection, to have a sense of oneself and a clear understanding that the research is also another person's personal life experience (Alase, 2017). A useful tool to enhance self-reflection is a journal, which was used to record emerging thoughts and beliefs. These were then discussed during formal supervision sessions with her academic supervisors.

3.8 Ethical considerations

The current study conformed with the ethical requirements and guidelines of the World Medical Association Declaration of Helsinki (2013). This is a statement of ethical principles for conducting medical research involving human subjects as well as research on identifiable human material and data. The research also conformed with the National Statement on Ethical Conduct in Human Research (2018) and Victoria University Human Research Ethics Committee guidelines. As the focus of the study was primarily on RACS care staff experience and educational needs in caring for residents with mental-palliative comorbidity, it was considered a low-risk study, and was approved by the University's Human Research Ethics Committee (Approval Number: HRE17-143). The key ethical issues addressed in the study included informed consent; the right to withdraw; privacy, confidentiality and anonymity; data storage, access, and disposal; and minimising the risk of harm to participants and the RACS organisation.

3.8.1 Informed consent

A major aspect of research ethics is the idea that people's autonomy should be respected. Informed consent is crucial to protecting the participant in research. It has two elements: a verbal component, which consists of a discussion, generally between the potential investigator and the participant, and a written element, which involves documents given to the potential participant, and is anticipated to facilitate discussion with the potential participant (National Health and Medical Research Council, 2007). Informed consent is an important ethical principle in protecting research participants and informing them of the benefits and risks of a study (Polit & Beck, 2014). First, the participant information letter and consent form were supplied to RACS staff participants before obtaining informed consent. Once the researcher had held information sessions with RACS staff, informal one-to-one meetings were then held with prospective participants, the latter of which were also given a written and verbal explanation of the study. The explanation included the purpose, procedures, participant rights, confidentiality, and consent. The potential benefits and risks of the study were explained thoroughly. Prospective participants were encouraged to ask questions about their participation, which were answered fully, prior to written consent being obtained.

3.8.2 Right to withdraw

Autonomy, in research ethics, has been associated with whether researchers are infringing on people's right to self-determination (Hammersley & Traianou, 2012). Self-determination is a 'basic psychological need for competence, autonomy, and relatedness' (Wehmeyer et al., 2017, p. 192). This concept is closely related to the right for research participants to terminate their participation at any time. However, participant withdrawal can be detrimental to research and the community, by delaying studies, making data less reliable and increasing costs (Edwards, 2011). Nevertheless, participants were made aware of their right to pause or terminate the interview and/or withdraw from the study. In the current study, no participants withdrew.

3.8.3 Privacy, confidentiality and anonymity

Protecting participants' confidentiality extends to the storage of data, including field notes, audio/video-recordings, other documents, and transcriptions need to be kept in a secure location that makes it hard for others to access (Hammersley & Traianou, 2012). This relates to the physical storage of printed as well as to electronic records on computers, computer servers, or in data storage clouds. The researcher considered carefully how to protect participants' privacy and confidentiality, to ensure this was not compromised. The participant's interviews were conducted with allocated time gaps in between each participant interview to ensure privacy and confidentiality was maintained. There was no concern raised by participants about being identified. In relation to data protection, the researcher, working with her supervisors, ensured that data remained securely transferred and stored in a timely manner. All electronic data were password protected. In this study an anonymous approach to recruitment and reporting was undertaken to uphold privacy. It may also serve to protect people from harm; for example, public embarrassment, or physical or financial risk (Hammersley & Traianou, 2012). The researcher maintained participant data as anonymous by (electronic and printed) de-identified via the use of a unique identifier code and use of pseudonyms.

3.8.4 Data storage, access, and disposal

It is the obligation of the researcher to provide adequate safekeeping and security of all data collected (National Health and Medical Research Council, 2007). All electronic material and printed material were stored and saved and or scanned to the university's secure R-drive. Data are accessible to the student researcher, chief investigator and associate investigator and are password protected. All hardcopy documents are kept securely in a locked cupboard. All data will be disposed of after five years, when hard copy information will be shredded and electronic files deleted.

3.8.5 Minimising the risk of harm

One of the most debated and crucial principles of research concerns harm minimisation (Hammersley & Traianou, 2012). Although the risk of physical harm to participants was considered low in the current study, there was a risk of participants experiencing emotional discomfort. Efforts to reduce this risk included setting up a safe and private environment to conduct each interview, as well as the voluntary nature of the interviews. All participants were given information about the National Nursing and Midwifery Health Program (www.nmhp.org.au), which provides a free, confidential and independent support service for nurses, midwives and students.

Another safeguard was the experience and skills of the researcher. In the current study, the researcher is a RN, with specific experience in mental health and palliative care settings. She had practiced in similar RACS settings and understood the operational and personal considerations that needed to be considered when conducting research in these settings. The researcher's experience made her well-placed to develop and maintain positive relationships with participants that fostered open, honest and respectful communication. Furthermore, the researcher had valuable prior experience in quality management, particularly in conducting qualitative interviews in a similar workplace setting, collecting data from staff. In the current study, two participants became mildly upset during interviews , the participants had a short pause, were offered 1-1 support, including acknowledgement, validation and empathy by the researcher a Registered Mental Health Nurse. The participants were offered tissues and a warm drink. In addition they were given information related to seeking available professional counselling services. The participants were able to easily compose themselves and chose to resume the interview.

3.9 Data analysis

The interview data and field notes were transcribed verbatim and analysed in line with the IPA methodological approach. The researcher read the transcribed data several times and immersed herself in the data. Listening and re-listening to audio recordings and repeated readings of the transcripts is vital to promote reflection, on the developing themes and topics, and that also may need clarification (Wagstaff & Williams, 2014).

Because interviews were audio-recorded, verbatim transcripts represented exactly what was said at the current time of the interview. Thus, participants were not asked to revise their interview transcripts. While views differ on the value of 'interviewee transcript reviews' (also known as ‘member checking’), in qualitative research there is evidence that participant reviews add little to the accuracy of data (Hagens et al., 2009; Thomas, 2017).

A qualitative research software program was used initially to facilitate data analysis and theme identification. Notes, thoughts and reflections were documented from the recorded interviews. This allowed the researcher to focus on the language used, content discussed and provided context (Pietkiewicz & Smith, 2014). These notes included the researcher’s questions, recurring phrases, the researchers own feelings, and descriptions of, or comments on, the language used. The notes were used to document points that the researcher observed while reading the text, these notes were documented as initial notes in one margin of the transcript (Smith, 2011). An important aspect of IPA is offering interpretative analysis which is joined closely to the description coming from the participant. A common characteristic of IPA is its idiographic dedication to the thorough analysis of the personal experience of each participant, so in the final report, the experience of each person still has a presence and there is a formulation of both divergence and convergence within the study sample (Smith, 2011). In keeping with this approach, data were analysed to identify recurring themes about RAC staff experiences of caring and services for residents with mental-palliative comorbidity. Specific words raised by participants were coded, and codes were grouped into conceptual themes. In addition, a process of data reduction occurred to exclude incomplete data. All data were analysed until a consensus in themes was reached (Smith, 2011).

3.10 Study rigour

Several factors can impede upon the effectiveness of qualitative approaches. A researcher’s lack of methodological knowledge, where there is minimal understanding of the complexities of the chosen methodology before beginning the research, can result in flawed research (Holloway & Galvin, 2016). Another difficulty is ‘drowning in data’ and the need for time, to conduct the study. Qualitative research produces large amounts of data, within a short space of time, which requires time to enable comprehensive analysis and reflection. The data transcripts were firstly read then uploaded, analysed and coded manually. In addition, ‘methodolatry' can occur when an over-reliance on method instead of the substance of the data can occur (Holloway & Galvin, 2016). Consequently, this may lead researchers to distance themselves from participants, by valuing method over participants’ ideas and thoughts. In this study risks were mitigated through regular research supervision.

Another key consideration concerns ‘romanticism' and ‘emotionalism,' where researchers get too close to participants while describing their experience (Holloway & Galvin, 2016). Instead, it is recommended that researchers listen to the voice of participants and explore their world. Researchers also need to be mindful of ‘method slurring' as qualitative research includes a variety of approaches for data collection and analysis, based on different philosophical positions and various disciplinary perspectives. Neophyte researchers can have difficulties differentiating qualitative methodologies, methods, procedures, assumptions, and unique characteristics of each and thus ‘slurring' or ‘muddling' can occur (Holloway & Galvin, 2016). When applying methodologies, issues can arise, especially if using a mixed methodology, where interchanging concepts — if poorly understood — may lead to inconsistency and damage to the integrity of the selected approach. Important processes, like coherence, consistency, and clarity within a single approach, need to be maintained. In contrast, other stances are taken by researchers to utilise flexibility in research; identifying what can be mixed and used in an approach is useful (Holloway & Galvin, 2016).

In research, use of the term ‘rigour’ suggests that the research is managed systematically and to a high standard. Hence, the more rigorous the research process, the greater the probability that the research outcomes are deemed relevant and trustworthy (Holloway & Galvin, 2016). Essential criteria that can strengthen the trustworthiness of a qualitative study include credibility, dependability, transferability, and confirmability (Holloway & Galvin, 2016).

3.10.1 Credibility

Credibility refers to the truthfulness of the data, or the participants’ viewpoints and the researcher’s interpretation and representation of these viewpoints (Polit & Beck, 2012). Credibility is enhanced by the researcher describing his or her experiences as a researcher and verifying the research findings with the participants (Cope, 2014). Prolonged engagement in the research setting is key to allowing sufficient time to become acquainted with the participants and the context of the study. This may not be achievable and or necessary in some studies; for example, in one-off interviews. However, it is important to allow sufficient time for interviews and to establish rapport and trust so that participants feel able to communicate openly and honestly (Cope, 2014). This idea was embraced in the current study, by allowing sufficient time to complete each interview. Rapport and trust were established further by use of therapeutic communication skills, welcoming the participant allowing adequate time for introductions and explanations, offering tea/coffee and chocolates upon commencement.

Peer debriefing is an important way to increase creditability and includes inspection by a relevant professional peer researcher, who can challenge and provide support to the researcher. Records of peer debriefing should be part of the audit trail (Holloway & Galvin, 2016). In the current study, credibility was addressed in several ways by checking that the findings made sense. This was achieved by the findings being reviewed/audited with two research supervisors, with records of each draft being kept, as a way to enhance rigour. Triangulation can also help to confirm the data: this is achieved and drawn from a variety of sources, allowing conclusions to be obtained (Holloway & Galvin, 2016). In this process, the researcher can use various methods of data collection in an attempt to get an articulate, complete position of the phenomenon (Cope, 2014). Triangulation technique encompasses two or more theories, groups of participants, methods, instruments or investigators. Triangulation was fostered in this study through peer investigators, debriefing and fortnightly supervision meetings. In addition, triangulation was upheld by collecting participant interviews at three different RAC sites.

3.10.2 Dependability

The approach to enhance dependability is similar to those used to strengthen credibility and transferability. These include auditing, verification from participants, and asking colleagues and peers to scrutinise data collection and analysis techniques and interpretations (Baillie, 2015). Dependability allows for opportunities for auditing. A clear documentation of the audit trail of decision-making throughout the research process was upheld. Documentation and the process of the interviews were completed in the same way for all the interviews. In addition, each interview was recorded and the researcher referred to the same interview guideline sheet for all interviews. Finally, a reflective journal note of the interview was written after each interview by the researcher.

3.10.3 Transferability

Transferability is defined as the potential for findings to be transferred from one setting to another setting. Through rich description of the setting and participants, the researcher enable the audience to assess the transferability to other populations or contexts (Pietkiewicz & Smith, 2014). Transferability was demonstrated in this research by the completion of the participant socio-demographic information form and the interview guide. Furthermore, by giving a detailed description of each of RACS settings, this aided a greater understanding of the context and its transferability.

3.10.4 Confirmability

The criterion of confirmability relates to objectivity, in that it concerns neutrality and freedom from bias in the way in which the study is conducted, and the findings established (Cutcliffe & McKenna, 2004). In the current study, confirmability was supported by several practices to enhance the integrity of data collection and analysis. In particular, researcher journaling was incorporated. Journaling is instrumental in recording data, as this can support the development of interpretation and reflection (Vicary et al., 2017). Journaling also allows an intertwining of the double hermeneutic, as researchers attempt to make sense of the person attempting to make sense of what is happening (Smith, 2011). This is essential to the IPA approach. Reflective journaling also allows a further opportunity for the data to be validated. Therefore, a journal was kept by the researcher to enhance this reflective process.

3.11 Summary

This chapter presents the research design and methods, to ensure a sound and ethical framework was utilised for this research study. This study used a qualitative design, specifically the IPA approach. This enabled a comprehensive inspection and understanding of participants' lived experience and the meaning they attributed to that.

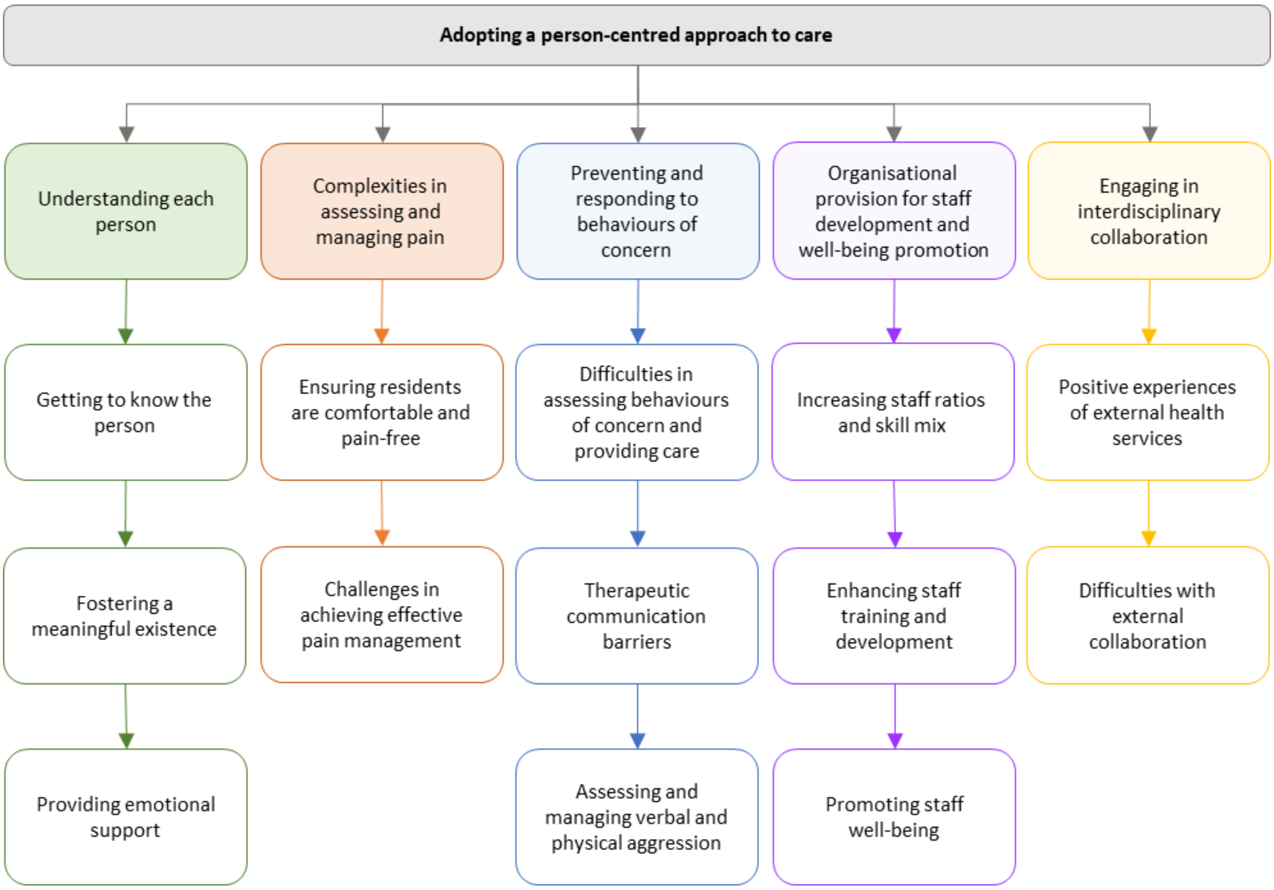
All ethical considerations were adhered to during the study. Data analysis involved coding and development of themes, which are presented in the next chapter.

CHAPTER 4:
Results

4.1 Introduction

In this chapter, the phenomenological and interpretative narrative of the experience of RACS staff caring for residents with mental-palliative comorbidity, is presented. The chapter begins with a summary of the socio-demographic characteristics of RACS staff participants. This is followed by an exploration of the overarching theme of *Adopting a person-centred approach to care* and five main themes: *Understanding each person*, *Complexities in assessing and managing pain*, *Preventing and responding to behaviours of concern*, *Organisational provision for staff development and wellbeing promotion* and *Engaging in interdisciplinary collaboration*. Each of the themes has related sub-themes (Figure 1).

Figure 1: Themes and related sub-themes



4.2 Sociodemographic characteristics

The study was undertaken in three RACS settings in Melbourne, Australia. A total of 12 participants took part in the study, including four female RNs, three female and one male EN, and four female PCAs (Table 1). The average age of participants was 37.7 years (range: 28-50 years). Two of the 12 participants were born in Australia, while 10 had lived in Australia for an average of 15.4 years (range: 2-48 years). Participants' average years of experience in the industry was 11.7 years (range: 2-26 years).

Table 1: Participant characteristics

Participant number	Role	Gender		Age bracket		Country of birth	Years living in Australia	Years of experience
		Male	Female	28-34 years	40-50 years			
1	RN	-	1	-	46	Australia	N/A	26
2	RN	-	1	31	-	India	9	10
3	RN	-	1	34	-	Philippines	4	3
4	RN	-	1	30	-	Philippines	8	7
5	EN	-	1	-	41	El Salvador	30	15
6	EN	-	1	-	50	Peru	27	22
7	EN	-	1	-	50	India	48	23
8	EN	1	-	-	40	India	12	10
9	PCA	-	1	31	-	Philippines	4	3
10	PCA	-	1	-	45	India	10	10
11	PCA	-	1	28	-	Nigeria	2	2
12	PCA	-	1	29	-	Australia	N/A	10

4.3 Overarching theme: Adopting a person-centred approach to care

The overarching theme of *Adopting a person-centred approach to care* was a central feature in the data. Participants highlighted that using this approach was paramount in caring for residents with mental-palliative comorbidity. The term 'person-centred care' was known by all participants, who recognised how a PCC approach contributed to residents' overall wellbeing and quality of life.

> *It's very important to making them Number One. So, they're the priority … they are there, so we have to be there for them. (Roslyn (EN))*

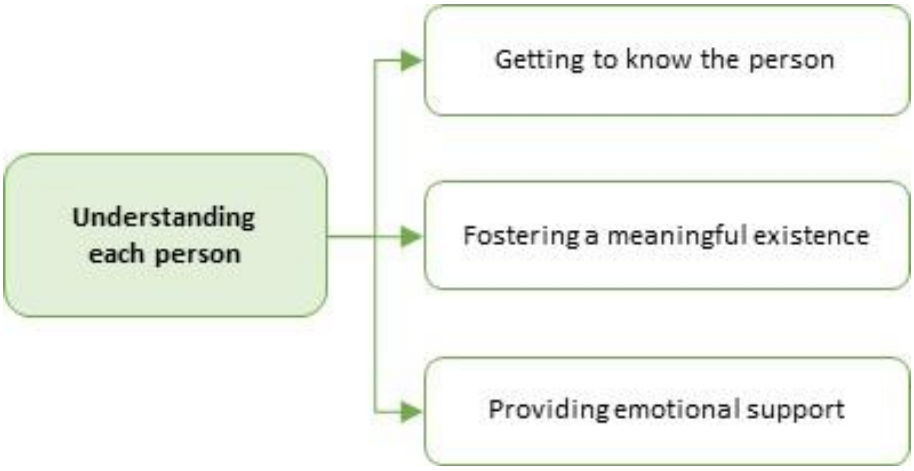
> [It's about] *the quality of life, not the quantity. So, you do your assessment, but make sure you value what he does as well. Like, what did he do before, what does he like, what makes him happy … that's your goal of care. (Imogen (RN))*

Understanding the importance of treating each resident as an individual, participants shared a commitment to tailoring their care and treatment to each resident's needs and circumstances. This commitment required understanding, flexibility and engagement by individuals and organisations. Within the overarching theme of *Adopting a person-centred approach to care,* five inter-related main themes were conceptualised as *Understanding each person, Complexities in assessing and managing pain*, *Preventing and responding to behaviours of concern*, *Organisational provision for staff development and wellbeing promotion*, and *Engaging in interdisciplinary collaboration*. Each is explored with its related sub-themes.

4.4 Main theme 1: Understanding each person

In the first theme, understanding each person was specifically highlighted as an important aspect when caring for the older person. Understanding each person's lived experience and actively listening to the person's life story allowed for a deeper understanding of the person. This was highlighted in three sub-themes: getting to know the person, fostering a meaningful existence and providing emotional support (Figure 2).

Figure 2: Understanding each person



Based on a clear understanding of the resident as an individual, staff were more likely to support a meaningful existence in which individualised and purposeful activities could be planned and implemented. An important component of this was giving one-on-one emotional support, which gave multiple benefits to the older person's overall wellbeing.

4.4.1 Getting to know the person

In this first sub-theme, several participants highlighted the importance of getting to know the resident personally, encouraging the resident to tell 'their life-story'. Understanding residents' past history and lived experience played a crucial part in the provision of care. Several participants highlighted that provision of care should be tailored and personalised to the resident's individual needs. This included being familiar with residents' care plans which detailed the values, needs and choices related to residents' future health and personal care wishes. This fostered respect for resident's rights, choice and preferences. Consequently, the resident became the central focus of care—a person with unique needs—rather than someone labelled with a diagnosis of mental illness needing treatment.

> *We have some residents with schizophrenia as well in their diagnosis. But they are actually doing well at the moment. Don't look at the diagnosis. You want to meet them personally and look at them as a person. I find that the diagnosis is not really the main thing. You always ask the story as well. (Imogen (RN))*

> *So now obviously the residents, they interact more in their care, their care plans are very important to us, what they used to do, we try to incorporate that in everyday, or in their everyday care. (Chelsea (EN))*

4.4.2 Fostering a meaningful existence

In this second sub-theme, participants commented that staff provided opportunities for residents to have a meaningful existence. A person's day should involve meaningful activities; these can be described as gratifying activities that engage the person to improve either their cognitive status, physical function or emotional wellbeing (Weber et al., 2015). A sense of life's meaning is associated with a belief that 'being', or existence, is valuable and worthwhile. This can be seen as a protective factor in enhancing mental wellbeing (Weber et al., 2015).

> *I think by allowing them to do some things, get them into activities, don't just abandon them. Some of them love painting, let them paint. Some of them love knitting, they can do it so sit down, do it in front of them, let them watch, it would bring back memories and that will really, really improve their life, their mental health. (Mavis (PCA))*

> *If we can get the carer to take them out shopping or even down the street for a cup of coffee, or even a walk in the garden or something small. (Chelsea (EN))*

Participants emphasised the importance of all residents choosing and being actively engaged in purposeful activities in their daily lives. These activities might include walking in the garden, going on community outings, staff promoting self-care abilities and independence, and resident collaboration and participation in undertaking activities of daily living. Opportunities to engage in meaningful activities had favourable effects on residents' mental health, wellbeing and overall quality of life.

> *Some people get depressed because they are unable to do things they can do. As an example ...* [at meal times], *give them a spoon and see if they can eat by themselves. (Mavis (PCA))*
>
> *It's always about quality of life ... it'll always go back to quality of life. (Chelsea (EN))*

4.4.3 Providing emotional support

In this third sub-theme, participants reported that spending time with residents enabled the provision of emotional support. This element of care was particularly important for residents with mental-palliative comorbidity, whereby emotional support positively affected the psychological stability of residents and family members.

Emotional support involves feeling and expressing care, listening, empathising respecting and supporting human dignity. It is also shown through sharing information, providing guidance and offering counselling. To this end, emotional support included sitting with, listening to and encouraging residents to express themselves. It also involved the use of therapeutic touch. A form of complementary therapy, therapeutic touch—which may simply involve holding a person's hand—provides an opportunity to strengthen rapport, demonstrate empathy and connection, and relieve emotional distress (Hanley et al., 2017).

> *It's just the emotional support, TLC* [tender loving care] *and stuff like that. Sitting there, holding their hand, just listening, sometimes not talking too much, just letting them express it (Kerin (PCA))*
>
> *We make time when we just sit down, whether we give them a cup of tea, just provide support, or just listen. (Imogen (RN))*

Participants also described the role of families and friends in promoting residents' emotional wellbeing. Wellbeing was also associated with a home-like environment, in which visitors were welcomed, shown care and empathy, and received information and education about their relative’s health and wellbeing status.

> *Not only for* [the resident], *but for the family as well … when they come to visit, we try to make it like at their home, you know, by giving attention, love and also explanation. So, we have to see are they happy with the care … and are the family happy? They need looking after as well … making all comfortable. You feel great when they say, ‘Thanks for talking care of my mum’. So, they know good things have been done for them. (Roslyn (EN))*
>
> *We also update the family, so they know the changes that are happening. (Norma (RN) (RN))*

4.5 Main theme 2: Complexities in assessing and managing pain

In the second theme, *Complexities in assessing and managing pain* were recognised as crucial in the nursing intervention (Figure 3).

Figure 3: Complexities in assessing and managing pain

Pain is common for residents in aged care facilities and several barriers make effective pain management more difficult to achieve in these settings (Savvas & Gibson, 2015). In the current study, participants described residents who were living with chronic physical and a co-existing mental illness, and whose lives were limited, and the many palliative care strategies used to manage their pain. A biopsychosocial[8] approach to care, with the goal of reducing distress and enriching the resident’s quality of life was used (Alderman et al., 2018). Participants wanted to ensure that residents had adequate pain management, however were cognisant of the challenges that impeded effective pain management. For those living with chronic health problems, life

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[2] Biopsychosocial describes three major dimensions (biological, psychological, and social) in the development of psychiatric disorders, that a person does not suffer as isolated organs but rather as a whole (Tripathi et al., 2019).

may be limited and effective palliative care strategies are introduced to manage pain. These are discussed in the following two sub-themes.

4.5.1 Ensuring residents are comfortable and pain-free

In the current study, several participants emphasised that it was imperative for residents to be comfortable and pain-free. They indicated that the provision of effective and consistent pain assessment and management was underpinned by comprehensive care planning and implementation. Participants used regular and PRN (as required) analgesia medication[9] that was prescribed in advance and readily available. However, participants described that a pain management plan was not always completed or in place. Once a resident was at the stage requiring end-of-life palliation, the primary focus was on ensuring the resident was comfortable and pain-free.

> *I put residents on pain charting. I make sure they're on pain medication, because I truly believe that a lot of the behaviours is always pain [related]. If a resident has got mental health issues, dementia, and is in an aged care facility, then they have got pain, then this makes it a thousand times worse. (Marni (RN))*

> *If you see that the resident is in pain, they're restless or they're distressed, what you can do is just inform your team leader and they can give painkillers. You can't do much* [in terms of acute medical intervention] *anymore; they are at an end stage, so just make sure that they are comfortable because it's just like really quality care and can't do anymore if they're at an end stage. (June (PCA))*

> *The resident could have PRN medications, like PRN morphine, PRN anything for when the time comes* [for end-of-life care] *so you're actually prepared. Have a nice care plan set-up for the resident so everything's in place. (Marni (RN))*

4.5.2 Challenges in achieving effective pain management

Participants highlighted that pain assessment and management was not always planned, delivered promptly and managed effectively as there were particular challenges in caring for this cohort of residents. The challenges related to residents' mental illness, dementia and language barriers, and staff lack of training in pain management and adequate assessment of pain. Consequently, nurses frequently assessed and relied on residents' non-verbal cues and were required to communicate with families to determine the level of pain and discomfort. Non-verbal cues included facial expressions and grimacing, which were evident during care

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[9] Analgesics are medications used specifically to manage pain these include paracetamol, nonsteroidal anti-inflammatory drugs (NSAIDs) and opioids.

activities such as re-positioning the resident. Participants also pointed out that residents’ behaviours can be exacerbated by pain, and that pain and behaviour were interrelated. Participants expressed the need for additional skills and training in effective pain assessment and management.

> *I'm talking now about residents. When caring for them. This lady was hard because you would say to her, ‘do you have pain?’ or you would assess her for pain and things like that, but because of* [resident’s] *language* [barrier] *and dementia, you don't know how much the resident really understands, and you have to go on non-verbal cues and other types of assessments to see if she is in pain or talk with the husband. (Rhonda (EN))*

> *You cannot see if the resident is in pain or not, as they cannot tell you. So, I have learnt that it’s important to give some medication. In your mind you can then say, ‘I know this person is not in pain because I’ve been giving their medication.’ We are able to check at a certain hour and then assess, ‘I don’t think they are in any pain.’ So that, for me, made me happy that the resident is not in pain. (Roslyn (EN))*

> *But I find that a lot of the behaviours come from pain. Even though they tell you they're not in pain, but you look at their non-verbal cues. Like you say, ‘Oh, have you got any pain?’ And the minute you move them,* [resident states] *‘Ouch’. Or, you see it on their face. So, pain causes a lot of behaviours. (Rhonda (EN))*

A final challenge related to perceived lack of support from GPs. Participants perceived the practice or views of some GPs impeded the administration of pain medication, as they seemed reluctant to prescribe analgesia to palliative care residents. Staff attributed this reluctance to the GPs’ limited understanding of palliative care. Once a resident was at the stage requiring end-of-life palliation, the primary focus was on ensuring the resident was comfortable and pain-free.

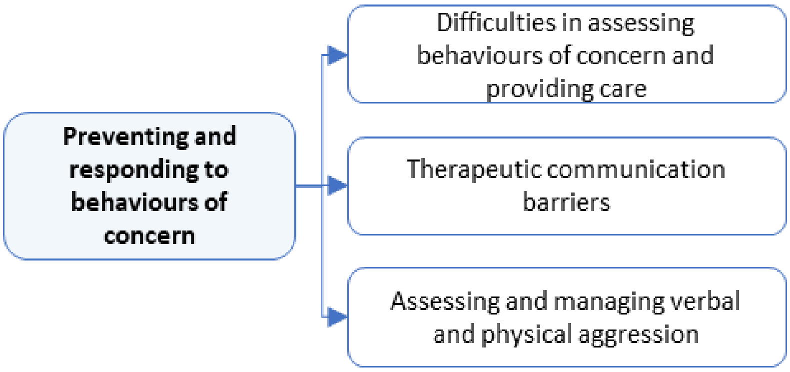
> *If I don't feel like their care needs are met, I actually will resort to external palliative care services, as sometimes you get doctors that block you* [non-provision of analgesia]. *They don't really believe in palliative care. One doctor said, ‘Palliative care is just a word.’ I won't mention names. The newer doctors that are out there are very good with palliative care and they're very ‘switched on’* [skilled in this area] *and they actually understand it. But there are particular older doctors that have been around for a while ... they just don't really see it as palliative care. I'm trying to get someone with mental health issues and end-of-life on the right medications and the right care for the resident, but the doctor doesn't believe that there's such thing as palliative care. So, I make sure they're not in pain, I end up getting a palliative care agency involved or make sure they've got the palliative care mediations if they're actually at the end of life-stage. (Marni (RN))*

4.6 Main theme 3: Preventing and responding to behaviours of concern

In the third theme, *Preventing and responding to behaviours of concern*, participants claimed that the mental illness component of the resident's comorbidity added a layer of difficulty to the effective provision of mental-palliative care to this cohort. Behaviour is considered 'challenging' when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others, and is likely to lead to responses that are restrictive, aversive or result in exclusion (Royal Australian College of General Practitioners, 2021). For residents with a diagnosis of dementia, incidents of behavioural and psychological symptoms of dementia (BPSD)[10] were also identified. Participants identified that they had difficulties assessing behaviours of concern, they felt threatened by verbal and physical aggression and that this had a detrimental impact on their therapeutic communication with the resident. They also felt that, because of their lack of knowledge and skills, they had difficulties in conducting a comprehensive mental health assessment and providing related care in this context.

Three sub-themes were abstracted from the data relating to these challenges: *Difficulties in assessing behaviours of concern and providing care*, *Therapeutic communication barriers*, and *Assessing and managing verbal and physical aggression* (Figure 4).

Figure 4: Preventing and responding to behaviours of concern



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[10] BPSD refers to the non-cognitive presentations of dementia, such as agitation, aggression, psychosis, depression and apathy (Royal Australian College of General Practitioners, 2021).

4.6.1 Difficulties in assessing behaviours of concern and providing care

In this sub-theme, participants recognised the difficulties of a mental illness diagnosis and the effect it had on the person requiring mental-palliative care. Undertaking an accurate mental health assessment was seen as challenging, with staff claiming they lacked sufficient knowledge to distinguish between behaviours associated with mental illness and those related to biological, physical, social and or emotional needs. Participants highlighted difficulty in recognising the underlying cause of the behaviour. An additional concern was a lack of knowledge of the residents' mental health and related history. Consequently, participants claimed that they frequently had inadequate resident assessment and background information available. Hence indicating gaps in the system in handover from family and other health professionals and access of comprehensive resident information. In addition, participants found that newly admitted residents with complex issues, required an extensive and thorough assessment process and this effected the ability for staff to provide prompt and effective care for these residents.

> *Someone who doesn't have a clear diagnosis, but does show something ... you feel like there is really something going on ... that's a bit of a challenge to find someone to actually say there is something wrong. Because, the family, the children, don't know that much. You talk to the GP, but they don't know him much because he's just been admitted here. (Imogen (RN))*

> *Getting residents that have mental problems, they're quite tricky to manage because sometimes they play up* [exhibit behaviours of concern]*. You don't know exactly what's going on with them mentally or physically, because you never know if what they're trying to explain to you is it real or just behaviour problems. So, we have to really assess them thoroughly. (Norma (RN))*

4.6.2 Therapeutic communication barriers

This sub-theme relates to the difficulties staff had in engaging and developing a therapeutic relationship[11] with residents with mental-palliative comorbidity. Participants identified a range of communication barriers in caring for this group of residents, including English as second language, delirium and raised levels of anxiety. Further, participants reported these instances were compounded when staff were busy, and were unable to give residents proper explanations. These barriers hindered residents' understanding of the care being provided to them. This

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[11] A positive therapeutic relationship between individuals and health professionals has a significant effect on health outcomes. This relationship—also known as a 'therapeutic alliance'—is based on shared values and beliefs, and respect for each other's expertise in managing treatment (Mace et al., 2017).

would often lead to confusion and distress and an escalation in residents' verbal and physical aggression.

> *When you're attending to them and they don't understand what you're trying to do, that's when all the* [challenging] *behaviours come out. A resident might have anxiety, increased confusion ... they don't understand what's happening. A lot of times staff might be in a rush, not explaining themselves properly, which increases their aggression ... and language barriers. If you've got mental health issues and they can't communicate because of the language barrier, it* [results in] *increased aggression, increased falls, missed pain* [diagnosis], *unless someone really understands the non-verbal cues. But sometimes there isn't enough skill-mix on the floor to see that. (Marni (RN))*

> *The main difficulty is to convince her that we understood her problems and we are here to help. At the start, she wouldn't believe that we understood. So, one of the challenges was staff and client resident interaction and relationship. (Roslyn (RN))*

4.6.3 Assessing and managing verbal and physical aggression

In this sub-theme, participants associated residents' episodes of verbal and physical aggression with dementia and/or mental illness. These behaviours of concern made the delivery of care more difficult and complex. Participants described how they would try to recognise causes and triggers for the aggression, and develop effective interventions that enabled them to manage the behaviour, while respecting each resident's autonomy and interests. One important strategy for managing verbal and physical aggression, for example, was to provide meaningful and purposeful activities to residents. These activities enabled residents to be engaged in activities that distracted and occupied them. If these strategies were not developed or applied, there was an increased risk of upsetting or disrupting the resident, which could lead to an escalation of aggression.

> *Most of the time, I find their behaviours come out because there's something going on ... someone is wandering and yelling, there's a new face, new staff. For example, a new staff member came through the door and sat him in the wrong chair ... he always wants same seat. You know, it's their routine. And you have to value it ... it's not like you're pampering ... but if they've been folding their clothes at 5:00am all their life, why would you change it now? So, that's always the goal. (Imogen (RN))*

Participants described their use of pharmacological and non-pharmacological measures to manage verbal and physical aggression in residents. Medications were a core intervention, mainly in the form of the administration of benzodiazepines[12]. In relation to pharmacological interventions, there was limited description of other medications were used, such as

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[12] Benzodiazepines are a class of psychoactive drugs used primary to relieve symptoms of anxiety, insomnia and seizures (Foster et al., 2021).

antipsychotics, or pain medication. Nor was there any information given to residents about the effects of medications or side effects. Further emphasis by participants was that pharmacological interventions were not always the only and or most appropriate option.

> *It's a combination of non-pharmacological and pharmacological treatments, medications with nursing comfort, like one-on-one interaction with a resident. (Norma (RN))*
>
> *Go for a PRN medication relaxant, but they're* [RACS] *always having a big push on behaviour management. Finding the problem. What's the problem? And, you know, you might have the same problem for one week and it might change the following week, but you know, it's not always the medication (Imogen (RN))*

Several non-pharmacological behaviour management interventions were adopted, such as simply being with the resident and providing one-to-one interaction, active listening, providing emotional support, and offering the resident a warm beverage. These interventions were seen as fundamental to participants' efforts to de-escalate[13] behaviours of concern. Frequently, the effectiveness of these strategies was determined by how well the participant understood the resident's individual circumstances and needs. This understanding of the individual was crucial in enabling the provision of PCC.

> *We have strategies in place that settle them down nine times out of 10. For a lot of our residents, it's basically just sitting with them and listening to them. So, we make time, where we just sit down, give them a cup of tea, provide support, or just listen. (Kerin (PCA))*
>
> *While working in this facility, I have had lots of residents who have different behaviours of concern. Sometimes, when you sit down and talk to them one-on-one, they are really good ... emotionally, they like it. But sometimes you have to face the challenging behaviour ... the resident can be aggressive, they can be physically aggressive and verbally aggressive ... it depends on the* [delivery of] *mental care. (Maree (PCA))*

Other ways to de-escalate residents' anxiety and reduce the risk of aggression were more complicated. For example, singing could be effective for one resident, but have the opposite effect and cause agitation to others. This again highlights the importance of knowing the residents and their individual preferences.

> *I have a resident who has trouble with anxiety ... they are ready to hit you, but I've been able to calm them down with my talent, because I sing a lot. But some also get agitated with the singing, I've got to know what each one of them wants, how I can get them settled. (Mavis (PCA))*
>
> *If that person continues making that noise,* [other resident] *sometimes can come and just, you know, get physical with that resident. So, we have to intervene there and remove the*

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[13] De-escalation involves the use of behaviours or techniques intended to prevent escalation of conflict.

> *resident, or maybe give something to make her forget what happened, or take her to do some activities according to her background or care plans (Roslyn (EN))*

Participants also described occasions on which verbal and physical aggression could not be decreased in a timely or effective manner, by pharmacological or non-pharmacological means. These events often had a detrimental effect on the individual person, as well as residents and staff. Other residents become more agitated and distressed, staff and residents both experienced increased levels of frustration.

> *One of the hard things is dealing with the behaviours. It can get a little bit frustrating sometimes, and for them as well, because they get themselves into a state where it's really hard to provide that reassurance and support and stuff like that. (Mavis (PCA))*

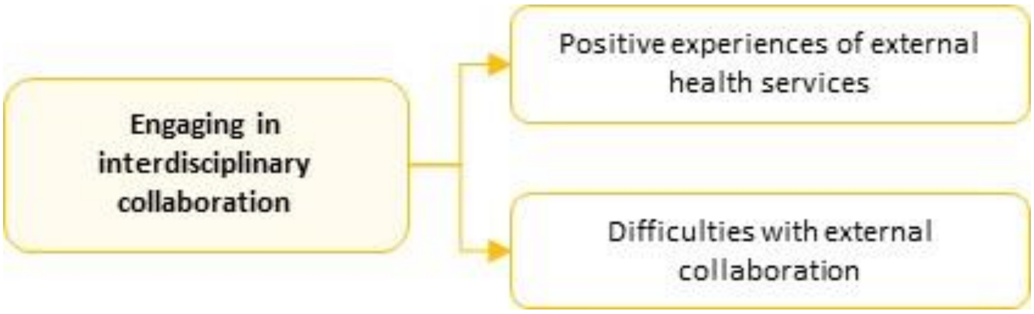
> *Sometimes she will say, 'All right, I'm getting up. I'm walking out of the glass door and I'm leaving you'. She starts saying bizarre things. That's how I know we're getting towards that stage, before she hurts herself or she aggravates others and they try to hit her. (Rhonda (EN))*

> *When she is unwell, she can't even string a sentence together. She cannot feed herself. She can barely walk, she's paranoid, she suddenly starts swearing at you. She'll be scratching at her skin … it's not very nice. (Chelsea (EN))*

4.7 Main theme 4: Engaging in interdisciplinary collaboration

The fourth theme, *Engaging in interdisciplinary collaboration,* centres on the interaction of RACS staff with other external health professionals, such as medical practitioners, specialist external services and allied health services (Figure 5). Interdisciplinary collaboration involves interprofessional collaboration between two or more disciplines, and communicating with one another about resident care (Fox & Reeves, 2015).

Figure 5: Engaging in interdisciplinary collaboration



Fostering clear communication and collaborative relationships between different disciplines and external health organisations and overcoming multiple barriers, is imperative element for quality and consistency in care (O'Connor & Fisher, 2011). Collaborative interdisciplinary health care includes a number of different health care professionals in the care of a person, but also involves various professionals communicating and working together in co-operative manner, with progress towards a shared goal. Interdisciplinary collaboration between health professionals is a requirement for providing PCC, especially in circumstances where people require specific expertise from numerous clinicians to effectively manage complex chronic health disorders (Kerosuo, 2010). Interdisciplinary collaboration is an essential element of health care. Effective interprofessional collaboration among various health care providers has long been considered pivotal for delivering good quality PCC (Fox & Reeves, 2015). Interprofessional collaboration can be challenging to attain, related to collaboration issues such as, a lack of understanding of each other's professional responsibilities, restricted communication, and inadequate teamwork (Fox & Reeves, 2015). Two opposing sub-themes were abstracted from the data relating to interdisciplinary collaboration: *Positive experiences of external health services,* and *Difficulties with external collaboration*.

4.7.1 Positive experiences with external collaboration

Positive collaboration between services requires clear communication, problem solving and cooperatively working together towards the shared goal of improving the health and wellbeing of the person (O'Connor & Fisher, 2011). Several participants commented favourably on the collaboration that occurred between aged, mental and palliative external health services and RACS. Participants highlighted that external services were prompt in responding to referrals, and made timely contact with RACS staff. Some participants indicated that they were able to access various support services effortlessly, and that interactions with these services were generally positive. In addition, the external service was supportive, useful and of good standard.

> *They are easy to access because if we let them know what the problem is with the resident, they will be in touch with us straightway. (Norma (RN))*

> [Aged care consulting service] *is an excellent service for us, you know. They're just a phone call away during the day and they're always very helpful. Sometimes they're a bit cranky, some of the nurses, but overall, they're pretty good. (Rhonda (EN))*

> [External] *palliative care services always help us and give us instruction on what to follow, and sometimes when we struggle a little bit we call them back and they're happy to come and continue to explain to us further. And, giving us more information on what to, and what needs to be done for the person (Roslyn (EN))*

4.7.2 Difficulties with external collaboration

Some participants held contrasting views about the value of external health services to residents with mental-palliative comorbidity. They stated they often experienced difficulties in initially accessing support from mental health services. Participants indicated that mental health services seemed to be overstretched in workload and had multiple measures of screening when referring residents, requiring them to use geriatrician services to gain the required assistance.

> *I've had to replace* [mental health service] *with geriatricians, because I get the geriatrician to come out but to get* [mental health service] *to help? It's not going to happen. There must be too many cases, they must be in big demand, because I've never really got any help from them, to be truthful. I ring, no one answers the phone. I leave my messages, they finally get back to me, tell me, 'Do your screening and this and this and that.' I don't find them very helpful. (Marni (RN))*

> *Mental health services will just tell you, 'Do your behaviour chart'. But actually, they'll do blood test. So, they want to look at the medical aspect first, making sure there's no infection that might cause the severity of the behaviour, and then do our assessments. As I said, basically our one is the Cornell only and the PAS, which you find that sometimes it depends who is answering the assessment, on what the input is. (Imogen (RN))*

Several participants indicated that the collaboration with external services placed additional workload demands on RACS staff. Additional workload demands and duties included residents requiring multiple pathology tests; bowel charts and additional documentation to be completed. Participants indicated these additional demands on staff time caused staff stress and frustration. Another point raised was additional external services demands interfered with their ability to coordinate and complete regular clinical care in a timely manner. This further highlighted the accumulating workload demands and time constraints experienced by RACS staff.

> *Sometimes these services give us more jobs to do. Even if it's good for the residents, it's just more jobs to do ... we're dealing with other residents who also need our time, so we couldn't complete the recommendations, so sometimes it takes a while for us to complete all the recommendations that they've given us. (Norma (RN))*

> *The challenge with external services is that I find is that they come at inappropriate times, you know. I could be doing something and you've just got to drop everything. So, you're trying to be with the geriatrician or the aged care but having other roles and responsibilities as well. (Rhonda (EN))*

> [A mental health service] *have got a lot of crap that we've got to go through. But once we finally get through it, in terms of they want a barrage of tests, and they want all the information set out before they come. And yeah that, it's really frustrating. (Chelsea (EN))*

> *There's a lot of extra work for us leading up to it because we've got to have, you know, urine pathology results, you know, blood, this, and that. Well obviously, they're looking for other things, they're looking for underlying issues. You know? So, we do totally understand, sometimes it's really difficult, we've got to have the bowel charts, we've got to have, you know, everything. But that's okay, it takes us quite a while but once we get it all together. (Chelsea (EN))*

One participant identified that there may be problems with the collaboration between RACS staff and external services. Involving external services was helpful only to a certain degree, as these services could offer suggestions, but had limited involvement in everyday resident care. While direct and clinical care was delivered by RACS staff, improvements are needed in interdisciplinary collaboration and sharing of workload and information between RACS and mental and palliative external health care services. Participants noted feelings of isolation in resident care delivery and on many occasions not being able to do anything to improve the residents' complex health issues.

> *External services and other professionals can only help to a certain degree, but the hard work gets done here. We're the ones that have to monitor, redirect, put interventions in place, stop them from going in people's rooms, chase people up, keep doing charting. External services may give suggestions, but they're already being implemented by us, because we know what we can try ... often, there's not much you can do. (Marni (RN))*

Lastly, difficulties in one-to-one communication between the RACS staff and external health professionals were identified as problematic by participants. A participant expressed the challenge of having English as their second language stating struggles in confidently communicating with external services staff.

> *I'm finding that because there are a lot of new nurses in aged care, like me, when I started, I can't say a word to the paramedics. It's just because it's my language. It's me, it's my culture. I don't know if I said the pronunciation right and everything, and so I prefer not to talk to the family or to external services. There's a lot of nurses who can't express themselves very well. They do care, but they just can't say it. (Imogen (RN))*

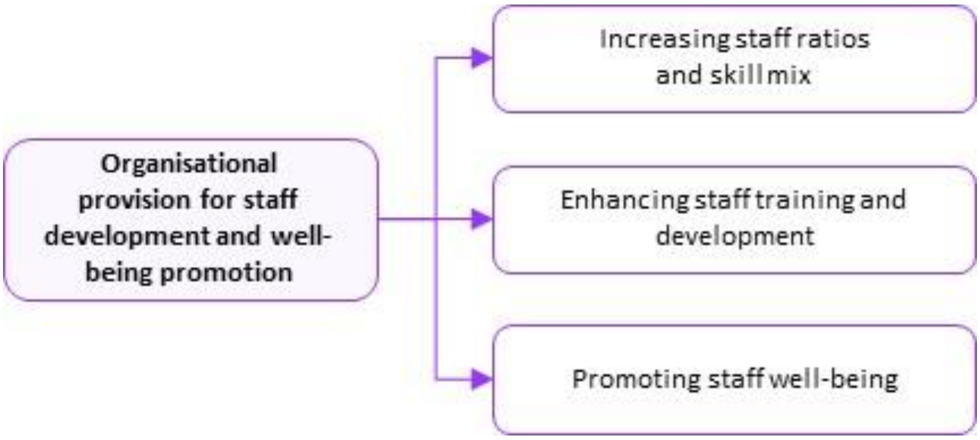
When liaising with external health professionals, participants reported that they often overstated resident issues, to ensure a problem was noticeably presented, to be able to gain access to the external health service. Alternatively, participants also indicated that initial issues and struggles in communication were often overcome, which enabled positive interactions, communication and collaboration experiences with external services.

> *You know your residents well, but ... you have to make it a little bit exaggerated. You can't blame* [external service]*, but if you're presenting a problem, you really have to make sure it's presented, and that you have a problem. (Imogen (RN))*

4.8 Main theme 5: Organisational provision for staff development and wellbeing promotion

In the fifth and final theme, *Organisational provision for staff preparation and wellbeing promotion*, participants highlighted the need for improvements to their working conditions, increased staff training and continuing development, and greater attention to be given to promoting the general wellbeing of staff, to develop and enhance their capability to care for residents with mental-palliative comorbidity (Figure 6). Three sub-themes were abstracted from the data associated with this theme: *Increasing staff ratios and skill mix*, *Enhancing staff training and development,* and *Promoting staff wellbeing*. The sub-themes illustrate the increased demands placed on participants practising in RACS settings in providing PCC for residents with mental-palliative comorbidity.

Figure 6: Organisational provision for staff development and wellbeing promotion



4.8.1 *Increasing staff ratios and skill mix*

In this sub-theme, participants expressed difficulties in being able to provide PCC due to heavy and enduring workload demands and time constraints. In particular, limited staffing resources, insufficient staff rostering and consequential low staff-to-resident ratios. Additionally, participants described the impact of these shortcomings on the quality of care provided to residents with mental-palliative comorbidity. Participants claimed that when staff were new to the role and inexperienced, this impacted adversely on their ability to provide PCC and, as a consequence, increased the overall workload and responsibility of more experienced members of the RACS health team.

> *It is hard, sometimes, in aged care, because we're really 'under the pump'* [pressured for time]. *Sometimes we don't have a lot of time to always sit with them. (Kerin (PCA))*
>
> *An issue is the skill mix. That's something that we got to work on. Because if you don't have the right skill mix of like say, ENs and PCAs, sometimes…it's hard, and depending on how much exposure they've had, like, the care staff. Have they just completed their certificates, or have they had a year or a couple of months, that is also challenging to the dynamics of the team. (Rhonda (EN))*

A common experience reported by participants was the considerable workload pressure and stress. Caring for residents with mental-palliative comorbidity, resulted in increased requirement to complete more care-related documentation and therefore less time to adequately deliver PCC.

> *I think with the time restrictions at the moment, as you know, there's too much paperwork and things to do, and caring for people is what we need to do, and that's what we miss* [focus on the resident]. *(Imogen (RN))*
>
> *Everything's rushed. You're always rushing in aged care because they're so many people and the clients are different* [higher complexity] *now. (Marni (RN))*
>
> *The ratio of the staff, especially these people you need to spend more time with them. If the ratio is less, you got more patients to look after, then it's really challenging for them too and it won't succeed. (Ethan (EN))*

4.8.2 Enhancing staff training and development

In this sub-theme, participants emphasised the need for greater staff preparation, development and ongoing training to fulfil their role. In particular, several highlighted that many RACS staff possessed inadequate skills, knowledge and experience to care for residents with mental-palliative comorbidity. In particular, inexperienced staff providing end-of-life care were frequently affected adversely by the death of residents, causing noticeable distress. Participants claimed that staff debriefing was essential and beneficial following the death of a resident.

> *I know how damaging this kind of work can be* [aged care]. *Especially when you've got new staff on, they're not used to people dying, they're only just finished their course, and I can see it in their face. (Marni (RN))*
>
> *We have some PCAs are just like turning 18, so they're very young, inexperienced, and to deal with a death, you know, at their age, it's a big shock for them. So, debriefing after someone's death helps. (Rhonda (EN))*

A second challenge related to knowledge and skill deficits of staff about the care of residents with mental-palliative comorbidity. Participants acknowledge a lack of experience in mental health and needed more information about the effects and lived experience of people living with a mental illness. Further staff expressed struggles in ascertaining resident's mental and physical problems, leading to issues in accurate resident assessment.

> *Staff need experience in mental health and more exposure. The staff, it's a learning point for them. They can learn more about schizophrenia, not in detail but some effects of schizophrenia on a person, and they can be motivated to give proper care to, like person-centred care. Residents that have mental problems, they're quite tricky to manage because sometimes they play up* [challenging] *with their behaviour. You don't know exactly what's going on with them mentally or physically because sometimes you never know if what they're trying to explain to you is real or just behaviour problems. (Roslyn (RN))*

> *How are these staff trained to communicate with someone who's got, for instance, dementia, mental health issues and then language barrier? How do you communicate with them? (Marni (RN))*

4.8.3 Promoting staff wellbeing

In this sub-theme, the importance of *Promoting staff wellbeing* was highlighted. The fundamental aspects that can measure a person's wellbeing include a life of happiness, life satisfaction, opportunity to uphold personal beliefs, engaging in positive relationships, maintaining good physical health, and psychological functioning (Islam et al., 2017). Participants identified several factors that adversely affected the physical and mental wellbeing of staff. Participants stated that they had formed close attachments to residents in general, and with those with mental-palliative comorbidity in particular. This attachment sometimes caused considerable staff emotional distress and burnout. They suggested that staff often implemented a range of effective measures to minimise harm to staff, including mutual support of each other, offering rest periods, enabling staff to leave work early, as necessary, and offering reassurance and positive verbal support.

> *It has happened twice. One of the residents was here a long time ago, and I was really attached to her. When we found that she passed away, I couldn't control myself; I was just crying and crying. And then one of the ENs, she took me to her room when the body was even here. Then she said, 'look, don't cry, if you want to go home, have a rest, you can go home. But look at this lady, she is really peaceful, you should be happy.' But yeah, it always happens when you get attached to someone, the resident, and something happens, you just emotionally distressed, yeah, it happens, always. We can't stop, these are our emotions. (Maree (PCA))*

Participants claimed that when staff become overwhelmed several support strategies were available to them, such as employee counselling, debriefing with managers and general one-to-one staff supportive interactions. While participants did not indicate if the RACS counselling was accessed easily and routinely by staff, for those who sought debriefing with managers they found this to be particularly helpful.

> *I know that sometimes you do get very overwhelmed, and sometimes you need someone to talk to. So, I know the RACS has a counselling service that you can make an appointment, or someone to talk to. We also grieve over the residents and, you know, not having them and so it helps … And also, I know that previous managers, when someone has passed away, they will have like a debriefing and that helps a lot. (Rhonda (EN))*

> *I'm a clinical care coordinator, so if it's my team, I'm always there to help them emotionally, clinically, debriefing or emotional support, anything. But if it goes beyond me, we have counselling services available, so we can ring them … they can give us a telephone conversation and counselling support. (Roslyn (RN)).*

Participants also identified that a difficult and unavoidable aspect of their work was having to respond to behaviours of concern such as residents' verbal and physical aggression. At times, these incidents were directed towards staff and, as a consequence, staff physical and mental wellbeing was affected adversely. In particular, participants reported feeling this injury is an unavoidable aspect of the work.

> *It's like you're not affected mentally but you're affected physically because you're getting hurt. But then, you just think, at the end of the day, 'Oh, it's part of your job'. Yeah, we're just going to need to put up with it and do the job. That's it. I don't think so, to be honest. It's just part of your job, so you've got to do it. (June (PCA))*

An important consideration in maintaining staff wellbeing is occupational health and safety in the workplace. Participants conveyed that the complexities of their work, meant being exposed to resident physical aggression. Resident aggressive behaviours, reported by participants, linked and related to an increase in staff workplace injury compensation claims. Participants reported that these increased incidents of aggression, was a negative component of their work and adversely effected staff wellbeing. In particular effected staff retention and attrition, with staff ultimately leaving the workplace.

> *For example, they are really aggressive, of course you can't* [be aggressive to them]. *You can be patient in a frame of time but you can't be patient to anything. For example, they are hitting you already but you're just doing your job to provide them the care but they don't understand it. So, you'll get affected. And then there's one staff who's on WorkCover*[14] *at the moment because he was really affected. (June (PCA))*

> *I can see why no one's really sticking to the job and people just fill in for a couple of months and then leave, fill-in and leave, because it's too hard. My colleagues are the support people but they're crumbling and when I see great nurses crumbling and hurt because the system is no longer fair, it's really heartbreaking. (Marni (RN))*

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[14] Australian workers' compensation cover (www.worksafe.vic.gov.au).

4.9 Summary

In RAC, there are challenges in caring for older adults with mental-palliative comorbidities. Several factors need to be considered in the provision of a person-centred approach. The overarching theme, *Adopting a person-centred approach to care* highlights the importance of giving individualised and holistic care across multiple care need domains. In support of this commitment, the main themes were conceptualised as *Understanding each person, Complexities in assessing and managing pain*, *Preventing and responding to behaviours of concern*, *Organisational provision for staff development and wellbeing promotion*, and *Engaging in interdisciplinary collaboration*.

CHAPTER 5:
Discussion

5.1 Introduction

The purpose of this chapter is to present and discuss the results of the study. It starts with the principal findings, with mention of the research aims. The overarching theme of *Adopting a person-centred approach to care* and five interrelated themes are presented. The results are discussed and connected to current literature on care for older people and mental-palliative comorbidity. The provision of PCC for aged care residents with mental-palliative comorbidity is then considered.

5.2 Principal findings

The aim of this study was to understand the experiences, education and support needs of RACS staff caring for residents with mental-palliative comorbidity. IPA was used to gain a comprehensive understanding of the main factors influencing how mental-palliative care is provided in RACS settings. The data revealed the importance of implementing a PCC approach for residents with mental-palliative comorbidity. Conceptualised as *Adopting a person-centred approach to care*, the overarching theme comprised five interrelated themes of *Understanding each person*, *Complexities in assessing and managing pain*, *Preventing and responding to behaviours of concern*, *Engaging in interdisciplinary collaboration* and *Organisational provision for staff development and wellbeing*. IPA enabled an in-depth understanding of the themes of the data, which identified successful resident-centred and/or organisational frameworks and interventions, while revealing potential barriers and complexities in enabling a PCC approach to care for residents with mental-palliative comorbidity.

5.2.1 Overarching theme: Adopting a person-centred approach to care

A PCC approach was threaded throughout all five themes, with findings representing many elements of this approach. PCC is a dynamic process that facilitates individualised social, emotional, spiritual, and physical support and is based on a person's needs, aspirations, values and preferences (Kogan et al., 2016). A systematic review by Rossiter et al. (2020) reported that while PCC was defined in a variety of contexts, it was commonly understood as the ability to 'identify and address individuals' needs, values and preferences, providing respectful care and enhancing patients' autonomy and personal control (2020, p. 17). Thus, PCC promotes wellbeing of self through the experiences of living a life of comfort, enjoyment, purpose, belonging, and meaning (Roberts et al., 2015; Rossiter et al., 2020).

In the current study, participants identified the importance of *Adopting a person-centred approach to care* for all residents, and felt this was central for caring for residents with mental-palliative comorbidity. This reflected a genuine commitment to putting residents first and making them central in all care delivery (Edvardsson et al., 2008). Consistent with the literature (see, for example, Kogan et al., 2016; Rossiter et al., 2020), participants emphasised the importance of getting to know the resident as a unique person, respecting their lived experience and personal choices and preferences. This can only happen when staff understand what is valued by the individual, and support them to live a meaningful life, with opportunities to engage in purposeful and meaningful activities (Boyle et al., 2010). This can happen when time is spent with the person in a way that supports emotional expression, connection and engagement (Kitwood, 1997), and confirms how important it is for healthcare professionals to embrace the PCC principles of respect, humanity, holistic interactions, and mutual communication (Kogan et al., 2016; Oppert et al., 2018; Rossiter et al., 2020).

When describing their efforts towards *Adopting a person-centred approach to care*, participants highlighted the importance of completing and maintaining individualised care plans that included specific information about their interests, preferences, values and beliefs systems. This ongoing process has been aptly described as 'necessary backstage activities' (Lindqvist et al., 2012, p. 6). In addition to general care requirements, care plans contained information on how to meet residents' particular mental and physical healthcare needs. Integral to the provision of PCC in end-of-life and palliative care, participants sought to ensure residents were comfortable and pain free (Holloway et al., 2018; Peisah et al., 2014). This was done by conducting verbal and nonverbal pain assessments and administering pain relief interventions that aligned with the needs and preferences of the resident, family and multidisciplinary team. By reducing, preventing and responding to behaviours of concern, and implementing a PCC approach in the delivery of pharmacological and non-pharmacological interventions, care staff can minimise resident distress (Alderman et al., 2018). These efforts, in turn, enhance residents' quality of life and overall wellbeing, as they can better understand their own health and develop skills to perform and manage self-care activities (Sjögren et al., 2017). This, in turn, leads to increased satisfaction with health professionals, better physical and psychological wellbeing and enhanced quality of life. Thus, from a health system perspective, PCC also leads to lower admissions, readmissions and length of hospital stays (Rossiter et al., 2020). However, the provision of PCC is not always straightforward in practice.

Participants in the current study encountered several challenges in adopting PCC. As reported in related studies (see, for example, Bökberg et al., 2020; Ryan et al., 2010), these challenges related to complexities in assessing and managing pain, working with residents with mental illness and/or dementia, cultural and language barriers, and inadequate staff skill and knowledge in pain management. In addition, participants in the current study claimed that the mental illness component of the resident's comorbidity added significant complexity. This was emphasised by participants when preventing and responding to residents behaviours of concern. The specific behaviour management challenges that were inadequate included poor resident information, inadequate skills and knowledge in mental health assessment and care, therapeutic communication barriers and deficits in assessing and managing verbal and physical aggression. Lastly, several non-resident barriers existed related to difficulties with external health services, interdisciplinary collaboration, insufficient staff ratios and skill mix, staff training and development and staff wellbeing. These factors are known to influence the implementation of PCC (Frey et al., 2015; Kerosuo, 2010; Low et al., 2015), as was evident for residents with mental-palliative comorbidity. An evaluation of PCC in RACS before and after implementing an informative intervention about palliative care identified both positive and negative resident viewpoints of their care and the care environment (Bökberg et al., 2020). One of the experiences was that the staff were focused on the practical tasks, rather than being accessible to interact and socialise with the residents, making it less homelike. Further, residents reported a need for more staff and time, as they found that the staff were stressed attempting to manage multiple responsibilities (Bökberg et al., 2020). In other words, the bulk of staff–resident interactions were task focused and lacked a PCC approach.

Similarly, a study of the views of RACS care managers in Australia on end-of-life care for residents living with dementia (Borbasi et al., 2021) highlighted the important role of front-line staff, including RNs and ENs, PCAs, pastoral care staff and volunteers within the facility, in providing person-centred palliative care. However, managers noted front-line staff differed in their confidence levels, likely due to a lack of experience, in administering end of life medications and deficits in the communication skills needed to direct diverse end of life discussions with families (Borbasi et al., 2021). They recommend ongoing front-line aged care staff skill development, frequent family consultation, and partnership building between RACS staff and GPs, to encourage optimum end of life dementia care in RACS settings (Borbasi et al., 2021). These studies correlate with the findings of the current study, demonstrating that several actions are required to optimise PCC for all residents, and for those living mental-palliative comorbidity.

5.2.2 Main themes

Five main themes and related sub-themes were represented in the data that can influence PCC delivery for residents requiring mental-palliative care: *Understanding each person*, *Complexities in assessing and managing pain*, *Preventing and responding to behaviours of concern*, *Engaging in interdisciplinary collaboration* and *Organisational provision for staff development and wellbeing*. Although these are considered separately, they are interrelated and typically influenced each other.

5.2.2.1 Main theme 1: Understanding each person

The findings from the current study highlighted the need for a comprehensive and clear understanding of the person. Three sub themes emerged: G*etting to know the person*, *Fostering a meaningful existence* and *Providing emotional support.*

Getting to know the person was highlighted by several participants, which enabled care that is tailored and personalised to the resident's individual needs. Participants expressed the importance of being familiar with residents' care plans, which detailed their values, needs and choices regarding their health and personal care. This approach fostered respect for residents' rights, choice and preferences. Several studies support that getting to know the person and their life story as a means of maintaining personhood, supporting relationships and improving quality of life (Doran et al., 2019; Gibson & Carson, 2010; Sjögren et al., 2017). One way this can be done is through life-story, in which the person as an individual is acknowledged, and supported to maintain their identity. This is particularly useful for those living with mental illness (Doran et al., 2019; Gibson & Carson, 2010). Chapman et al. (2018) suggest strengthening the therapeutic connection by inviting residents into conversations that delve into their life story, significant events and accomplishments, and acknowledging them for who they are as individuals. This connection, in turn, may assist staff in managing a resident's distress. Furthermore, exploring an older person's lived experience provides insight into the person's core values and gives an opportunity to recognise grief and loss, thereby providing the person with a sense of dignity and resourceful solution to their care needs (Gridley et al., 2020).

For a person living with dementia and/or mental illness, life-story should be tailored to the resident's specific requirements. In a study of best practice approaches for life story work in person-centred dementia care, Gridley et al. (2020) reported the importance of tailoring strategies to the individual needs and preferences of the person with dementia, recognising that not all residents will want to participate in life story work and that some people may find it distressing, and the role of the person with dementia in leading the process. The study also identified the requirement for training and support for staff, carers and volunteers, to support life story work as a way of honouring the person's life today and for the future (Gridley et al., 2020). Notwithstanding its value, working together to develop a resident's life story can be challenging, largely due to lack of staff time (Gibson & Carson, 2010) and the absence of a standard format for collecting resident information (Pearson et al., 2021).

Fostering a meaningful existence was strongly emphasised by participants in the current study. This was described by participants as incorporating occupational meaningful activities, which were gratifying to residents. Participants in the current study also emphasised the significance of residents choosing and being actively engaged in purposeful activities in their daily lives; for example, walking in the garden, community outings, staff promoting self-care abilities and independence, resident collaboration and participation in meeting their activities of daily living. Participants claimed this impacted favourably on residents' mental health, wellbeing and quality of life. There is an abundance of literature reporting that rewarding activities that engage the resident, have positive impacts on the resident's emotional wellbeing, physical function and/or cognitive ability (see, for example, Culph et al., 2015; McCarthy et al., 2019; Scott et al., 2015). Palacios-Ceña et al. (2016) reported how residents utilise time in unique and different ways within RACS, and have opportunity for engagement in meaningful activities that help them feel useful. A key consideration is to develop activities based on each resident's needs, functional abilities and individual preferences. Conversely, a lack of occupation can be a precursor to residents having apathy, boredom, behaviours of concern, limited confidence and social isolation (Palacios-Ceña et al., 2016).

The current study highlighted the importance of *Providing emotional support* and spending time with residents in helping to foster the provision of emotional support and thus improved care, especially for residents with mental-palliative comorbidity. As well as being with the resident, the study found sitting with, listening to, and encouraging the resident to express themselves verbally, resulted in the resident feeling supported. A study by Erdmann and Schnepp (2016), found that health care professionals and families of residents in RACS endorsed the application of validation therapy interventions, as being beneficial to resident wellbeing. This resulted in decreased agitation in residents, with a reduction in the administration of neuroleptics and benzodiazepine medications. This clearly supports the need for 1-1 therapeutic engagement and emotional support, such as validation interventions when caring for residents with mental-palliative comorbidity. A study by Pejner et al. (2012) explored reasons why RNs gave emotional support to older adults. The current study found RNs were able to provide emotional support to older adults with the aim to allow relief from their emotions, enabling improved coping of daily living. In particular, residents' own strength was supported to progress towards recovery. This same study found RNs at times felt helplessness and then removed themselves from providing this type of emotional support. Interestingly, the Pejner et al. (2012), study found that health care staff may decline and avoid providing emotional support, when feeling incapable, lacking confidence and feel they cannot manage the situation. Similarly in a study by Hazelhof et al. (2016), there was a direct connection between nursing staff experiencing stress and burnout in the circumstances of behaviours of concern from residents with dementia.

5.2.2.2 Main theme 2: Complexities in assessing and managing pain

This theme comprised the two sub-themes of ensuring residents are comfortable and pain-free and challenges in achieving effective pain management. In the current study, several participants emphasised that pain is a significant issue for individuals with mental-palliative care needs. Further, participants reported pain can be especially evident during palliation and/or at the end stage of life. They identified and promoted the importance of quality care in ensuring that residents are as comfortable and free from pain as possible. It is estimated almost one in four adults (24%) aged 85 and over experience chronic pain, which may be related to them having an increased likelihood of multiple health conditions (Australian Institute of Health and Welfare, 2020a). In a study of pain in RAC, Savvas and Gibson (2015) found many residents experienced persistent chronic pain, with several challenges making effective pain management more complicated. Barriers in this regard included resident attitudes and beliefs, and altered age-associated medication response profiles (Savvas & Gibson, 2015). Similar findings were reported by Holloway et al. (2018), with older people living in RACS likely to experience complex persistent pain due to chronic diseases, geriatric syndromes, psycho-social, emotional and spiritual factors.

In the current study, participants acknowledged that a comprehensive understanding of the resident pain was required to ensure the provision of effective and consistent pain assessment and management. Consistent with the literature, they understood that pain could be expressed by residents in a multitude of ways and that there was a link between behaviours of concern and pain (Atee et al., 2021; Holloway et al., 2018). Hence, having a holistic and comprehensive assessment was necessary to identify complex needs for residents living with mental-palliative comorbidities. In a recent study of the likelihood of pain as a contributor to behavioural changes in older adults living with dementia, Atee et al. (2021) found a fairly positive linear relationship between pain levels and the incidence of BPSD. More specifically, higher pain levels resulted in greater incidence and severity of BPSD presentations, which were, in turn, associated with distress experienced by the carer (Atee et al., 2021).

There are significant challenges to effective assessment and management of pain. While pain is routinely assessed and recorded in RACS in Australia, this is more often protocol-driven rather than a resident-centred intervention, and is often conducted as a part of the accreditation process (Peisah et al., 2014). Thus, the acknowledgement of resident's pain and the instigation of adequate pain relief is often insufficiently characterised and not completely understood by staff (Peisah et al., 2014). Both pharmacological and non-pharmacological interventions are used, but in an irregular, unstructured means, with multiple staff, resident, and attitudinal obstacles coming between residents' personal experience of pain and its relief (Peisah et al., 2014). Comparatively, the current study, found several barriers existed in the provision of effective pain assessment and management. These challenges related to residents with palliative and/or physical deterioration, dementia, language barriers and a lack of adequate staff training in pain assessment and management. Participants stated that, pain was often difficult to assess and dependent on nursing observation skills. Consequently, nurses relied on residents' non-verbal cues to ascertain the resident's level of pain and discomfort. Non-verbal cues included facial expressions and grimacing, which were evident during care activities such as re-positioning the resident. Furthermore, participants described how actively engaging with residents' families assisted them to gain a clearer understanding of resident pain levels. A study of best practice care for those living with dementia and near the end of life found that optimal care required RACS staff to utilise a palliative care approach which allowed them to identify subtle changes in the progression of the disease (Thompson & McClement, 2019). The current study also identified that RACS staff understood the need to move past a reliance on verbal reporting of pain by residents with dementia, to focus on non-verbal cues. In so doing, RACS staff should aim to foster and maintain the resident’s sense of self, which can be achieved by embracing care philosophies that value openness, presence, being proactive and inclusion of families, allowing the potential to create an enriched environment that increased the likelihood of a comfortable death for the resident (Thompson & McClement, 2019).

Pain can be responded to and managed using multiple therapeutic evidence-based approaches. One approach to pain management is the use of pharmacological interventions such as analgesics to alleviate the symptoms of pain. These medications work to decrease the intensity of a resident’s pain, so that they are able to undertake activities of daily living. In the current study, participants emphasised the use of regular and PRN (as required) analgesia medication that could be prescribed in advance and readily available to residents, while also describing the use of opioid medications like morphine to manage pain. An analysis of medication reviews for Australian RACS residents with either low or high dependency care needs identified the need to promote the prescribing and administration of regular paracetamol as a first option for analgesia and ongoing therapy for pain management, to lessen opioid use (Veal et al., 2014). The study highlighted a need for caution when opioid medications are administered, as the use of sedatives and opioids is widespread in this specific age group, and can be a contributing factor to a heightened risk of falls and fractures (Veal et al., 2014). The recommendation for improved training of RACS staff and medical practitioners in this area is supported by other studies (Alderman et al., 2018; Pearson et al., 2021). Current evidence of a substantial number of older people whose pain remains untreated and undiagnosed, presenting as behavioural symptoms, highlight the need for clear guidelines, direction, assessment processes and ongoing review of pharmacological strategies in the RACS environment (Aitken et al., 2020). A review of medication use in RACS by Aitken et al. (2020) described the importance of access to medicines at the end of life, while noting the challenges of polypharmacy and total medication numbers, use of symptomatic versus preventive medications, and ‘inappropriate’ medications’ (p. 844). Additional emphasis was placed on promoting individualised approaches and care interventions to improve medication use for people living in RACS, which should bright together the expertise and knowledge of clinicians in advanced geriatric care and palliative care (Aitken et al., 2020).

An alternate approach to pain management is the use of non-pharmacological interventions that can relieve the symptoms of pain and distress. While the current study participants did not discuss non-pharmacological interventions to reduce pain for residents, several studies highlight the need to promote the use of a combination of pain strategies. A study by Gilmartin-Thomas et al. (2019) reported that in clinical practice, there is often an overreliance on pharmacological approaches to manage chronic pain in older people, even though chronic pain often responds poorly to analgesics alone. Likewise, Tredgett (2020) reported non-pharmacological interventions can be useful in palliative care and pain management, for example heat pads, acupuncture and transcutaneous electrical nerve stimulation. In addition the importance to identify and met psychological, social and spiritual factors, that could benefit referral to psychiatry, psychology, physiotherapy, social care services or pastoral care teams. In exploring non-pharmacological caregiving activities for late-stage palliative care, Lindqvist et al. (2012) reported the benefits of carrying out or refraining from bodily contact and care; active listening and understanding; creating a pleasant and safe environment; planning, organising and evaluating, observation and assessment, being present in the moment and facilitating the presence of others, performing ceremonies surrounding dying and death; facilitating and guiding, communicating written and oral information and advice.

Furthermore, Holloway et al. (2018) suggest that it is common for treatment and recognition of persistent pain in older RAC residents to be inadequate, which increases their disability, pain and frailty, thus also affecting their quality of life. Further, the present pain management in RACS are passive interventions, based on a biomedical model of care. Calls have been made for a more robust biopsychosocial approach where various pharmacological and non-pharmacological interventions are used as part of the care plan (Tripathi et al., 2019). This would require a comprehensive assessment that includes verbal or non-verbal observational tools, review of residents’ history, comorbidities, medications, mood, quality of life, physical assessment and detailed pain assessment.

A multidisciplinary approach to pain management was another key consideration identified by the current participants. There was a perception that GPs delayed or prevented the delivery of pain medication because of their reluctance to prescribe analgesia. Staff attributed this reluctance to the GPs’ limited understanding of palliation. However, staff felt that palliative care services were very supportive, but recommendations were difficult to follow up due to ongoing issues in collaboration and care partnerships with GPs. Poor collaboration and an absence of shared goals for pain management were felt by staff to affect pain relief measures being adequately received for residents in RACS. Similar findings were reported by Frey et al. (2020), who identified that bereaved families perceived palliative care communication with GPs to be an area of difficulty. Particular problems related to how communication was handled by GPs, and the degree to which GPs showed respect for families and residents. While this study implemented an intervention called SHARE that aimed to improve the palliative care skills and knowledge of RACS nursing and health care assistant staff, GPs were not included in the intervention (Frey et al., 2020). Also aimed at improving palliative care, Rainsford et al. (2020) explored GP and RACS staff perceptions of palliative and end-of-life care before and after the introduction of Needs Rounds. These monthly meetings about managing end-of-life care were attended by RACS staff and led by a palliative medicine specialist. This approach enhanced staff confidence in achieving objectives of care, accessing specialist support was improved, enhanced teamwork and communication (Rainsford et al., 2020).

5.2.2.3 Main theme 3: Preventing and responding to behaviours of concern

In the third main theme, three sub-themes were abstracted from the data: *Difficulties in assessing behaviours of concern and providing care, Therapeutic communication barriers* and *Assessing and managing verbal and physical aggression*. The occurrence and prevalence of mental illness and/or behaviours of concern in RACS are well known (Bautrant et al., 2019; Hazelhof et al., 2016; Loi et al., 2015). Agitation[15] and/or behaviours of concern are recognised by visible non-purposeful verbal or physical behaviours, extensively thought to be linked to internal distress and connect to unmet needs for an individual (Pritchard & Brighty, 2015). Behaviours of concern can be exhibited in a variety of ways, including self-injury, assault or socially inappropriate behaviour, as well as verbal and physical aggression, repetitive movements, restlessness and undressing inappropriately (Hazelhof et al., 2016; Watson & Hatcher, 2021). In older adults, this is frequently associated with complex medical conditions, neurocognitive disorders and polypharmacy. Impaired communication and comprehension for those living with dementia adds difficulties to assessment and management. Hence, agitation and behaviours of concern are multifaceted and difficult to manage in RACS setting (Watson & Hatcher, 2021). In the current study, behaviours of concern were experienced by residents

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[15] Agitation refers to the subjective experience of inner tension. It may be observable by others in the person's behaviour, such as excessive motor activity (Howard et al 2001).

with co-existing health conditions. In particular participants highlighted residents with a mental illness added further difficulty and complexity to the effective provision of care, especially mental-palliative care. The participants recognised that a resident with a diagnosis of dementia also could exhibit behaviours of concern, and this contributed to increased resident complexity. In a systematic review, Goldhagen and Davidtz (2021) found a correlation between severe mental illness, older adults, and aggressive behaviour. Older adults with severe mental illness may be at an increased likelihood of acquiring dementia, and therefore had an increased risk of aggressive behaviour (Goldhagen & Davidtz, 2021). Similar findings were reported by Wharton et al. (2018), whose review of electronic medical record for older adults with dementia identified that those with dementia and a co-existing mental illness were at an increased risk of aggression during their hospital stay. This demonstrates the complexity of managing a resident with a mental-palliative diagnosis and the need for further research into this area.

The majority of participants in the current study reported difficulties in assessing and managing behaviours of concern and/or aggression. Behaviours of concern require significant assessment and training to identify underlying causative factors that may be triggering this emotional response. A concept analysis of literature by Hazelhof et al. (2016) found that to effectively manage behaviours of concern, complex health, psychological and/or behavioural needs RACS team profiles require nursing staff be of an older age, have a level of higher education, and be comprehensively trained, with practical experience and specialised training in dealing with residents levels of complex needs. Similar findings were identified in the current study, with participants reporting challenges in deciphering between behaviours associated with mental illness and those related to biological, physical, social and/or emotional needs.

Thompson and McClement (2019) reported that health staff are adequately positioned to be able to recognise changes in a resident’s normal patterns of behaviour patterns and signpost when such changes have occurred, these changes can be related to a transition to end of life. In addition, they recommended the significant importance of assessment in the detection of considerable changes in the resident behaviour. There were six critical behaviours identified in caring for residents dying with dementia. These included identifying and responding to changes in a resident’s pattern of behaviour; caring for the person in a holistic manner; collaboration with the family; connecting and engaging all key individuals; being responsive once the death has happened; and having an affirmative attitude toward end-of-life care (Thompson & McClement, 2019). This denotes a specific complexity of caring for a resident with mental-palliative comorbidity. A study by Melander et al. (2018) focused on the capability of RACS staff to assess and evaluate behavioural and psychological symptoms of dementia (BPSD). They found that RACS staff face challenges in distinguishing and evaluating various behaviours, and determining when and how to provide interventions. Using observation to assess behaviours is particularly challenging when a resident's verbal ability has been compromised, and they have specific needs that are always changing. This study noted the importance of four core considerations that could strengthen the assessment process of BPSD. Firstly, a resident's decline in ability and awareness should be taken into account. Secondly, individual and contextual factors that may be connected to BPSD behaviours of the resident with dementia should be incorporated. Thirdly, variations in resident behaviours and ambiguous interpretations of the assessment tool should be overcome. Lastly, assessment tool questions should encourage RACS staff to discuss and reflect on different elements of the resident behaviour. .

Similar to those with dementia, residents with mental illness present with various behaviours which make assessment difficult. In the current study, participants noted that obtaining a comprehensive mental health assessment was compounded by a lack of knowledge of residents' mental illness and related history. Consequently, participants claimed that they frequently had inadequate resident assessment and background information available. This indicates gaps in the systems of handover from family and other health professionals, and access to comprehensive resident information. In addition, participants found that newly admitted residents with complex issues needed an extensive and thorough assessment process to enable them to provide prompt and effective care for these residents.

The current study identified obstacles related to communication barriers in the assessment and management of residents with behaviours of concern. In particular, participants found it difficult to engage and develop a therapeutic relationship with residents with mental-palliative comorbidity. Participants identified a range of communication barriers including staff with English as their second language, residents with delirium and raised levels of anxiety, that complicated the assessment process. Staff also commented on being busy, and not having adequate time for adequate one-to-one communication and explaining care giving to residents. These barriers often resulted in the resident feeling confused and distressed, which could exacerbate residents' verbal and physical aggression. Thus, additional time must often be spent by RACS staff to assess causative factors of agitation in people with dementia, compared with those without dementia, with impaired communication making detection of these causes more problematic (Watson & Hatcher, 2021). Interventions are needed to ensure that residents with impaired communication are assigned the required resources and time to identify causative factors for agitation and/or behaviours of concern. These include staff training in communication skills and de-escalation techniques for responding to residents with dementia who are experiencing distress (Livingston et al., 2019; Watson & Hatcher, 2021).

Participants in the current study described a combination of approaches to assess and manage verbal and physical aggression, in particular the importance of valuing and fostering a resident's independence and autonomy, and preserving the resident's meaningful and/or purposeful activities of daily living. Strategies included just 'being' with the resident and providing one-to-one interaction, undertaking active listening, providing emotional support, and offering the resident a warm beverage. These interventions were seen as pivotal to the provision of emotional support and de-escalation of resident distress and behaviours of concern. Similarly, resolution of these behaviours was often determined by how well the staff member understood the resident's individual and mental health needs. McCann et al. (2015) also found that nurturing a positive social environment can be valuable in preventing aggression in older person mental health inpatient units, and advocated for care staff to implement PCC in a positive social environment that fosters a therapeutic environment. The current study also identified the use of distraction activities to de-escalate anxiety and mitigate behaviours of concern. Conversely, inappropriate diversional activities can have the opposite effect and cause agitation to some residents (McCann et al., 2015). This highlights the importance of knowing the resident and their personal individual preferences, and the importance of fostering a PCC approach.

BPSD and behaviours of concern may also be reduced when basic environmental readjustments are made to improve temporal and spatial orientation (Bautrant et al., 2019). These environmental adaptations included skylike ceiling tiles in part of the shared premises, gradual decrease of the light at night, calming music, reinforcement of appropriate light during the day, walls painted in light beige, oversized clocks in corridors, staff clothing colours that signified the time of day (Bautrant et al., 2019). Similar findings were reported by Roberts et al. (2015), whose 'ABLE model' aimed to increase the ability and capacity of residents living with dementia, using environmental modifications, staff training and community and organisational engagement, using a Montessori[16] philosophy. The ABLE model was related to positively altering BPSD, improving staff awareness and confidence of PCC and enhancing family satisfaction with the care provided to their relatives (Roberts et al., 2015).[17]

The participants in the current study described pharmacological intervention as one of the main ways they managed and reduced residents' behaviours of concern, specifically by administering benzodiazepines that had been prescribed by a GP. GPs have a key role in managing behaviours of concern, which may include pharmacological therapy (Loi et al., 2015). Loi et al. (2015) suggest that utilisation of psychotropic medications may be suitable in some clinical circumstances, but can have significant side effects including increased over-sedation, risk of falls, and increased mortality. For residents with increased behaviours of concern, a combination of non-pharmacological and pharmacological strategies might be necessary (Bautrant et al., 2019).

Participants in the current study indicated that the management and de-escalation of behaviours of concern could be difficult to navigate. Staff reported that residents would often present with increased agitation and at times, timestaff had difficulty in being able to settle the resident and relieve their emotional distress. In these instances, both staff and resident would experience increased levels of frustration. Participants felt unprepared and threatened by residents who displayed verbal and physical aggression and this had a detrimental impact on their therapeutic relationship and communication with the resident. The current study indicated that the RACS participants felt ill-equipped and overwhelmed to manage residents with serious mental illness. Many participants related this to lack of knowledge and skills, ongoing training and skill mix in caring for individuals with serious mental illness to limited time and resourcing. Likewise, Holst and Skär (2017) found that RACS staff had experiences of aggressive behaviour in older adults living with dementia. The results revealed that RACS staff found dealing with aggression as a difficult task. Resident aggression that emerges suddenly and without any visible causes created feelings of fear and uncertainty in staff. The findings also indicated that RACS staff recognised the significance of identifying triggers/causes this enabled recovering

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[16] The Montessori model is an approach for fostering engagement of individuals living with dementia. Everyday activities and interactions are applied as a means to reconnect those living with dementia and generate opportunities for connection and engagement within their community (Camp, 2010).

[17] The Royal Commission into Aged Care Quality and Safety (2019) highlighted the need to improve environmental design in aged care facilities. The creation of supportive, familiar and therapeutic environments can assist in the provision of person-centred care. While environmental adaptions and non-pharmacological interventions can be of significant benefit in reducing behaviours of concern and enhancing resident wellbeing, a deeper discussion on this was beyond the scope of the current study.

a sense of control and ability to develop interventions to manage aggressive behaviour (Holst & Skär, 2017). In a study of quality of care of person's living with serious mental illness in RACS, it was reported that further understanding of the implications of these trends should be reflected in government legislation, policies and guidelines, while RAC providers should better understand how to meet this population's specific needs (Jester et al., 2020).

5.2.2.4 Main theme 4: Engaging in interdisciplinary collaboration

The sub-themes that emerged under the fifth main theme included *Positive experiences of external health services* and *Difficulties with external collaboration*. Interdisciplinary collaboration occurs when health providers with diverse skills and knowledge interact to effect patient care (Fox & Reeves, 2015). Several participants in this study highlighted that external health services were generally easily accessible to palliative and geriatric specialist services, and these services responded to RACS referrals quickly, and made timely contact with RACS staff. Some participants indicated that they were able to access various support services offering informative explanations and direction and that one-to-one interactions with these services were mostly positive. However, participants also noted that accessing support from external mental health services could be difficult. Participants felt that mental health services often appeared to be overstretched in workload and were difficult to access. Additionally, the referral process was complicated by the need for multiple screening, which makes getting access and support challenging. Regarding the degree to which psychological services are accessible in aged care, Stargatt et al. (2017) reported that access to psychological services and psychologists remains deficient in Australian RACS. It was recommended that access may be enhanced in several ways, improving funding mechanisms for residents to access psychological services, developing a workforce of clinical gero-psychologists and addressing staff understanding about depression and anxiety (Stargatt et al., 2017). These needs remain current.

Participants in the current study emphasised how collaborating with external services placed additional workload demands on RACS staff. These included the requirement for multiple pathology tests and additional documentation on the resident, which caused staff to feel stress and frustration, and interfered with their ability to coordinate and complete regular clinical care in a timely manner. Overall, participants indicated that improvements were needed to interdisciplinary collaboration, sharing and delegation of workload and improved collaboration between RACS and mental and palliative external health care services. Indeed, the provision of PCC requires effective collaboration and teamwork, important contributory relationships, strengthened staff relationships and additional resources (Oppert et al., 2018).

In the current study, professional one-one communication between the RACS staff and external health professionals was identified as problematic. Participants felt that RACS staff with English as their second language was a barrier to being able to confidently communicating with ambulance staff and mental health external services. Culture is known to be a major influence on the delivery of sensitive and person-centred dementia care (Brooke et al., 2018). Acculturation of migrant healthcare staff to the culture of the host country, work environment, and support with communication are essential for the delivery of person-centred dementia care (Brooke et al., 2018). It is also important to understand cultural diversity between and among staff, by promoting cultural awareness and supporting cross-cultural understanding (Gillham et al., 2018).

Participants reported resident issues were often overstated and not always presented in a clear and factual way to external health providers. Participants expressed a need to embellish resident's symptoms, to ensure a problem was noticeably presented, to be able to gain access to mental health external health service. Alternatively, participants also indicated that initial issues and struggles in communication, were often overcome, which enabled positive interactions, communication and collaboration experiences with external services. A study by Rainsford et al. (2020), utilised a mixed-methods, pre- and post-intervention method and reported that palliative and end-of-life care for older people in RACS may be improved through communication, collaboration, planning and education. This study recommended running Needs Rounds via telehealth and/or employing a multidisciplinary approach to care. Additionally Rainsford et al. (2021) found multidisciplinary educational case conferences have promise to reinforce advance care planning, including the prescribing of anticipatory medications, within rural RAC. However, these case conferences continue to be time consuming to organise and often are inadequately funded and/or resourced and often rely on the goodwill of involved individuals. This is not a long-term sustainable solution, adequate formal acknowledgement of specific resourcing and roles is needed to safeguard the sustainability of RACS educational case-conferences.

In a study of decision-making around hospital transfer and/or referral of residents to a Residential InReach (RiR) service in Australia, Amadoru et al. (2018) explored the viewpoints of RACS staff, GPs and RiR and RNs. They was reported that there was low RACS staffing levels and limited GP accessibility, declining numbers of RNs, deteriorating standards of RACS staff training and qualification, and inadequate access to timely medical care. The accessibility of timely and suitable medical and nursing care in RACS influenced increased referrals to RiR and transfers to the hospitals. In addition, RiR was used to complement or substitute usual care available to residents. This study emphasised the need for further improvements, resources and evidence regarding RiR in RACS (Amadoru et al., 2018).

The previous literature emphasises the importance of effective and supportive interdisciplinary engagement. Effective teamwork has been found to foster and facilitate PCC by increasing important contributory relationships, strengthening staff relationships with each other and allowing for increased resources for PCC delivery (Oppert et al., 2018). In the current study, participants highlighted that engagement with interdisciplinary collaboration was deficient. Participants described several challenges that impacted on teamwork and partnership to deliver PCC. These included difficulties in accessing external services related to screening measures, external services adding additional workload demands on RACS staff, deficits in interdisciplinary collaboration and sharing of workload and information and issues in interactions, communication and collaboration. These factors hindered interdisciplinary collaboration and the ability to provide holistic PCC approach.

5.2.2.5 Main theme 5: Organisational provision for staff development and wellbeing

Participants in this study proposed the need for improved organisational provision for staff preparedness and wellbeing. Participants reported three sub-themes related to increasing staff-to-resident ratios and skill mix, enhancing staff training and development and promoting staff general wellbeing. Participants felt extreme demands in the RACS environment, and that improvements in these key areas would assist to develop and increase their capability to provide PCC care for residents with mental-palliative comorbidity.

Staff experience of large workload demands and time constraints is significant within this study and across the aged care sector in Australia. Participants reported that staffing levels were inadequate to meet the expectations of their caring role, and the complex needs of the residents. Challenges included inadequate and inconsistent staff numbers allocated on each shift, poor rostering, increased sick leave and non-replacement of those on leave, issues with staff recruitment and retention, and increased use of agency (external, casual) staff. The Royal Commission into Aged Care Quality and Safety (2019) found that over half of Australian aged care residents were living in facilities with inadequate and low staffing levels. The report further indicates this significant issue has impacts on available time for staff to time to interact compassionately and meaningfully with residents (Royal Commission into Aged Care Quality and Safety, 2019). This is consistent with other research that identifies inconsistent staffing and limitations in funding as widespread problems in the sector, that negatively impact on health and safety of nurses, and the ability of staff to deliver the level and type of quality care required to meet the needs of residents (Isherwood et al., 2018; Ludlow et al., 2021; White et al., 2020). Exploring aged care staff job characteristics which pose significant risk for health and to identify recommendations, Hart et al. (2021) found that time restraints resulted in a task-oriented approach, which caused additional staff stress and reduced their desire and ability to delay retirement. Recommendations from their study included a requirement to instigate minimum staffing policy, to allow more time for staff-resident therapeutic interactions and the development of mutual understanding, enhance job satisfaction with roles that are meaningful and rewarding, and increase staff morale (Hart et al., 2021).

While residents often know that staff levels are inadequate, RACS managers face additional challenges as they attempt to balance limited resources with care delivery (Ludlow et al., 2021). Overall, RACS staff felt the biggest difficulty in conducting health assessments was the lack of allocated time within the RACS current work structure and practices (Bauer et al., 2018). Similar findings were reported by Kihlgren et al. (2021), who reviewed core values of dignity applied by the healthcare staff caring for older adults. They identified the importance of adequate assessments to meet older adults’ needs with dignity and consider their personal values required access to information from the older adults, their relatives and different healthcare providers. Although attaining this information was time-consuming and challenging in practice, additional barriers included a conflict of staff-organisational goals, lack of resources (especially staffing and time), which resulted in inadequately meeting older person core values and dignity of care (Kihlgren et al., 2021).

The current study found that RACS staff were increasingly caring for residents with more complex needs, such as mental-palliative comorbidity, which required extra duties and documentation that reduced their capacity to provide adequate PCC. This resulted in personal distress and a sense of inadequacy when they could not adequately meet their resident care and professional obligations. Furthermore, inexperienced staff providing end-of-life care were often more negatively affected by the death of residents. There is potential to improve practice by learning from other services. For example, in a study of the experiences of providing palliative care to people with intellectual disabilities, Ryan et al. (2010) identified the need to support intellectual disability staff who provide palliative care, and to extend this support after the death of a resident. Similar to RAC, areas of need included skill mix and staffing levels, training and support in palliative care practice and decision making, assistance for carers and bereavement support (Ryan et al., 2010). While responsible for meeting these needs, RACS staff lack skills and experience in this area, and more studies are needed to better understand the experiences and issues of staff and residents in this regard.

Traditionally, approaches to changing practice have focused on improving staff knowledge and skills (Low et al., 2015). One such strategy is the TOrCCh intervention to support systematic change, facilitated by research staff working with facility work groups who acted as ‘champions’ within each RACS (Venturato et al., 2020). Work groups aimed to support and facilitate staff progression in communication, leadership and teamwork, resulting in improved staff and resident outcomes (Venturato et al., 2020).

Participants in the current study highlighted knowledge deficits in this mental-palliative care area. Residents with mental-palliative comorbidities have various specialised care needs. Participants identified gaps in knowledge related to palliative care and end of life that, present unique challenges related to resident factors of pain and comfort and loss and grief experienced by the family and RACS staff. In a study by Borbasi et al. (2021), managers reported that front-line staff differed in their confidence, potentially due to a lack of experience, in administering end-of-life medications and deficient communication skills required to conduct diverse end of life conversations with families. There is a clear need to improve RACS staff knowledge and skills in appropriately supporting palliative and end-of-life care for those living with mental disorders and/or dementia (Thompson & McClement, 2019).

In addition to the need for better education, other workforce issues relate to turnover, absenteeism and burnout. In a survey of Australian RACS nurses, Gao et al. (2014) found that decreased levels of turnover were influenced by a larger sense of work challenges, not the level of stress produced by work challenges. An important finding in that study was the ability to reduce turnover of RACS nurse. Managers could identify staff member’s individual needs for personal development, through the use of work plans (Gao et al., 2014). They could then allocate appropriate workload and responsibilities to individual staff based on their needs and capacities. Findings further suggest that work plans encouraged positive stimulating aspects of work and supported stress reduction strategies (Gao et al., 2014). These strategies may better place RACS to retain their suitably qualified nursing staff and meet the future demands of the ageing population.

5.3 Staff wellbeing

Findings from the current study indicated that there was a significant negative impact on staff overall health and wellbeing in caring for residents with mental-palliative comorbidity. A problematic and unavoidable aspect of their work was having to respond to behaviours of concern such as residents' verbal and physical aggression. In particular, participants felt these injuries were an unavoidable aspect of their work. Participants believed these had long-term consequences and led to staff taking prolonged sick leave, instigating workover claims and resulted in some staff leaving the RACS workforce altogether. Current statistics estimate 14.1 work cover claims per 1,000 community and personal service workers from serious injury claims in which the injury or disease caused the employee to have five or more days absences from work. In comparison to other occupations, community and personal service workers had the third highest incidence rate of claims (Australian Institute of Health and Welfare, 2020d). It has been established that challenging and/or aggressive resident behaviours may pose hazardous environments for staff and family with whom the aggressive individual interacts (Holst & Skär, 2017; McCann et al., 2015; Shea et al., 2017). Aggressive behaviours among older people with dementia are particularly challenging for care staff, resulting in increased care burden, negative self-esteem, feelings of being overwhelmed, apathy, fatigue, hopelessness, absenteeism and resignation (Shea et al., 2017).

Participants in the current study proposed several ways to manage and/or improve overall health and wellbeing, when caring for residents with mental-palliative comorbidity. They felt a number of strategies that could be implemented by the organisation. These included talking with their supervisor and/or manager, debriefing with co-staff, the provision and attendance at mental and/or palliative training, connecting with counselling services, taking planned and adequate annual leave, engagement in recreational and outside work activities and positive connection with friends and family. All these strategies helped to minimise and combat the negative impacts of RACS work stressors. These findings are similar to those reported in studies of stress and coping in the dementia care workforce, which recommend promoting the importance of staff orientation within RACS, purposively at the early stages of employment. (Elliott et al., 2016; Robinson et al., 2014). In addition, learning and applying clinical psychology theory and concepts that are fundamental for coping and adjustment in the RACS setting can build workforce resilience and capacity for dementia care (Elliott et al., 2016). Supporting staff confidence in work responsibilities in the early career stages can play an important role for enhancing their resilience and, in turn, support workforce retention (Eltaybani et al., 2018; Frey et al., 2015).

In the current study, participants indicated a need for measures which would aid in building their capacity to cope. Several participants reported feelings of frustration, distress. Application of theoretical models and/or processes, such as building staff resilience, confidence and comprehensive orientation may offer opportunities to develop and promote improved capacity of the aged care workforce. There is a clear indication of the need to better understand burnout among RACS staff (Frey et al., 2015; Shea et al., 2017).

5.4 Summary

Although PCC is critical when caring for all residents, in the case of mental-palliative care this approach is even more important. This study has highlighted that PCC in associated with understanding each person, complexities in assessing and managing pain, preventing and responding to behaviours of concern, engaging in interdisciplinary collaboration and organisational provision for staff development and wellbeing promotion. There are inherent challenges to embed and met residents' mental-palliative care needs, utilising a PCC evidence-based approach. This is due to multiple causative factors contribute including inadequate staffing levels and skills-mix, deficient current and ongoing staff training and development, CALD barriers to care, difficulties in interdisciplinary collaboration add to RACS overwhelming responsibility and negative effect to RACS staff health and wellbeing. There is a need for organisational supportive frameworks and processes to effectively support RACS staff providing PCC mental-palliative care.

CHAPTER 6:
Implications and conclusion

6.1 Introduction

The final chapter details the strengths and limitations of the study. This is followed by consideration of the implications for future practice and research, related to the requirements for caring for residents with mental-palliative comorbidity and the conclusion.

6.2 Strengths and limitations of the study

The present study applied an IPA approach to data collection and analysis, this aided in focusing on the current gap in knowledge of the under researched area. This study has provided an opportunity for increased awareness and understanding of the education and support needs of RAC staff caring for residents with mental-palliative comorbidity.

6.2.1 Strengths

The key strength of this study was using an IPA approach that allowed for exploration of rich and comprehensive data, uncovering a greater understanding of the experience of RACS staff caring for residents with mental-palliative comorbidity. Qualitative research and the utilisation of IPA, in particular, has increased within health and social contexts, as it has proven useful in allowing understanding of the intricacy of the research phenomena. This can, in turn, inform and potentially improve clinical practice (Biggerstaff & Thompson, 2008; Cuthbertson et al., 2020; Tomkins & Eatough, 2010).

Mental-palliative comorbidity is an under-researched area, and few studies have focused on this specific area. There are a large cohort of older individuals that require mental-palliative care. This population is often hidden within residential services are underdiagnosed and their mental health is poorly treated. There is a need for continued research to explore current service models and develop best-practice guidelines for meeting mental-palliative health needs in RACS settings (Amare et al., 2020).

Another strength was that data were collected from three different RAC homes, which provided a range of staff experience and perspectives, of how these separate facilities operate and meet the care needs of residents living with mental-palliative comorbidity. A final strength was that participant interviews were conducted with a mix of staff designations and staffing roles that included RNs, ENs and PCAs. This variance in roles allowed for deeper understanding and enhanced inclusion of staff perspectives and showed some differences in responses related to scope of practice. It is clear from the literature that the perspectives of all RACS staff, including managers, RNs and ENs, PCAs, pastoral care staff and volunteers are pivotal in the planning and provision of PCC (Borbasi et al., 2021).

6.2.2 Limitations

Although data were collected from three RACS homes, it is a limitation that these belonged to one private service provider. There is potential for larger study, with correlation between organisations, and differences related to private, public and not for profit organisations. Another limitation was that the study had no funding for additional research resources, and therefore interviews were conducted by only one student researcher at one RACS organisation. Increased funding benefits would include additional scope for more researchers at interview phase, enhancing the level of support provided to the student researcher. Also, additional researchers may allow for recruitment of multiple aged clinical organisations, allowing for increased participant size. Although, there was scheduled fortnightly or as required support and supervision from experienced researchers. A further limitation is that the data and results were only collected from semi-structured interviews, further data collection methods that involved a mixed methods approach, using cross triangulation of RACS documentation and or direct observation, could add further enrichment and validity to findings. Lastly, the mix in designation and responsibility level of participants’ positions may have limited the depth of findings for that particular designation.

6.3 Implications of the study findings

6.3.1 Practice implications

This study assists in promoting the awareness of RACS staff, external health care providers and RAC organisations in being more responsive to the needs of older adults with mental-palliative comorbidity. This can lead to improved treatment and care in this cohort.

This research has the potential to add further justification for governing and regulatory bodies to provide mandated and regulated staffing-resident ratios and increased mental-palliative pre-requisite training, all of which are needed to enhance care delivery and improve resident outcomes. It is evident that higher staff-to-resident ratios are required especially for those with complexity and/or neurocognitive disorder (Watson & Hatcher, 2021). Residents requiring mental-palliative care require staff with specialised skill in mental health. A potential consideration is the recruitment of mental health specialist registered nurses, holding key roles within the residential aged care sector. In addition increased opportunities for liaison and collaboration with mental health services. Participants in the current study acknowledged that they had a lack of experience in mental health and needed more information about the effects and lived experience of people living with a mental illness.. This information related mostly to mental health assessment, understanding of mental disorders, best practice treatments and care interventions. RACS health staff require specific mental health, palliative care and end of life training. This study found that training requires enhancement within the curriculum of their initial PCA, EN and or RN qualification. The promotion and implementation of mental-palliative training can reduce the negative effects on residents and staff causing poor work practices, lack of cohesion and work inefficiency are well known (Frey et al., 2015; Gillham et al., 2018).

In addition continual mental-palliative training should be tailored to meet RACS staffs individual learning needs and professional development plans, in a mode of delivery that can be readily accessible and embedded into the workplace, providing the prospect of practical and clinical application.

Another key recommendation is the use of critical reasoning and reflective practice and the instigation of clinical case forums whereby complex resident care can be shared and discussed with the health care team and interdisciplinary care plans developed. This notion is supported by the provision of PCC, which requires culture change supported by targeted education and supervision for staff (Ruddick, 2010; Sjögren et al., 2017).

Increased opportunities for mental-palliative residents to experience a homelike environment, therapeutic relationships and meaningful activities and staff fostering the valued input from the resident, families and or nominated persons are essential in upholding resident’s rights, self-determination and PCC approach. (Garratt et al., 2021).

Finally acknowledging that the resident living with mental-palliative issues is at the centre of all care interventions. Further RACS are encouraged to adopt models of care such as PCC that can facilitate resident focused benefits, improve health care outcomes and enhance quality of life for residents (Edvardsson et al., 2008; Sjögren et al., 2017).

This research underpins the need for the development of RACS clinical practice guidelines that focus on mental-palliative comorbidity and care. These guidelines should be practical and streamlined in approach for ease of use and adaptability to RACS setting needs. In addition these guidelines require current mental-palliative evidence based literature, interdisciplinary and resident and family collaboration and input. The study provides increased awareness to RAC organisations that are uniquely placed to make localised changes to their model of care, staffing profiles, policy and procedures and education and training provision.

6.3.2 Research implications

Research into the lived experiences of older adults living with mental and palliative issues is scarce. With limited research in this field, there is a need for further studies to build the evidence base for practice in mental-palliative care. Future studies should consider residents and families, the lived experience perspectives of mental-palliative needs and the care that is required. This evidence can provide insight and meaning, that can be translated into improved care and quality outcomes for residents (Reynolds et al., 2020).

Further research is required within organisations providing aged care to determine the needs of the mental palliative residents. It has been highlighted in many studies the importance of adequate organisational support in the delivery of mental-palliative care particularly in regards to adequate staff-to-resident ratios and skill mix (Hart et al., 2021; Hayes et al., 2012; Ludlow et al., 2021), enhancing staff training and development (Low et al., 2015; McCabe et al., 2009) and promoting staff general wellbeing. This support has been found to translate in improved resident outcomes (Eltaybani et al., 2018).

6.4 Closing remarks

A PCC approach is required in the delivery of care for all residents. People living with mental-palliative comorbidity experience a myriad of complex physical and mental health issues. A holistic, interdisciplinary and PCC approach is critical to ensure their unique and complex care needs are met, while upholding their dignity, enabling self-determination, maintaining comfort and ensuring quality of life. The current study has identified several strategies to enhance mental-palliative care in RACS. These include understanding the person, addressing complexities in assessing and managing pain, preventing and responding to behaviours of concern, engaging in interdisciplinary collaboration, organisational provision for staff development and wellbeing. There are inherent challenges for RACS staff in caring for residents with mental-palliative comorbidity. The challenges relate to the main themes identified. Advancements in government and organisational supportive systems and frameworks, further research in mental-palliative comorbidity and care and focus on the identified key themes can assist in improving RACS staff overall health and wellbeing and retainment of qualified staff in the RACS setting. The continued advancement ultimately promotes improved delivery of PCC and aids in beneficial outcomes for older adults requiring mental-palliative care.

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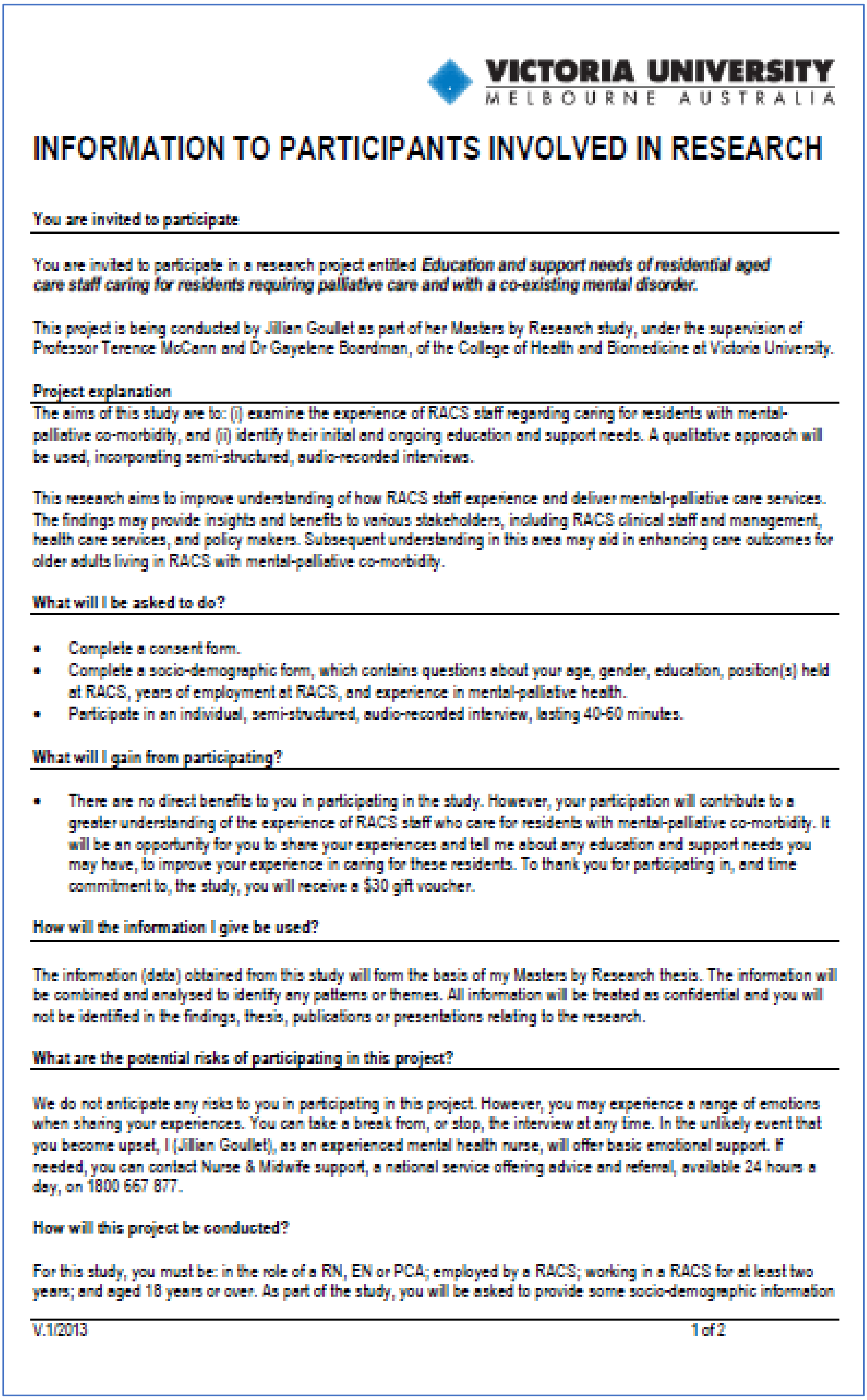
Appendix 1: Participant information form



VICTORIA UNIVERSITY
MELBOURNE AUSTRALIA

INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH

You are invited to participate

You are invited to participate in a research project entitled ***Education and support needs of residential aged care staff caring for residents requiring palliative care and with a co-existing mental disorder.***

This project is being conducted by Jillian Goullet as part of her Masters by Research study, under the supervision of Professor Terence McCann and Dr Gayelene Boardman, of the College of Health and Biomedicine at Victoria University.

Project explanation

The aims of this study are to: (i) examine the experience of RACS staff regarding caring for residents with mental-palliative co-morbidity, and (ii) identify their initial and ongoing education and support needs. A qualitative approach will be used, incorporating semi-structured, audio-recorded interviews.

This research aims to improve understanding of how RACS staff experience and deliver mental-palliative care services. The findings may provide insights and benefits to various stakeholders, including RACS clinical staff and management, health care services, and policy makers. Subsequent understanding in this area may aid in enhancing care outcomes for older adults living in RACS with mental-palliative co-morbidity.

What will I be asked to do?

- Complete a consent form.
- Complete a socio-demographic form, which contains questions about your age, gender, education, position(s) held at RACS, years of employment at RACS, and experience in mental-palliative health.
- Participate in an individual, semi-structured, audio-recorded interview, lasting 40-60 minutes.

What will I gain from participating?

- There are no direct benefits to you in participating in the study. However, your participation will contribute to a greater understanding of the experience of RACS staff who care for residents with mental-palliative co-morbidity. It will be an opportunity for you to share your experiences and tell me about any education and support needs you may have, to improve your experience in caring for these residents. To thank you for participating in, and time commitment to, the study, you will receive a $30 gift voucher.

How will the information I give be used?

The information (data) obtained from this study will form the basis of my Masters by Research thesis. The information will be combined and analysed to identify any patterns or themes. All information will be treated as confidential and you will not be identified in the findings, thesis, publications or presentations relating to the research.

What are the potential risks of participating in this project?

We do not anticipate any risks to you in participating in this project. However, you may experience a range of emotions when sharing your experiences. You can take a break from, or stop, the interview at any time. In the unlikely event that you become upset, I (Jillian Goullet), as an experienced mental health nurse, will offer basic emotional support. If needed, you can contact Nurse & Midwife support, a national service offering advice and referral, available 24 hours a day, on 1800 667 877.

How will this project be conducted?

For this study, you must be: in the role of a RN, EN or PCA; employed by a RACS; working in a RACS for at least two years; and aged 18 years or over. As part of the study, you will be asked to provide some socio-demographic information

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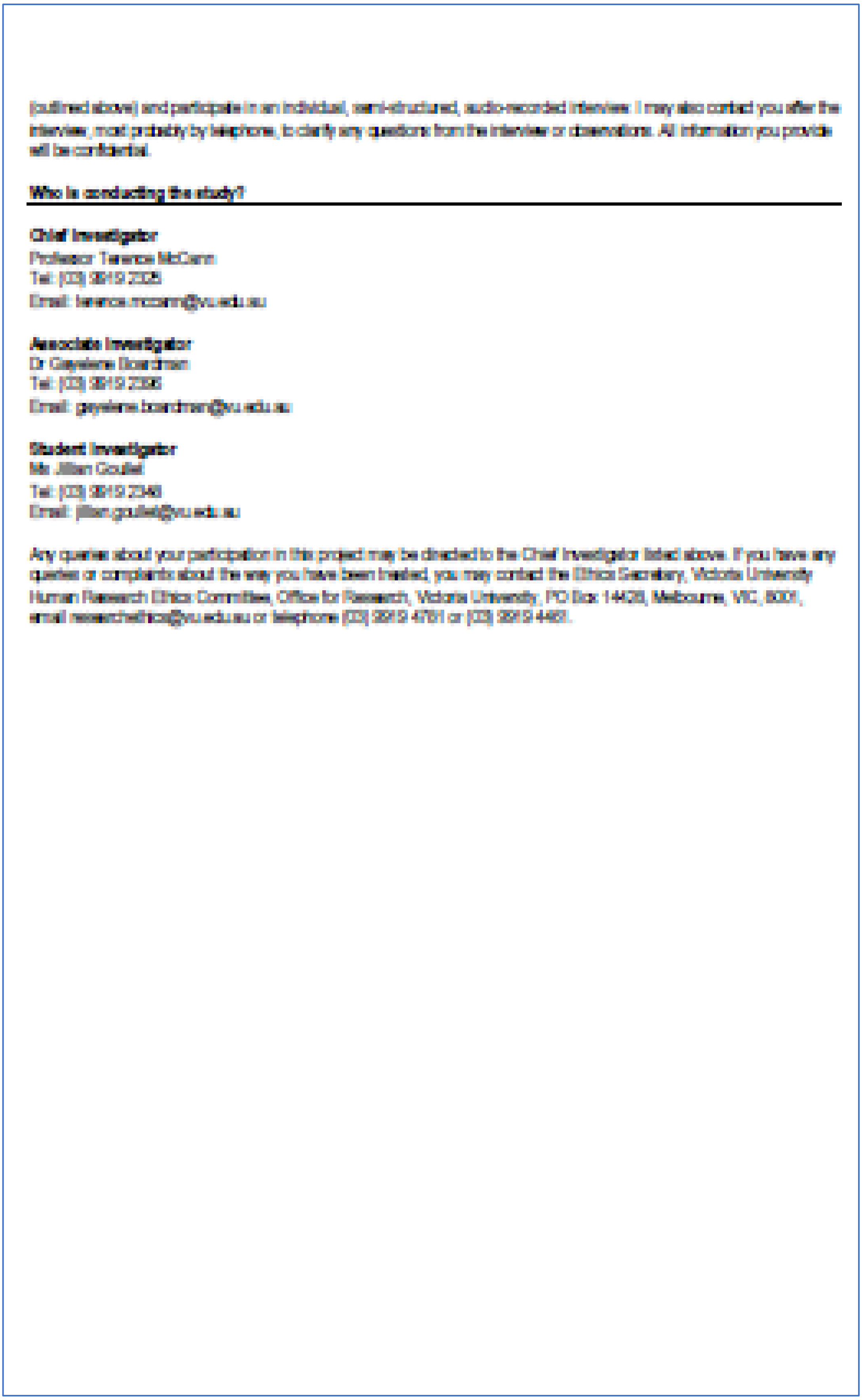


(outlined above) and participate in an individual, semi-structured, audio-recorded interview. I may also contact you after the interview, most probably by telephone, to clarify any questions from the interview or observations. All information you provide will be confidential.

Who is conducting the study?

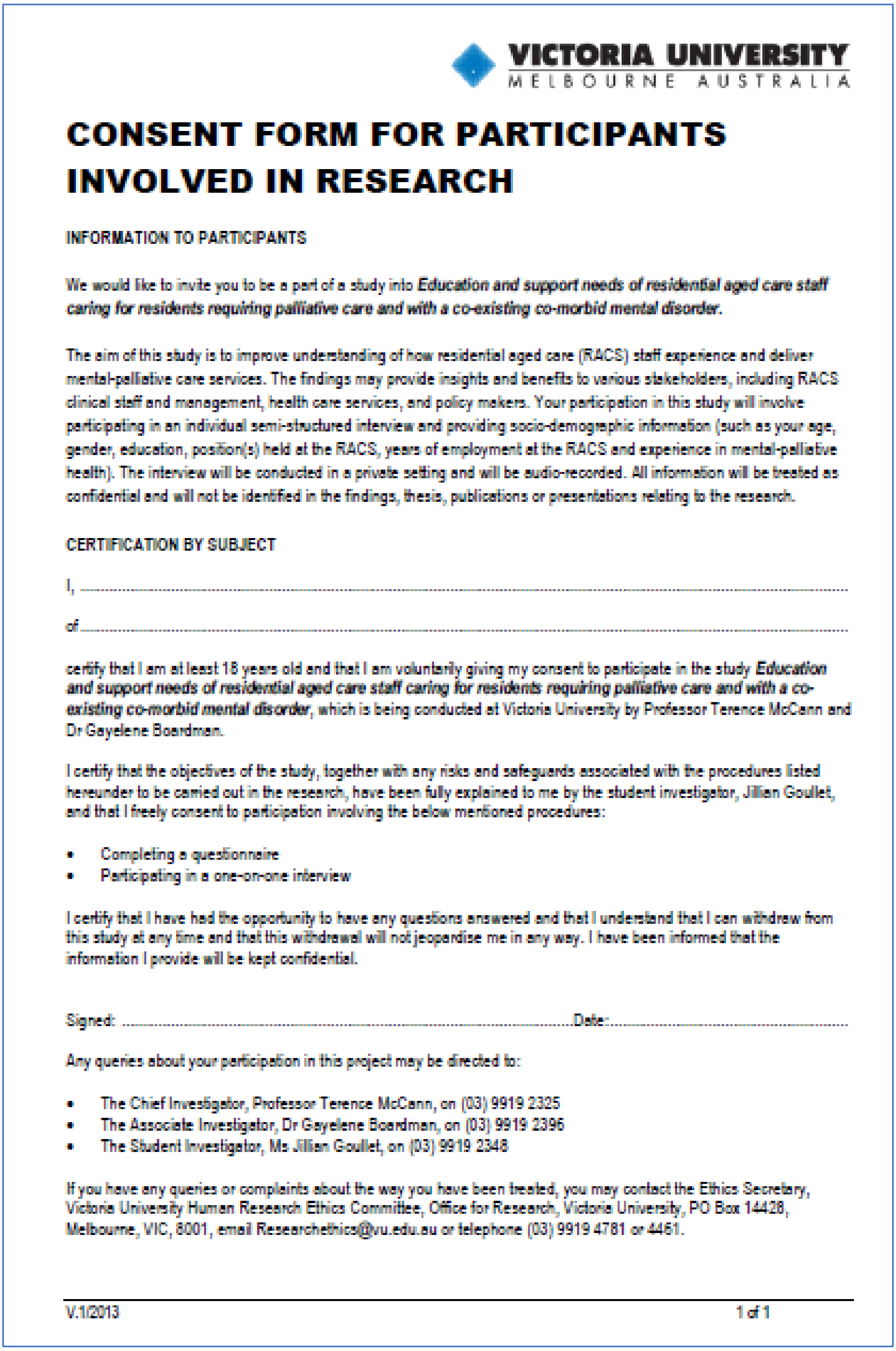
Chief Investigator
Professor Terence McCann
Tel: (03) 9919 2025
Email: terence.mccann@vu.edu.au

Associate Investigator
Dr Gayelene Boardman
Tel: (03) 9919 2396
Email: gayelene.boardman@vu.edu.au

Student Investigator
Ms Jillian Goullet
Tel: (03) 9919 2348
Email: jillian.goullet@vu.edu.au

Any queries about your participation in this project may be directed to the Chief Investigator listed above. If you have any queries or complaints about the way you have been treated, you may contact the Ethics Secretary, Victoria University Human Research Ethics Committee, Office for Research, Victoria University, PO Box 14428, Melbourne, VIC, 8001, email researchethics@vu.edu.au or telephone (03) 9919 4781 or (03) 9919 4461.

Appendix 2: Participant consent form



VICTORIA UNIVERSITY
MELBOURNE AUSTRALIA

CONSENT FORM FOR PARTICIPANTS INVOLVED IN RESEARCH

INFORMATION TO PARTICIPANTS

We would like to invite you to be a part of a study into *Education and support needs of residential aged care staff caring for residents requiring palliative care and with a co-existing co-morbid mental disorder.*

The aim of this study is to improve understanding of how residential aged care (RACS) staff experience and deliver mental-palliative care services. The findings may provide insights and benefits to various stakeholders, including RACS clinical staff and management, health care services, and policy makers. Your participation in this study will involve participating in an individual semi-structured interview and providing socio-demographic information (such as your age, gender, education, position(s) held at the RACS, years of employment at the RACS and experience in mental-palliative health). The interview will be conducted in a private setting and will be audio-recorded. All information will be treated as confidential and will not be identified in the findings, thesis, publications or presentations relating to the research.

CERTIFICATION BY SUBJECT

I, ……………………………………………………………………………………………………

of ……………………………………………………………………………………………………

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study *Education and support needs of residential aged care staff caring for residents requiring palliative care and with a co-existing co-morbid mental disorder*, which is being conducted at Victoria University by Professor Terence McCann and Dr Gayelene Boardman.

I certify that the objectives of the study, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by the student investigator, Jillian Goullet, and that I freely consent to participation involving the below mentioned procedures:

- Completing a questionnaire
- Participating in a one-on-one interview

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way. I have been informed that the information I provide will be kept confidential.

Signed: ……………………………………………………………………… Date: ……………………………………

Any queries about your participation in this project may be directed to:

- The Chief Investigator, Professor Terence McCann, on (03) 9919 2325
- The Associate Investigator, Dr Gayelene Boardman, on (03) 9919 2396
- The Student Investigator, Ms Jillian Goullet, on (03) 9919 2348

If you have any queries or complaints about the way you have been treated, you may contact the Ethics Secretary, Victoria University Human Research Ethics Committee, Office for Research, Victoria University, PO Box 14428, Melbourne, VIC, 8001, email Researchethics@vu.edu.au or telephone (03) 9919 4781 or 4461.

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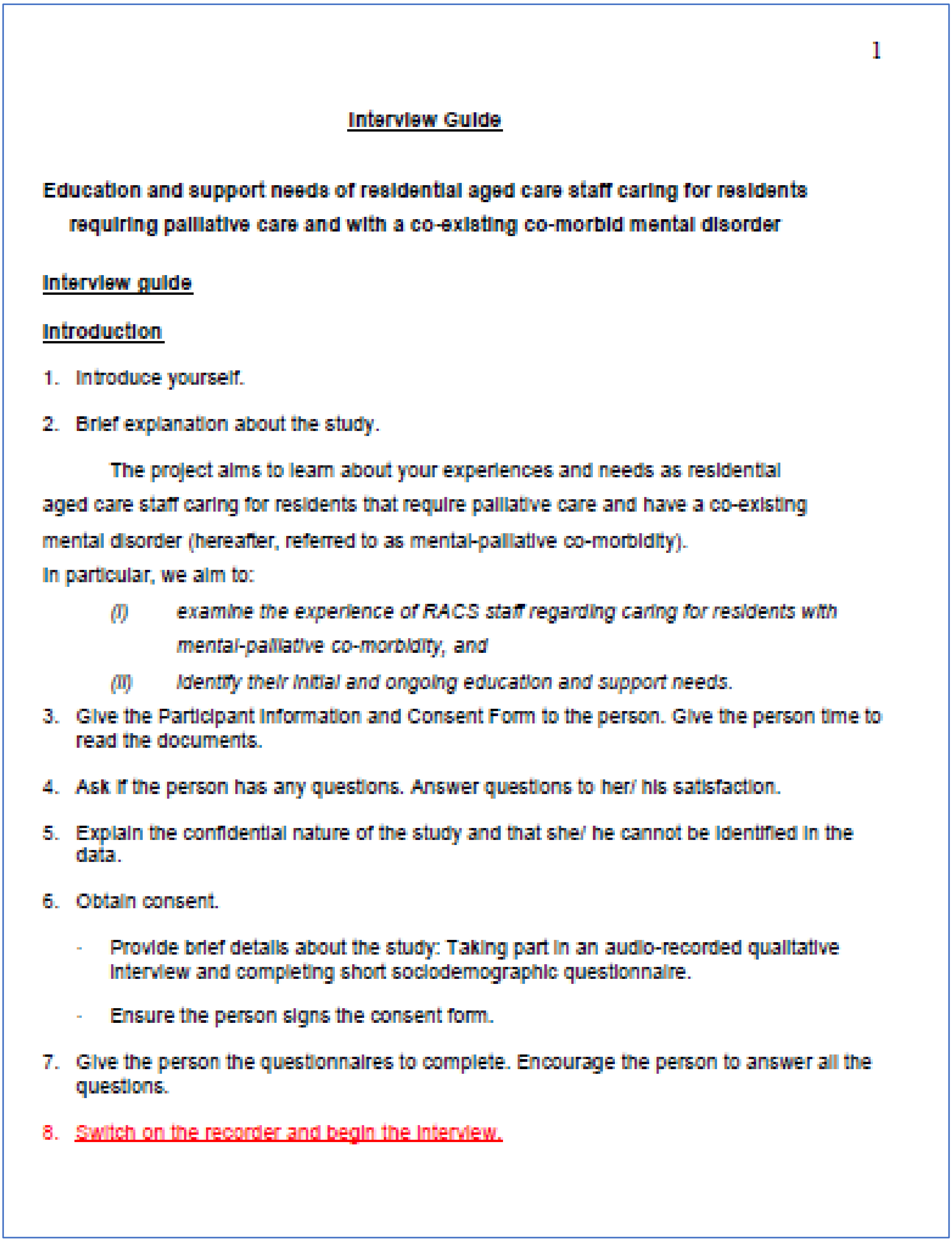
Appendix 3: Interview guide



Interview Guide

Education and support needs of residential aged care staff caring for residents requiring palliative care and with a co-existing co-morbid mental disorder

Interview guide

Introduction

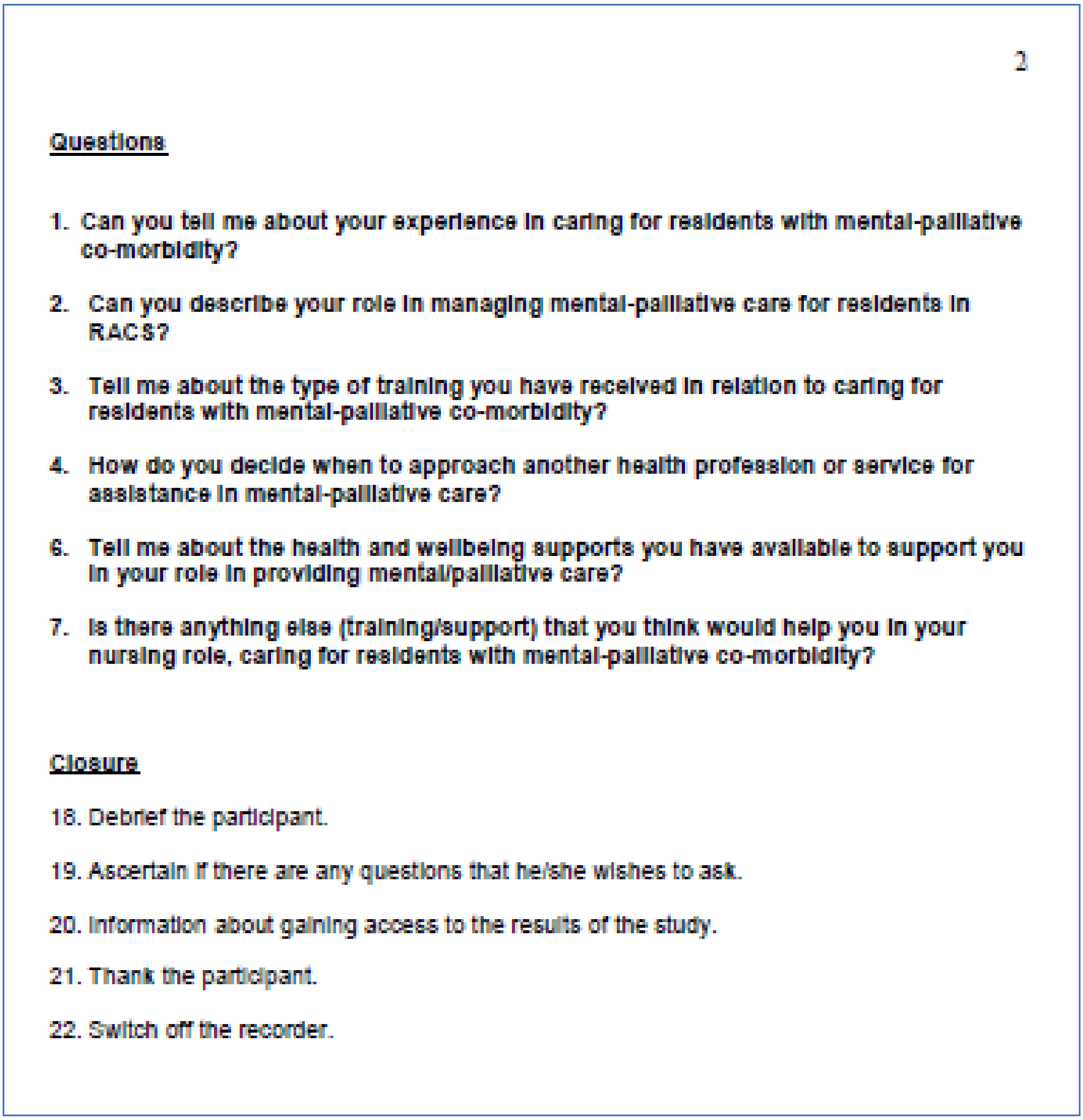
1. Introduce yourself.
2. Brief explanation about the study.

The project aims to learn about your experiences and needs as residential aged care staff caring for residents that require palliative care and have a co-existing mental disorder (hereafter, referred to as mental-palliative co-morbidity).

In particular, we aim to:

- *(i)* *examine the experience of RACS staff regarding caring for residents with mental-palliative co-morbidity, and*
- *(ii)* *identify their initial and ongoing education and support needs.*

3. Give the Participant Information and Consent Form to the person. Give the person time to read the documents.
4. Ask if the person has any questions. Answer questions to her/ his satisfaction.
5. Explain the confidential nature of the study and that she/ he cannot be identified in the data.
6. Obtain consent.
   - Provide brief details about the study: Taking part in an audio-recorded qualitative interview and completing short sociodemographic questionnaire.
   - Ensure the person signs the consent form.
7. Give the person the questionnaires to complete. Encourage the person to answer all the questions.
8. Switch on the recorder and begin the interview.



Questions

1. Can you tell me about your experience in caring for residents with mental-palliative co-morbidity?

2. Can you describe your role in managing mental-palliative care for residents in RACS?

3. Tell me about the type of training you have received in relation to caring for residents with mental-palliative co-morbidity?

4. How do you decide when to approach another health profession or service for assistance in mental-palliative care?

6. Tell me about the health and wellbeing supports you have available to support you in your role in providing mental/palliative care?

7. Is there anything else (training/support) that you think would help you in your nursing role, caring for residents with mental-palliative co-morbidity?

Closure

18. Debrief the participant.

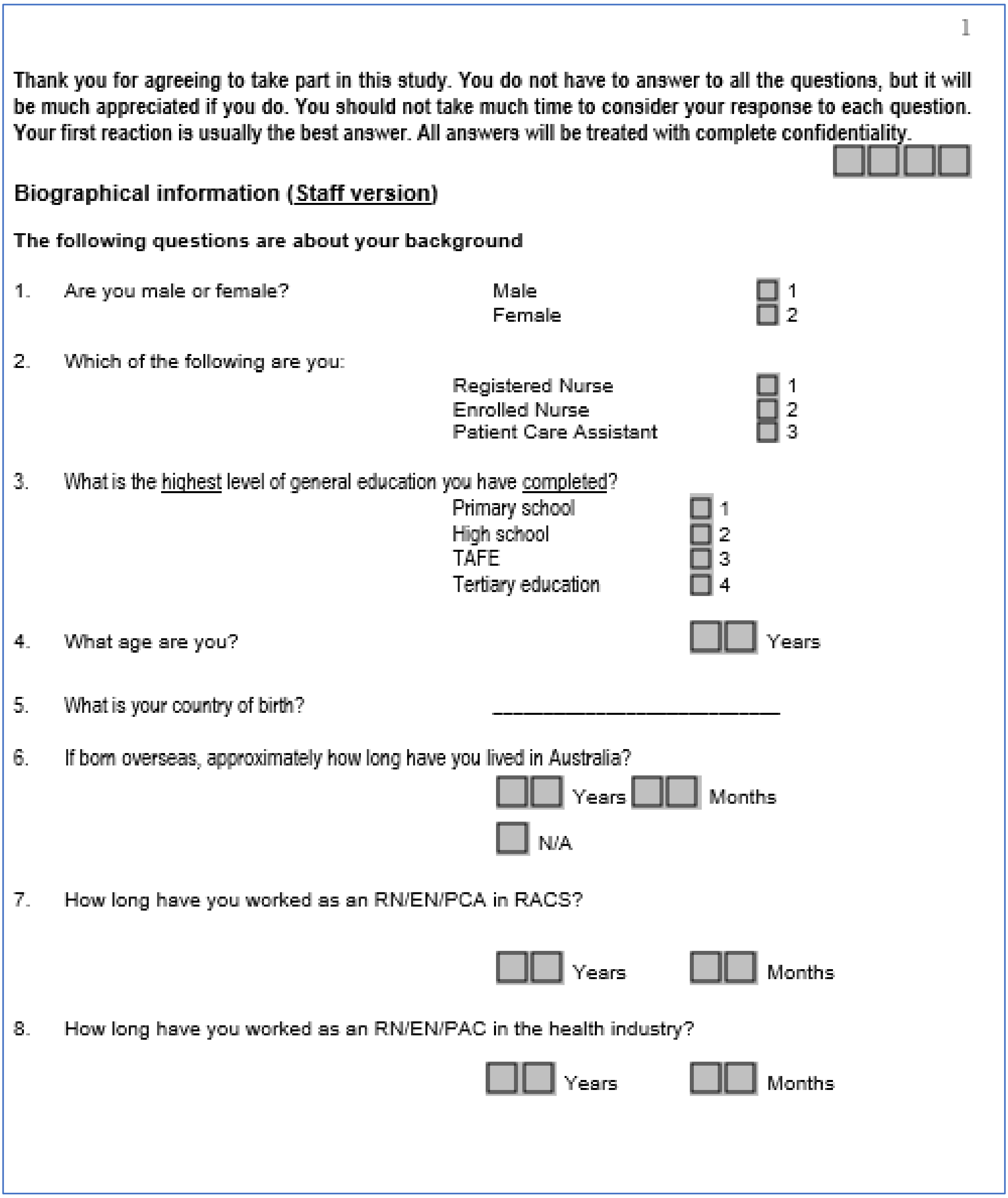
19. Ascertain if there are any questions that he/she wishes to ask.

20. Information about gaining access to the results of the study.

21. Thank the participant.

22. Switch off the recorder.

Appendix 4: Participant demographics form



1

Thank you for agreeing to take part in this study. You do not have to answer to all the questions, but it will be much appreciated if you do. You should not take much time to consider your response to each question. Your first reaction is usually the best answer. All answers will be treated with complete confidentiality.

☐☐☐☐

Biographical information (<u>Staff version</u>)

The following questions are about your background

1. Are you male or female?
   - Male ☐ 1
   - Female ☐ 2

2. Which of the following are you:
   - Registered Nurse ☐ 1
   - Enrolled Nurse ☐ 2
   - Patient Care Assistant ☐ 3

3. What is the <u>highest</u> level of general education you have <u>completed</u>?
   - Primary school ☐ 1
   - High school ☐ 2
   - TAFE ☐ 3
   - Tertiary education ☐ 4

4. What age are you? ☐☐ Years

5. What is your country of birth? ____________________________

6. If born overseas, approximately how long have you lived in Australia?

   ☐☐ Years ☐☐ Months

   ☐ N/A

7. How long have you worked as an RN/EN/PCA in RACS?

   ☐☐ Years ☐☐ Months

8. How long have you worked as an RN/EN/PAC in the health industry?

   ☐☐ Years ☐☐ Months