Nurses' Perceptions of Quality Nursing Care in Dementia Specific Care Units

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Abstract

This thesis presents a Grounded Theory study of nurses' perceptions of quality nursing care in the Dementia Specific Care Unit. Dementia is a progressive, degenerative neurological disease with currently, no cure (World Health Organization [WHO], 2017b). Currently, more than 24 million people globally live with dementia and this figure is forecast to rise to 135.5 million by 2050 (Backhaus, Verbeek, van Rossum, Capezuti, & Hamers, 2014; McGilton et al., 2016; Nursing and Midwifery Board of Australia, 2018).

Registered Nurses, Nurse managers, educators, researchers, healthcare organisations and policymakers appear to have differing views of just what constitutes quality nursing care in the Dementia Specific Care Unit, with no clear definition apparent (V. Parker et al., 2019). Understanding how Registered Nurses perceive quality nursing care in the Dementia Specific Care Unit is important and will provide valuable information about nursing practice in this environment for nurses and decision makers.

This Grounded Theory study aimed to understand the Registered Nurses' perception of quality nursing care in Dementia Specific Care Units. The study involved interviewing nine Registered Nurses working in Dementia Specific Care Units in Queensland, Australia. Data was collected during semi-structured interviews and then analysed using the constant comparative method, in line with Grounded Theory methodology (Glaser & Strauss, 1967). The data revealed the complexity of delivering quality nursing care in Dementia Specific Care Units and the challenges nurses faced daily in the delivery of that care.

The themes identified from the data are Caring at the Coalface, Labour of Love and The Business of Dementia Healthcare. The theory generated from this study is: *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding*.

Statement of Authorship

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

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All research procedures reported in the thesis were approved by the La Trobe University Ethics Committee (see Appendix A) and Ozcare Management and Ethics Committee (see Appendix B).

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Chapter 1

Introduction

This chapter introduces the researcher, my background, nursing career, interest in dementia nursing care and completed education in both nursing management and law. The motivation to investigate quality nursing care in the Dementia Specific Care Unit and why this Grounded Theory study was thought to be extremely important is also discussed. The Dementia Specific Care Unit is introduced and the role, responsibilities, training, education and nursing-care practice of Registered Nurses working in Dementia Specific Care Units are described. The impact of a dementia diagnosis on the individual, their families and the community is revealed. Elder abuse, which can result from inadequate care in the Dementia Specific Care Unit, is discussed along with the issues related to the cost of supporting, managing and operating this care unit. Chapter 1 concludes with an overview of each chapter in this thesis.

Currently, more than 24 million people live with dementia globally, and this figure is forecast to rise to 135.5 million by 2050 (Dening et al., 2019; Prizer & Zimmerman, 2018). As the world's population ages, the incidence of dementia is projected to rise in tandem (Prince, Comas-Herrera, et al., 2016; WHO, 2017b). The requirement for skilled, dementia-trained Registered Nurses who are able to provide quality dementia nursing care will have to increase accordingly to meet the needs of these individuals (Choi & Choi, 2019; Cousins, Burrows, Cousins, Dunlop, & Mitchell, 2016). Dementia care nursing is labour-intensive, physically and psychologically challenging work (Gerritsen et al., 2018; Monthaisong, 2018) that involves supporting individuals who are in cognitive decline (E. Chang, Johnson, & Hancock, 2018; Cronfalk, Norberg, & Ternestedt, 2018; Jutkowitz et al., 2016). As a result of this decline, a number of challenges associated with responding to and managing adverse patient behaviours often arise (Cen, Hasselberg, Caprio, Conwell, & Temkin-Greener, 2018; Evripidou, Charalambous, Middleton, & Papastavrou, 2019). Sub-optimal care and poor patient outcomes may result if nurses are not adequately trained or the workplace is inadequately staffed (Joyce et al., 2018; Gerritsen et al., 2018). Quality nursing care in this environment is critical because individuals with dementia are vulnerable and dependent on others to advocate for them (Gilbert & Croxon, 2019; A. Jensen, Pedersen, Wilson, Olsen, & Hounsgaard, 2019; C. Miller, 2018).

Quality nursing care, however, is difficult to describe, define and quantify (Gilbert, Ward, & Gwinner, 2019; Gilster, Boltz, & Dalessandro, 2018; Robertson et al., 2019; Sellevold et al., 2019). Exploring the Registered Nurses’ perceptions of quality nursing care in Dementia Specific Care Units is critical. Gaining a better understanding of quality nursing care in this care unit may result in better nurse education and an improved patient experience. It may also assist nursing organisations, residential aged-care facilities, government bodies and non-government agencies that support, manage and oversee Dementia Specific Care Units (B. McCormack & McCance, 2016; Holanda, Marra, & Cunha, 2015; Buchan & Seccombe, 2018).

Why Was This Study Important?

As the global population ages and the incidence of dementia is forecast to rise in conjunction with the ageing population, the number of individuals who will require admission to Dementia Specific Care Units for ongoing dementia care will also increase (Cousins et al., 2016). A Dementia Specific Care Unit is a small, locked unit within a residential aged-care facility that aims to minimise cognitive and physical decline and maximise the quality of life of patients with late-stage dementia (Adlbrecht, Bartholomeyczik, & Mayer, 2018; Ballard et al., 2017; Benson, Cameron, Humbach, Servino, & Gambert, 1987; G. Roberts, Morley, Walters, Malta, & Doyle, 2015). Dementia Specific Care Units also offer patients with late-stage dementia a safe, homelike environment supported by dementia-trained staff and dementia intervention programs to provide optimum quality of life and wellbeing (Crespo, Hornillos, & Gomez, 2013). The Dementia Specific Care Unit is a separate space for patients who are experiencing increasing agitation, aggression and adverse behaviours as a result of their dementia progression and aims to meet the specific needs of dementia patients (Adlbrecht et al., 2018; Ballard et al., 2017; Benson et al., 1987; M. Marshall, 1993; Sloane et al., 1991). These often adverse behaviours require close staff observation and intervention to maintain patient safety and preclude injury to patients and others (Chaudhury & Cooke, 2014; Gimm, Chowdhury, & Castle, 2018).

Individuals who experience significant cognitive decline as their dementia progresses and require nursing care, may be admitted to a Dementia Specific Care Unit to both support preservation of their cognition for as long as possible and to promote wellbeing (Evripidou & Charalambous, 2019).

Extensive research has been completed on dementia care in a variety of settings; however, little research has been undertaken into what Registered Nurses perceive to be quality nursing care in the Dementia Specific Care Unit (K. Anderson, Bird, & McPherson, 2016; Rodriguez-Martin, 2019; Zúñiga et al., 2015). Research into this specialty area of care is therefore paramount. The broad aim of this Grounded Theory study was to add to the existing knowledge and understanding of quality nursing care in the Dementia Specific Care Unit. Understanding current nursing practice and care delivery in this setting could help to inform decision-makers responsible for the provision of healthcare for patients living in the Dementia Specific Care Unit. In light of the current Australian Royal Commission into Aged Care Quality and Safety (Department of Prime Minister and Cabinet, 2018), findings from this study are important and may provide vital and timely information for the Australian Government and policymakers who provide funding for residential aged-care facilities and Dementia Specific Care Units. If more were known regarding what constitutes quality nursing care, decisions could be made that potentially enhance outcomes for patients in Dementia Specific Care Units.

Although this study focused on nurses working in Dementia Specific Care Units, findings from this study have wider significance through the provision of information and theoretical understanding of quality nursing care for nurses working in other clinical settings. Understanding how nurses perceive quality nursing care in the Dementia Specific Care Unit may assist Registered Nurses to understand what quality nursing care is and how they can influence and deliver quality nursing care in practice.

Aim of the Study

The aim of this Grounded Theory study was to describe and explore Registered Nurses' perceptions of quality nursing care in Dementia Specific Care Units.

The Impact of Dementia

This section presents a brief overview of what is known regarding dementia and the impact of dementia on both the individual and their family members. Dementia is the "umbrella" term for multiple neurological diseases that permanently and progressively disrupt cognitive ability and capacity (WHO and Alzheimer's Disease International, 2012). It is a common but complex cognitive condition that is characterised by the deterioration in the individual's ability to complete activities of daily living and in their general quality of life (Pink, O'Brien, Robinson, & Longson, 2018). Dementia is separate and different from the physical and psychological changes associated with normal ageing and is characterised by the persistent and progressive loss of cognition (Pink et al., 2018).

Currently, more than 24 million people globally live with dementia and this figure is forecast to rise to 135.5 million by 2050, with increased global population longevity directly linked to a dramatic increase in the incidence of dementia (Dening et al., 2019; Prince, Wimo, et al., 2015; WHO, 2017b). Given the ageing global population and the projected increase in the incidence of dementia, there is an urgent need for governments and communities to develop and consistently utilise strategies to finance and provide quality dementia nursing care for individuals afflicted with dementia (Dening et al., 2019). Failure to identify and develop these strategies will result in the untenable situation where the provision of quality dementia nursing care is not financially viable, resulting in poor patient outcomes and quality of life for individuals living with late-stage dementia (S. Lee, Chaudhury, & Hung, 2015; Fazio et al., 2018; Mariani et al., 2017).

The progression of dementia is individual and variable, affecting individuals differently in terms of onset, progression and symptoms experienced (Gerritsen, van Beek, & Woods, 2018; Prince, Bryce, & Ferri, 2011). Dementia progression is also often complicated by multi-morbidity, polypharmacy and associated physical frailty (Bennett et al., 2018; Maiese, 2018). The early stages of dementia are characterised by the gradual onset and subtle progression of memory impairment, personality changes and adverse behaviours (Low, Swaffer, McGrath, & Brodaty, 2018; Prince, Bryce, & Ferri, 2011). As the disease progresses, the individual may experience impairment in their gait and fine motor function and have difficulty with activities of daily living such as bathing, shopping or managing their financial affairs (Van Duen, Van Den Noortgate, Van Bladel, Palmans, & Cambier, 2019). For many, the loss of connection to past memories and experiences is common, as is maintaining independence, which is largely due to short-term memory loss, difficulty with communication, changes in personality and behaviour, and an altered perception of the world around them (Prince, Bryce, & Ferri, 2011; Petersen et al., 2019).

Many people living with dementia also experience increasing social withdrawal, loss of self-worth and purpose, and depression and anxiety because of their diagnosis (Farina et al., 2017). They may also experience a change in, or loss of, family relationships, which is associated with a diminished quality of life (Farina et al., 2017).

For some, their fear of the future is based on the negative depictions of people living with severe and advanced dementia who are totally dependent on others for care (Prince, Bryce, & Ferri, 2011). For others, the stigma associated with a diagnosis of dementia can be devastating, which can lead to significant emotional distress (Bennett et al., 2018). An individual diagnosed with dementia may also grieve for both the loss of their current physical and mental abilities as well as their lifestyle and their future expected life and goal achievements (Bennett et al., 2018; Prince, Bryce, & Ferri, 2011).

In the initial stages of the disease, family members typically care for the individual with dementia, providing support and assistance where required, but as the disease progresses, the impact of caregiving on family members can be profound (Farina et al., 2017; Srivastava, Tripathi, Tiwari, Singh, & Tripathi, 2016). With the advancement of dementia, the individual may experience hallucinations, delusions, changes in their personality and behaviour, increased aggression, and resistance to care (Manes, 2016; McFarlane & O’Connor, 2016; Young & Swaffer, 2018). For some family members, caring for a person with dementia can be fulfilling, but for others the continual physical, psychological and financial burden associated with providing care can become overwhelming, culminating in carer fatigue, depression and anxiety (M. Bauer, Featherstonhaugh, Blackberry, Farmer, & Wilding, 2019; G. Carter et al., 2018; Feast et al., 2016).

Some carers have discussed the dramatic changes to their life when caring for the person with dementia (Omranifard, Haghighizadeh, & Akouchekian, 2018; Srivastava et al., 2016), particularly their perceived loss of personal freedom and good health and the sometimes unrealistic expectations of themselves and others to provide continued care for the individual (Carter et al., 2019; Daley et al., 2019). Other carers have identified and discussed the external factors impacting on their ability to provide continued care for individuals with dementia, including the lack of external financial support and the perceptions of others regarding ongoing physical and socio-behavioural care provision (M. Bauer, Fetherstonhaugh, Blackberry, et al., 2019; Bennett et al., 2018; Daley et al., 2019; Rathnayake, Moyle, Jones, & Calleja, 2019). This sustained and unrelenting care burden can result in the often difficult decision by caregivers to permanently place the individual with late-stage dementia into a Dementia Specific Care Unit (Gresham, Heffernan, & Brodaty, 2018; L. Miller, Whitlatch, & Lyons, 2016).

Over 60 per cent of people diagnosed with dementia in Australia are currently admitted to residential aged-care facilities, with over 40 per cent of those with late-stage dementia then admitted to Dementia Specific Care Units (Toot et al., 2017). Whilst the direct comparison of patient admissions to Dementia Specific Care Units globally is complicated by country income, inherent health resources, and the prevalence of informal care, these admission rates appear to be replicated universally and are expected to increase exponentially in coming years with the ageing population and forecast increase in the incidence of dementia (Prince, Acosta, et al., 2012; Prince, Bryce, & Ferri, 2011; Wimo et al., 2017). The projected demand for specialised dementia nursing care requires nurses, healthcare organisations and governments to develop strategies to sustainably manage the increasing needs of these individuals and an ageing global population (Gilster et al., 2018; Prince, Bryce, et al., 2013).

Dementia Care Costs and Challenges

The cost of quality dementia nursing care globally is multifaceted, colossal and will have a profound effect on individuals, governments and communities who are required to fund this care into the future (Wimo et al., 2017). The provision of specialised nursing care for people living with dementia by 2050 is estimated to cost healthcare organisations and governments globally between $159 billion and $1 trillion and remains a focus for future discussion (WHO, 2017b; Wimo et al., 2017).

In 2015, the average annual cost of care for an individual living with dementia in a developed country was $143,680, with an expected increase to over $155,000 per year by 2030 (Wimo et al., 2017). The financial cost for the large number of individuals with dementia requiring long-term residential care consists primarily of government subsidised residential care, Medicare payments, subsidised pharmaceuticals and out-of-hospital, medical and other healthcare appointments (Gnanamanickam et al., 2018; Michalowsky et al., 2018; Prince, Ali, et al., 2016). One strategy to contain these costs may be for governments to support informal caregivers financially and socially in the community so they can continue providing dementia care for their loved ones for as long as possible (Chaio et al., 2015).

Family members continue to be the largest group of informal caregivers, providing most of the assistance required to allow people with dementia to live in the community (Armstrong, Gitlin, Parisi, Roth, & Gross, 2019). Informal dementia care is characterised by out-of-pocket financial costs for care services, missed opportunities for carer career advancement, and the often adverse impact on the carer’s psychological and physical health and wellbeing (Jennings et al., 2019; Zhu, Bruinsma, & Stern, 2018). The cost of informal care provided by family members is complex and multidimensional and is often considered by communities and governments to be free or a low-cost source of dementia care, and so may not be included in the true cost of reported dementia care (S. Cheng, 2017; Goldberg, Price, Becker, & Bindoff, 2018; Jutkowitz et al., 2017; Prizer & Zimmerman, 2018).

Acknowledgment of the important role informal caregivers have in the provision of cost-effective dementia care should be made by governments and communities globally (Jutkowitz et al., 2017). The provision of physical and financial resources by governments to support informal caregivers in the community may result in delayed institutionalisation of the person with dementia and provide a cost-effective alternative to the issue of long-term dementia care (S. Cheng, 2017; Jutkowitz et al., 2017; Zhu, Cosentino, et al., 2015).

The cost of dementia care in residential aged-care facilities in Australia is unknown as not all patients living in these facilities have been formally diagnosed with dementia and their care needs and associated costs vary considerably depending on their general health and any comorbidities (Gnanamanickam et al., 2018). The mandatory user fee component consisting of 85 per cent of the single aged-care pension forms the basis of care costs for patients with dementia but differing resource costs and care models within individual residential aged-care facilities add additional layers of complexity to determining the actual cost of dementia care in residential aged-care facilities (Department of Health, 2016).

Once individuals with dementia are admitted to Dementia Specific Care Units, the financial cost of care increases dramatically (Akerborg et al., 2016; Breitve et al., 2018; Hopkins, 2017). This increase in cost is largely due to the increased staff and physical resources required to provide specific dementia care that is directly linked to the patient’s cognitive decline and development of functional behaviours (Breitve et al., 2018; Martyr & Clare, 2018). Requisite resources include the provision of sufficient numbers of dementia-trained and competent staff, dementia-friendly meal and hygiene care delivery, and dementia-friendly organisational policies and procedures that aim to conserve patient cognition and independence for as long as possible (Evripidou et al., 2019; Hopkins, 2017; Midtburst, Alnes, Gjengedal, & Lykkeslet, 2018).

The cost of providing care in Dementia Specific Care Units has also been linked to the individual’s loss of independence as the disease progresses and they require additional support from staff to complete activities of daily living (Akerborg et al., 2016). This loss of independence may be further complicated by the development of challenging behaviours such as agitation (Surr et al., 2016). Agitation remains the most common adverse behaviour in dementia patients and includes verbal agitation and physical and verbal aggression (Inkley & Goldberg, 2016; Surr et al., 2016). Increasing levels of agitation in dementia patients have been linked to increased social isolation, decreased interaction with family members and others, and resultant poor patient quality of life (Surr et al., 2016).

Management of agitation can be challenging for nurses within Dementia Specific Care Units and can include the frequent administration of medications, including psychotropics and sedatives, that has resulted in an increased incidence of patient falls, injuries and mortality (S. Karlsson, Hallberg, Midlöv, & Fagerström, 2017; H. Shin, Gadzhanova, Roughead, Ward, & Pont, 2016; van der Spek et al., 2016). The frequent administration of psychotropic medications in Dementia Specific Care Units has been explored by researchers who have found that a hierarchical organisation structure and culture with strict protocols was associated with high levels of medication administration to dementia patients (Allers, Dörks, Schmiemann, & Hoffmann, 2017; Kirkham et al., 2017; Li, Grandner, Chang, Jungquist, & Porock, 2017; O'Connor et al., 2018; Peri et al., 2015). Recommendations from these studies include reducing the use of psychotropic medications by the establishment of an organisational culture based on person-centred care (Allers et al., 2017; Kirkham et al., 2017; Li et al., 2017; O'Connor et al., 2018; Peri et al., 2015).

This person-centred culture of care involves the individual being assessed continuously for behavioural triggers. Only the minimum amount of medications is administered to manage behaviours and strategies, such as distraction and patient engagement, and the medications are integrated into everyday nursing-care delivery (Allers et al., 2017; Kirkham et al., 2017; Li et al., 2017). As a result of the often indiscriminate administration of medications, such as sedatives or psychotropics in Dementia Specific Care Units, patients may experience falls or injuries requiring hospitalisation (Timmons et al., 2016).

The unfamiliar environment of a hospital can be confusing and distressing for the patient with dementia, leading to increased agitation and aggression (O'Connell, Orr, Ostaszkiewicz, & Gaskin, 2011; Zhu, Scarmeas, et al., 2015). Managing these behaviours requires additional trained staff numbers and resources to maintain patient safety, with additional associated cost to the healthcare system (Jennings et al., 2019; Timmons et al., 2016; Zhu, Scarmeas, et al., 2015). Admission of a person with dementia to a hospital has also been associated with a rapid deterioration in their current level of cognition and functionality that requires constant nursing interventions; again, at an increased financial cost (Bail et al., 2015; R. Briggs et al., 2015; Timmons et al., 2016; Zhu, Scarmeas, et al., 2015). The physical deterioration of the person with dementia in hospital can also be due to dehydration and malnutrition because the person with dementia may be unable to feed themselves or recognise and communicate to staff that they are hungry or thirsty (Sullivan, Mannix, & Timmons, 2017). Patients with dementia may also be discharged back to a Dementia Specific Care Unit from hospital shortly after admission because of their adverse behaviours and increased needs (Timmons et al., 2016). This early discharge can result in the rapid readmission of the person with dementia to hospital with the same or a more serious complaint; again, at an increased cost to the community and healthcare system (Timmons et al., 2016).

The Dementia Specific Care Unit

Dementia Specific Care Units emerged as separate areas within residential aged-care facilities in the late 1980s as a result of the increased number of people who had progressive dementia and the associated need to manage their often adverse behaviours (D. G. Morgan & Stewart, 1999). They were developed to provide specific dementia care and improved quality of life for patients as well as to reduce the stress experienced by staff members and other patients within residential aged-care facilities because of behaviours exhibited by patients with late-stage dementia (Berg et al., 1991).

Prior to the development of and common acceptance of Dementia Specific Care Units, patients with late-stage dementia lived in close proximity to other patients in the residential aged-care facility (Frisoni et al., 1998; Grant, Kane, Potthoff, & Ryden, 1996). This meant that patients with late-stage dementia shared common areas such as dining and lounge rooms with other patients, and this freedom of movement could often lead to intrusive and confronting disturbances, where dementia patients might enter other patients' rooms at night, steal other patients' property, or assault other patients (Leon & Ory, 1999; Ohta & Ohta, 1988). The aggressive and combative behaviours common to people with late-stage dementia were particularly challenging for residential aged-care facility staff and other patients prior to the development of Dementia Specific Care Units as there were limited resources available to manage these behaviours (Lai, Yeung, Mok,

& Chi, 2009). As a result, patients with advanced dementia were subject to increased use of physical and pharmacological restraint to manage their adverse behaviours, often with catastrophic outcomes including increased patient morbidity and mortality (Gold, Sloane, Mathew, Bledsoe, & Konanc, 1991; Sloane et al., 1991).

Researchers explored the efficacy of Dementia Specific Care Units as a legitimate alternative to the continual physical and chemical restraint of patients with late-stage dementia (Frisoni et al., 1998; Leon & Ory, 1999; D. G. Morgan & Stewart, 1999). Findings from this research have confirmed that admission to Dementia Specific Care Units has resulted in a reduction in the use of both physical restraints and psychotropic medication use (Appelhof et al., 2019; Leon & Ory, 1999; D. G. Morgan & Stewart, 1999). It had also been noted that patient behavioural disturbances – including delusions, hallucinations, anxiety and sleep disturbances – had significantly improved following admission to a Dementia Specific Care Unit (Frisoni et al., 1998). These findings confirm that the specific dementia care provided to patients admitted to Dementia Specific Care Units can significantly control behavioural symptoms without the use of additional restraint and medication.

Other research exploring the efficacy of Dementia Specific Care Units on patient wellbeing has confirmed that the admission of patients with moderate to late-stage dementia to Dementia Specific Care Units has resulted in the improvement in, or prevention of, patient falls, urinary incontinence and malnutrition (Bunn et al., 2016; Liang et al., 2017). Findings from these studies indicate that the social interactions and integration evident in Dementia Specific Care Units has a significant positive impact on patient behaviour, health and wellbeing (Abbott, Bettger, Hampton, & Kohler, 2015).

The presence of trustworthy relationships between staff and patients in Dementia Specific Care Units has been acknowledged as a fundamental feature of daily life that provides patients with a sense of belonging and safety (Royston, Mitchell, Sheeran, Strain, & Goldsmith, 2017). These relationships serve to establish and maintain a community within the Dementia Specific Care Unit that provides patients with social connection and interaction and improved quality of life (Aasgaard, Landmark, & Öresland, 2017).

Given the projected increase in the numbers of people diagnosed with dementia, one of the urgent challenges for residential aged-care facility managers is the design of appropriate and safe Dementia Specific Care Units for patients with advanced dementia

(Treadaway, Fennell, Kenning, Prytherch, & Walters, 2016). The design of the Dementia Specific Care Unit has been shown to significantly impact on the quality of life for patients with late-stage dementia (Talebzadeh & Lang, 2017; Treadaway et al., 2016). The use of a homelike design that replicates the patient’s own home, and so becomes a familiar environment for the patient, can significantly reduce their anxiety and agitation levels (Kuller, 2015). Other researchers have explored the importance of a homelike atmosphere within Dementia Specific Care Units and have confirmed that patient anxiety, agitation and aggression are reduced when the patient environment closely resembles a normal household (Mozley et al., 2017; Rokstad, Vatne, Engedal, & Selbæk, 2015; Stokes, 2017). Open-plan designed Dementia Specific Care Units, where patients can easily see various areas, such as their bedroom, kitchen and lounge room, have also been shown to reduce patient anxiety, confusion and adverse behaviours (O’Rourke et al., 2015).

In contrast, Dementia Specific Care Units with an industrial, clinical, purely functional appearance and atmosphere were linked to increased levels and incidences of agitation, aggression and combative patient behaviours (Charras, Eynard, & Viatour, 2016; Mozley et al., 2017; Stokes, 2017). Dementia Specific Care Units that are characterised by both private and community spaces were found to facilitate patient interaction and engagement with staff and other patients and promoted patient involvement in a variety of activities (Fleming, Goodenough, Low, Chenoweth, & Brodaty, 2015; Treadaway, 2016). Some of these identified activities include opportunities to engage in cooking, washing-up, handicrafts or spending time with their family members away from the general patient population (Ludden, van Rompay, Niedderer, & Tournier, 2019; S. Scott & Kidd, 2016). Dementia Specific Care Units were, and continue to be, recognised as an essential component in the provision of care for people with advanced dementia (Kok et al., 2016; Olsson et al., 2012; Sjögren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2013).

Elder Abuse and Neglect in the Dementia Specific Care Unit

Elder abuse and neglect has received increasing community attention recently, largely due to the widespread media coverage relating to physical assaults on elderly people in Australian residential aged-care facilities by staff members (Dow, Vrantsidis, O’Brien, Joosten, & Gahan, 2020; D. Smith et al., 2019; Wells, Brooke, & Solly, 2019). The WHO (2017a) defines elder abuse as “a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person" ("Elder Abuse", para. 1).

Elder abuse can include physical assault that results in fractures, contusions and other injuries, psychological aggression, neglect, financial abuse, and violation of personal rights (Cooper, Barber, Griffin, Rapaport, & Livingston, 2016; Friedman, Avila, Rizvi, Partida, & Friedman, 2017; Yan, Chan, & Tiwari, 2015). Research has confirmed that physical abuse and neglect unfortunately occur frequently in residential aged-care facilities and Dementia Specific Care Units (Jokanovic et al., 2019; Ostaszkiewicz, 2018; Sinclair, Gadsby, Abdelhafiz, & Kennedy, 2018).

Individuals living with progressive or late-stage dementia often require increasing levels of support from family members or caregivers to complete activities of daily living (J. Morgan, 2018). However, because of their cognitive decline and resultant adverse behaviours, they are at increased risk of being abused by their family members or caregivers (Mole, Kent, Abbott, Wood, & Hickson, 2018; D. L. Morgan, 2018; Prizer & Zimmerman, 2018). Current research literature confirms that psychological abuse remains the most commonly detected form of elder abuse of people with dementia, followed by physical abuse, neglect and financial abuse (Burnes et al., 2015; Nagaratnam & Nagaratnam, 2019; Pillemer, Burnes, Riffin, & Lachs, 2016; Roberto, 2016; Simone, Wettstein, Senn, Rosemann, & Hasler, 2016; WHO, 2017a).

People with late-stage dementia admitted to Dementia Specific Care Units are at even higher risk of elder abuse and neglect from nursing staff (A. Han, Kunik, & Richardson, 2019; B. Mitchell, 2018; Ostaszkiewicz, 2018). This increased risk of abuse is thought to be related to insufficient staff numbers, untrained staff, excessive staff workloads and staff job dissatisfaction (A. Han et al., 2019; Ostaszkiewicz, O'Connell, & Dunning, 2016; Wells et al., 2019). These factors have also been linked to decreased patient observation and poor levels of nursing care (A. Han et al., 2019; Wangmo Nordström, & Kressig, 2017). The literature highlights the experiences of Dementia Specific Care Unit patients suffering abuse and neglect including being left to lie in their urine or faeces without hygiene cares being attended to, patients being made to wait for a prolonged time before nurses respond to their needs, and nurses choosing not to provide patients with sufficient hydration and nutrition (S. Han, Olsen, & Mosqueda, 2019; C. Sharp, Moore, & McLaws, 2019; Wangmo et al., 2017).

Many Registered Nurses experience high levels of stress as a direct result of the physical and verbal aggression exhibited by patients in the Dementia Specific Care Unit. Registered Nurses have been shown to ration their nursing care, neglect patients, or be absent in the nurse–patient relationship because of this aggression (Mulders, Smallbrugge, et al., 2018). Other factors that have been identified to influence staff neglect or abuse of patients in the Dementia Specific Care Unit include the staff member's age, clinical education, specific-dementia training and years of experience working in the organisation (Davey, 2016; Dong, 2016; Fang & Yan, 2018; Hazelhof, Schoonhoven, van Gaal, Koopmans, & Gerritsen, 2016; Mulders, Smallbrugge, et al., 2018; Stutte, Hahn, Fierz, & Zúñiga, 2017). Over 90 per cent of patients with dementia will develop at least one adverse behaviour during the progression of their disease, which will escalate in number and incidence in accordance with the progression of their dementia (Devanand, 2017; Mulders, Fick, et al., 2016). Reasons for this behaviour include cognitive decline, the loss of patient independence and often the patient's inability to communicate clearly and make their need known to others, which leads to escalating frustration and aggression (Inkley & Goldberg, 2016).

Residential aged-care services and Dementia Specific Care Units in Australia are currently the subject of a Royal Commission review process as a result of allegations of elder abuse in a number of government-funded facilities (Wells et al., 2019). The Royal Commission into Aged Care Quality and Safety has invited members of the community to submit information regarding their experiences with aged-care services in Australia, with a view to identifying and addressing issues that relate to aged-care provision including the quality of nursing care (C. Johnson, 2019). Submissions heard by Commission members to date have included reports of poor nursing care including residents in aged-care facilities being assaulted by staff members, dehydration, malnutrition, excessive use of psychotropic medications, and continual physical restraint that has resulted in increased patient morbidity and mortality (Royal Commission into Aged Care Quality and Safety, 2019). This current Royal Commission review is highlighting the abuse and neglect that is occurring in aged and dementia care and places it firmly in the spotlight of public scrutiny.

The Dementia Specific Care Unit: Families and Carers

Admission to a Dementia Specific Care Unit affects not only the patient but also the family members who have cared for that person at home, often for many years

(Calkins, 2018; Sagbakken et al., 2017). This transition can result in feelings of guilt, loss and grief for family members (Roach, Drummond, & Keady, 2016). Some family members may be critical of nursing care when they compare the patient's past with their present, which are judgements often complicated by their own feelings of loss, guilt at placing their loved one in an institution, and their level of understanding of dementia and its progression (Calia, Johnson, & Cristea, 2019; Robertson et al., 2019). Nurses working in Dementia Specific Care Units may consider family involvement in patient care as challenging and may not fully consider the potential benefits of including family members in discussions regarding the patient and their care (Appleton & Pereira, 2019). The benefits may include establishing a relationship to learn more about the patient's preferences and their past life incidents that may have impacted on their life – for example, the death of a spouse or child (Calia et al., 2019). This information can assist nurses with caring for patients in the Dementia Specific Care Unit.

The establishment and maintenance of collaborative relationships between family members of patients admitted to Dementia Specific Care Units and nurses has been identified as essential to achieve optimal quality of life for patients (Abbott et al., 2015; Cooke, 2018). The involvement of family members in the care of a patient in a Dementia Specific Care Unit can prove mutually beneficial for staff and family members as they are often willing to assist nurses with the care of the patient, relieving some of the burden on nurses (Baumbusch, Puurveen, Phinney, Beaton, & Leblanc, 2018; Nell, Neville, Bellew, O'Leary, & Beck., 2016). The benefits of family member involvement in care can also include improved nutrition and hydration when family members are present at mealtimes as the patient is more likely to eat and drink for someone they are familiar with (Brannelly et al., 2019; Joyce et al., 2018). Family member involvement has also been shown to reduce the incidence and severity of patient behavioural disturbances and increase social interactions with other patients (Laybourne et al., 2019; Nell et al., 2016). As knowing the patient intimately is a requirement for the provision of person-centred care, information gathered from family members and others who know the patient well is important (Andersson, Dellkvist, Bernow Johansson, & Skär, 2019; Helgesen et al., 2014). Many patients admitted to Dementia Specific Care Units experience difficulty in communicating their needs and preferences effectively due to their cognitive decline (Gilbert & Croxon, 2019; Helgesen et al., 2014). Family members have important information regarding the patient, including their physical and psychological histories and life events, which can assist nurses to plan and deliver personalised nursing care (Hennings & Frogatt, 2019; O'Connor et al., 2018).

Conclusion

Chapter 1 has introduced this study, the study question, the aims of the study and the researcher’s motivation to conduct this study. The researcher’s career in nursing, management and the law and why research into quality nursing care in the Dementia Specific Care Unit is extremely important has been discussed. The Dementia Specific Care Unit was introduced and the role, responsibilities and practices of Registered Nurses working in the Dementia Specific Care Unit were discussed. The impact of a dementia diagnosis on the individual, their families and the community were also identified and discussed. Elder abuse, which can result from inadequate care in the Dementia Specific Care Unit and issues related to the cost of supporting, managing and operating a Dementia Specific Care Unit, were also discussed. Chapter 2 provides a review of the literature relating to quality nursing care in the Dementia Specific Care Unit. It also includes a discussion regarding the decision to complete both a preliminary literature review and a concurrent review of literature during the study. It explains why a Grounded Theory approach was chosen as being appropriate for this study, including the assumptions and expectations underpinning that decision. Chapter 3 explains the methods and processes of this study, including the origin, development and application of Grounded Theory methodology. The specific methods used in the conduct of this study, including data collection and analysis, which led to the identification of three themes are also discussed. In this chapter, the selection of the study sites, participant recruitment and selection, discussion regarding the research setting, and the ethics approval process are also presented. In addition, the interview, data coding, and constant comparison analysis process are addressed. Chapter 4 explores the participants’ responses and the three research themes: Caring at the Coalface, Labour of Love and The Business of Dementia Healthcare. Chapter 5 discusses the development of the substantive Grounded Theory. Chapter 6 discusses the limitations, recommendations, conclusion and the implications of this study for future nursing practice in the Dementia Specific Care Unit.

Chapter 2

Literature Review

In Chapter 1 the purpose and origins of this study were outlined, including a discussion on dementia and the Dementia Specific Care Unit. Chapter 2 expands and explores further the current literature in relation to several areas important to this study: the ageing population (particularly within an Australian context), characteristics of dementia, models of care, and what is currently understood to be quality nursing care within the Dementia Specific Care Unit. This chapter highlights studies that have been influential in guiding this Grounded Theory study and provides information for understanding quality nursing care in the Dementia Specific Care Unit. “Grey literature”, consisting of information and documents available on Australian Government websites as well as Alzheimer’s Australia’s and Dementia Australia’s websites, has also been included.

Review of the Literature

For this study, the literature review explored quality nursing care in general, with a specific focus on quality nursing care in the Dementia Specific Care Unit. The decision whether or not to complete an initial literature review is a unique challenge for researchers utilising Grounded Theory methodology due to the differing opinions of researchers regarding how it should be conducted. This section discusses recommendations for and against an initial literature review and provides justification for the decision to complete a literature review prior to the commencement of this study.

Classic grounded theorists have maintained that completion of a literature review should only occur after the substantive theory has emerged from the data (Glaser, 1992; Glaser & Strauss, 1967). Glaser and Strauss (1967) stress the importance of the literature review only being completed when the data has been collected and the data analysis, using the constant comparison analysis process, has finished. They consider that performing a literature review at this time allows for positioning of the new theory within the existing literature, provides context for the emergent theory beyond the data, and stops contamination of the emerging ideas with pre-existing theory (Glaser & Strauss, 1967).

Charmaz (2006) argues that obtaining an overview of the relevant literature prior to commencing Grounded Theory research helps to shape the direction of the research itself. Reviewing the literature in a Grounded Theory study can also justify and provide background for the study (Charmaz, 2006). Stern (2007) cautions the Grounded Theory researcher not to complete a literature review prior to commencing the study as they may amass large amounts of irrelevant data instead of focusing specifically on the research topic (Stern, 2007). In contrast, Charmaz (2006) believes that universities and research funding bodies require a researcher to complete a literature review before commencing a study and not completing one could be detrimental to the researcher seeking ethics and funding approval. Charmaz (2006) also considers that not completing an initial literature review may limit the researcher’s awareness of existing theories relating to the research topic, which could lead to duplication and a waste of resources.

The argument for completing a literature review prior to the commencement of a Grounded Theory study is compelling. Following consideration of the identified viewpoints, the decision was made to complete a preliminary literature review to both confirm that this research had not been completed previously and to identify if there were any gaps in the existing literature that related to nurses’ perceptions of quality nursing care in Dementia Specific Care Units. This decision is consistent with Grounded Theory research. The literature informed the choice of methodology, the topic and the initial questions used in each interview as well as informing the choice of the theoretical framework for this study. It informed the background to the study and served to locate the study within the existing theoretical knowledge. The preliminary literature review involved examining peer-reviewed journal articles, books and grey literature relating to nursing care in dementia settings that had been published in English between 2010 and 2016. This date range reflected the current relevant literature from the commencement of this research (2012) to the completion of data collection and analysis in 2016.

The Ageing Population

The issue of the ageing population and the link between ageing individuals and the projected increase in the incidence of dementia is not limited to Australia. The problem of increased pressure on healthcare systems from the expected increase in both the incidence of dementia and the ageing population is a global health issue (Barnicoat & Danson, 2015; Beard & Bloom, 2015; Bloom et al., 2015; Davies & James, 2016; Goel & Ramavat, 2018; Lopreite & Mauro, 2017; O’Connell & Ostaszkiewicz, 2005). Globally, the number of people aged 60 years and over is increasing at a rapid rate and will require additional financial and health resources to meet their healthcare needs into the future (Dwolatzky et al., 2017; Gannon, Banks, Nazroo, & Mumford, 2018; Howdon & Rice, 2018).

In Australia in 2015, there were 3.5 million people aged 65 years or older, with 5.2% living in residential aged-care facilities, an increase of 10.2% since 2010 (Australian Bureau of Statistics [ABS], 2015). This increase is mainly due to the large numbers of people in the "Baby Boomer" generation who belong to this age group, coupled with the increase in longevity as a direct result of modern medical treatments (Lowton, Hiley, & Higgs, 2017; McCulloch & Miller, 2019; Tonetti et al., 2017; Tsoi, Hirai, Chan, Griffiths, & Sung, 2016). This increase in life expectancy is expected to continue in future generations, further adding to the need for government financial resources to provide ongoing care for Australia's ageing population (Crimmins et al., 2018; R. Lee, 2019; Mathers, Stevens, Boerma, White, & Tobias, 2015; Ranabhat, Atkinson, Park, Kim, & Jakovljevic, 2018). Those classed as Baby Boomers (born between 1946 and 1964) are high consumers of preventative healthcare and are familiar with receiving subsidised healthcare across their lifetime (Leider, Coronado, Beck, & Harper, 2018; Seale et al., 2019; Vogenberg & Santilli, 2018). Many in this group are affluent and have actively contributed to the welfare of the community, with high expectations that they will receive individualised, high-quality healthcare as they age (H. Kim, Lee, Cheon, Hong, & Chang, 2018; Ralph, 2019; Shen, 2018).

Additionally, there is a projected increase in another section of the older population, that of the "oldest old" – those individuals aged 80 years or older (Flicker, 2018). Due to a greater incidence of chronic disease and co-morbidities, many people in this group will require additional healthcare resources (Flicker, 2018; Gaw, 2016; Haas et al., 2015; McCann, 2017; Steptoe, Deaton, & Stone, 2015). The number of people expected to reach 100 years or older is also increasing; again, largely due to advances in healthcare, with an expected increase of 18.2% to an estimated number of 78,000 by 2055 (ABS, 2015).

The number of aged Indigenous Australians requiring care is expected to increase also; again, due to increased healthcare initiatives for this group that is resulting in the earlier detection and treatment of disease and management of chronic health conditions (Buchanan, Collard, & Palmer, 2019; Chandra, Duri, & Smith, 2019; Hendry et al., 2018). The incidence of dementia in Indigenous Australians is currently three to five times that of the general Australian population (Goldberg et al., 2018; Radford et al., 2018). Given that there is a marked increase in the number and proportion of older

Indigenous Australians developing dementia, the need to understand and provide appropriate-quality dementia nursing care for this group is paramount (Cox, Hoang, Goldberg, & Baldock, 2019; Hulko, Wilson, & Balastrery, 2019; Lavrencic et al., 2019).

The projected increase in an ageing population has significant implications for government policy globally in response to the economic, social and healthcare requirements of the future (Davies & James, 2016; Ehrlich, Boström, Mazaheri, Heikkilä, & Emami, 2015; Nikmat, Al-Mashoor, & Hashim, 2015). As a result, there is an urgent need for global strategies to provide a sustainable, higher quality of care services for older people with dementia at a sustainable cost.

The Contemporary Context in Caring for Older Australians

In the 1800s, the responsibility for caring for older Australians who were unable to care for themselves or fund their own care was generally undertaken by family members and the community (Peng & Anstey, 2019). In 1909, as the Australian community changed and families were not always able to physically or financially care for older individuals, the Australian Government introduced the aged pension to assist older Australians who had little or no savings and who were unable to finance their own care needs (Temple & Williams, 2018). The aged pension is means tested and provides a minimal amount for beneficiaries, which can be supplemented by government-funded healthcare packages and payments if needed (Department of Human Services [DHS], 2019).

In 1980, it became apparent that the Australian Government would not be able to indefinitely fund aged pensions for the projected large number of retirees (DHS, 2019). This was largely due to the decrease in the number of working Australians generating government income through the payment of taxes and the resultant increase in the number of unemployed who also required government financial assistance (DHS, 2019). As a result, mandatory superannuation contributions for working Australians were introduced to fund the lifestyle and healthcare needs of older Australians in retirement (Naidoo, 2019). However, the increase in the number of older Australians relying on the aged pension, and the number of older unemployed Australians who will not have sufficient savings to support their retirement, has further increased the demand on government funding to provide healthcare and financial support for older Australians (DHS, 2019; Power, Mee, & Horrocks, 2018).

The Australian Government progressively increased funding for aged-care services from $14.9 billion in 2012–13 to $18.4 billion in 2017–18, with over two-thirds of this amount spent on residential aged-care provision (Australian Institute of Health and Welfare [AIHW], 2019). Although large, this amount may still not be sufficient to fund aged care as the Baby Boomer generation reaches retirement age, which is estimated to be between 2011 and 2021 (Bouma & Mason, 2018; O'Loughlin, Barrie, & Kendig, 2018; Piggott, 2016). The inability to continue to fund aged-care services and pensions at the current rate remains a real challenge for the Australian Government as the cost of healthcare, aged care and the provision of aged pensions increases with inflation (Bouma & Mason, 2018).

Also, the number of younger people who work and provide funds for the provision of this care through payment of their taxes is forecast to reduce even further, adding to the pressure on the Australian Government to fund care for older Australians (Kendig, McDonald, & Piggott, 2018). The projected funding of this care into the future may become untenable for the Australian Government once the Baby Boomer generation becomes older, thereby creating a persistent quandary for the Australian Government (Curryer, Gray, & Byles, 2018; Eckermann, Phillipson, & Fleming, 2019; O'Loughlin et al., 2018; Ofori-Asenso, Zomer, Curtis, Zoungas, & Gambhir, 2018).

The Impact of Ageing Australians on the Healthcare System

The Australian Government supports and subsidises a healthcare system that is a combination of both public and private healthcare providers and which overlap in terms of healthcare coverage and care provisions (Garcia-Goni, Fouda, Calder, & Paolucci, 2018). The federal government introduced Medicare in 1975, which consisted of a free hospital health service for all Australians and the subsidisation of many ancillary health services such as pathology and radiology (Duckett, 2018).

The literature confirms that as a result of the impact of age-related changes, many older people require increased hospitalisation and have increased lengths of stay in comparison to younger people (Afshar, Roderick, Hill, Dimitrov, & Kowal, 2015; Dent et al., 2016; Edney, Afzali, Cheng, & Karnon, 2018; Willis, Reynolds, & Keleher, 2016). Being hospitalised for prolonged periods can have a profound effect on an older person's independence and quality of life as their general health often deteriorates with the onset of acute illness (Y. Chen, Glass, et al., 2017). As a result, they may require increased financial and physical resources to support them during their recovery; again, at increased cost to the healthcare system (Y. Chen, Glass, et al., 2017; Dolja-Gore, Harris, Kendig, & Byles, 2017; Nair et al., 2016; Peeters, Gardiner, Dobson, & Brown, 2018). Older people may also require rehabilitation or complex discharge planning that involves the introduction of, or increase in, home care services in order for them to return to their homes, again increasing the cost to the healthcare system (Y. Chen, Glass, et al., 2017; Farag et al., 2015; Meuleners, Fraser, Bulsara, Chow, & Ng, 2016; Tesfaye et al., 2019).

Older people are high users of healthcare in general as a direct result of age-related changes, including frailty and the pressure of co-morbidities (A. Briggs et al., 2016; Comans et al., 2016; Dent et al., 2016; Harrison, Henderson, Miller, & Britt, 2016; Javanparast et al., 2018). Older people typically also require increasing amounts and types of medication to manage chronic health conditions and co-morbidities (Comino et al., 2015). Many of these medications are subsidised by the Australian Government under the Pharmaceutical Benefits Scheme, further increasing the cost of healthcare to the Australian community (Callander, Corscadden, & Levesque, 2017; Comino et al., 2015; Kalogianis et al., 2016; Nichols et al., 2016).

While the cost of healthcare for older people is high, it could be considerably higher if not for the unpaid care provided by informal carers and family members (Kent et al., 2016; Roth, Fredman, & Haley, 2015; Schmitz & Westphal, 2015; Stepurko, Pavlova, Gryga, Murauskiene, & Groot, 2015). This care is often initiated and sustained by informal carers who generally do not seek payment from the government, and so it is often discounted or not included in the true cost of aged-care healthcare services (J. Bauer & Sousa-Poza, 2015; Chari, Engberg, Ray, & Mehrotra, 2015; Curtis & Burns, 2015; Hampshire et al., 2016; O’Connell, Hawkins, Ostaszkiewicz, & Millar, 2012). In the absence of this unpaid care, the cost of healthcare to older Australians would further increase the financial burden on the Australian Government now and into the future (Gnanamanickam et al., 2018; Netten & Beecham, 2018; Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017).

Characteristics of Dementia

Dementia is characterised by memory impairment that ranges from mild forgetfulness in the early stages to the inability to recall past events and the names of loved ones as well as the loss of mobility in late-stage dementia (Piersma et al., 2018). Other common characteristics of dementia include language and speech difficulties, inability to recognise common, everyday objects and to plan and complete daily activities, such as grooming and hygiene (Rizzi, Rosset, & Roriz-Cruz, 2014; Skoog & Aevarsson, 2019).

Table 1 outlines the characteristics of the four most common forms of dementia and the frequent impact of each on the person.

Table 1

Common Forms of Dementia

Form of dementia	Characteristics	Impact on the person
Alzheimer's disease	Damage to the hippocampus from neurofibrillary tangles and dense plaques resulting in death of neurons (Goodman et al., 2017).	Difficulty with semantic memory, language, recognition and spatial awareness (Goodman et al., 2017).
Vascular dementia	Can occur in isolation or in conjunction with Alzheimer's disease. Caused by ischaemic and haemorrhagic white matter (Kalaria, 2018).	Behavioural and locomotor abnormalities – for example, dysarthria and autonomic dysfunction (Sun, 2018).
Fronto-temporal dementia	Marked atrophy of the frontal lobe, temporal lobes and cortex of the brain. Tends to occur more in younger adults (45–60 years), insidious onset and rapid progression (Y. Chen, Kumfor, et al., 2018).	Profound changes in personality, behaviour and language (Olney, Spinner, & Miller, 2017).
Lewy body dementia	Abnormal clumps of protein within neurons in the brain's cortex (Kane et al., 2018).	Vivid hallucinations, visuospatial impairment and rapid loss of cognition (McKeith et al., 2017).

Alzheimer's disease remains the most common form of dementia, followed by vascular dementia, fronto-temporal dementia and Lewy body dementia (Bjoerke-Bertheussen, Ehrt, Rongve, Ballard, & Aarsland, 2012; Broadstock, Ballard, & Corbett, 2014; Goodman et al., 2017; Kalaria & Ballard, 1999; Shi et al., 2018). Alzheimer's disease is characterised by damage to the hippocampus from neurofibrillary tangles and dense plaques, which kills the neurons (Carr, 2017; Dai, Zheng, Zeng, & Zhang, 2018; Eckerstrom et al., 2018; Gauthier et al., 2010; Winblad et al., 2016). As the disease progresses, damage to the cortex occurs when the brain shrinks in size, resulting in the person experiencing difficulties with semantic memory, language, recognition and spatial awareness (Caballero et al., 2018; Corbett, Smith, Creese, & Ballard, 2012; Kales, Lyketsos, Miller, & Ballard, 2019; Livingston et al., 2017; Smits et al., 2015). The continual loss of cognition associated with these changes results in the person experiencing increased confusion, disorientation, depression, agitation, and physical and verbal aggression (Carr, 2017; Corbett, Smith, & Ballard, 2012).

The second most common form of dementia is vascular dementia, which can occur in isolation or in conjunction with Alzheimer's disease (Skoog et al., 2018). Vascular dementia results from ischaemic and haemorrhagic white matter following infarcts and uncontrolled hypertension, which leads to intracerebral haemorrhages (Kalaria, 2018; Palesi et al., 2018; Skoog et al., 2018; Sun, 2018; Vinters et al., 2018). In addition to catastrophic cognitive decline, vascular dementia is characterised by both behavioural changes and locomotor abnormalities such as dysarthria and autonomic dysfunction (Bonnici-Mallia, Barbara, & Rao, 2018; Jorm & O'Brien, 2019; Kalaria, 2018; Shi et al., 2018). Behavioural changes associated with vascular dementia include insomnia, depression and high levels of agitation (Kalaria, 2018).

Fronto-temporal dementia is the third most common form of dementia that results from marked atrophy of the frontal lobe, temporal lobes and cortex, with an average survival rate of between five and eight years following diagnosis (Bang, Spina, & Miller, 2015; Burrell et al., 2016; Y. Chen, Kumfor, et al., 2018; Rabonovici, 2017). It commonly occurs in younger adults aged between 45 and 60 years of age and is characterised by an insidious onset with rapid progression and causes early and profound changes in personality, behaviour and language (Burrell et al., 2016; Kumfor, Baez, & Ibañez, 2016; Ng, Rademakers, & Miller, 2015; Olney et al., 2017).

Lewy body dementia is the fourth most common form of dementia that results from abnormal clumps of protein within neurons in the brain's cortex (Kane et al., 2018). Individuals diagnosed with Lewy body dementia experience vivid hallucinations, visuo-spatial impairment and a rapid loss of cognition (Gomperts, 2016; Kane et al., 2018; McKeith et al., 2017; Z. Walker, Possin, Boeve, & Aarsland, 2015). Onset and progression of Lewy body dementia is rapid, with many people experiencing symptoms within two years of diagnosis (Walker et al., 2015).

Risk Factors for the Development of Dementia

Researchers have identified a number of modifiable and non-modifiable risk factors for the development of dementia (Deckers et al., 2015; Killin, Starr, Shiue, &

Russ, 2016; Oliveira et al., 2018). The non-modifiable risk factors of advanced age, genetics and geographical location have long been linked to the incidence of dementia (Bang et al., 2015; Baumgart et al., 2015; Bethell et al., 2018; Fitzpatrick, 2019; Gibney, Ward, Sexton, & Shannon, 2017). The focus of researchers has now shifted to identifying and educating communities about the modifiable risks for developing dementia later in life (Fitzpatrick, 2019; Peters et al., 2019). Identified modifiable risk factors for up to one-third of dementia cases globally include uncontrolled diabetes mellitus, hypertension, obesity, sleep disorders, smoking, depression, cognitive and physical inactivity, and low economic status (Ciudin et al., 2017; Groot et al., 2016; Livingston et al., 2017; J. O'Brien & Thomas, 2015; Peters et al., 2019; Qizilbash et al., 2015; Shi et al., 2018).

Evidence confirms that effective management of these risk factors early in life can effectively reduce an individual's risk of developing dementia as they age (Brayne & Chertkow, 2018; Chertkow, 2018; Livingston et al., 2017). Therefore, the presumption can be made that interventions – including cognitive training, improved dietary choices, the widespread use of supplements to improve individual health, and the education of communities regarding the importance of exercise and management of cardio-metabolic health conditions – can have a dramatic public health impact on the incidence of dementia (Mar, Soto-Gordoa, Arrospide, Moreno-Izco, & Martínez-Lage, 2015; Pickett et al., 2018; Prince, 2017; Yaffe, 2018; Ye, Luo, Xiao, Yu, & Yi, 2016).

Given the projected increase in the incidence of dementia and the consensus that the development of dementia for many in the community may be preventable, understanding dementia risk reduction is a major public health priority (Deckers et al., 2015; Winblad et al., 2016). Understanding how to prevent or delay the onset of dementia through the management of risk factors will have a profound impact on financial and human resources required to provide quality nursing care for dementia patients into the future (Brookmeyer et al., 2016; Hernandorena, Duron, Vidal, & Hanon, 2017; Rutten, 2017; G. E. Smith, 2016). In an economic climate of financial restraint, understanding and identifying further potentially modifiable risk factors is therefore imperative to improve the general health of the ageing population and reduce the incidence of dementia (Brasure et al., 2018; Shatenstein & Barberger-Gateau, 2015; Soto-Gordoa et al., 2015; Webster et al., 2017). Reducing the risk of dementia will lower the incidence of the disease and would mean that available healthcare resources could be utilised to provide quality nursing care for people who are living with dementia.

Living with Dementia

As discussed previously, ageing is one of the key risk factors for the development of dementia (van Baal, Morton, Meltzer, & Brouwer, 2019). As the global population ages, the number of individuals living with dementia will increase commensurately (Murphy & Shwartz, 2018). Many individuals diagnosed with early dementia are initially cared for by family members or carers in their own home (G. Carter et al., 2018; Jeon, McKenzie, Krein, Flaherty, & Gillespie, 2017; L. Miller, Whitlatch, & Lyons, 2016). The quality of life, cognitive function and social connections for individuals with dementia living in the community, and especially in their own home, have been found to be significantly higher than those living in institutional care (Nikmat, Hawthorne, & Al-Mashoor, 2015).

In the early stages of dementia, an individual may experience cognitive impairment and behavioural decline that is characterised by mild confusion, forgetfulness and associated feelings of anxiety (Cummings, Tong, & Ballard, 2019; Ismail et al., 2018; J. Morgan, 2018; Prizer & Zimmerman, 2018). Some will experience a marked decline in their ability to complete activities of daily living, such as financial management, shopping, meal preparation and medication management (Cholerton et al., 2018; Lim & Sharmeen, 2018; Mole et al., 2018; Whitlatch & Orsulic-Jeras, 2018; Young & Swaffer, 2018). In comparison, activities such as eating, toileting and mobility appear to be intact for longer periods of time, suggesting that they are linked with motor function rather than cognitive decline (Austrom, Boustani, & LaMantia, 2018; Haaksma et al., 2018).

Medications used to manage the effects of cognitive decline often have limited efficacy largely due to dosage and administration issues, but alternative treatments such as cognitive stimulation have proven to provide benefits in maintaining cognition levels for longer periods of time (Corbett et al., 2012; Liang et al., 2017). Physical activity and regular exercise have also been shown to provide multi-component benefits in the maintenance of cognitive and physical function for patients living with dementia (Liang et al., 2017). Despite increased knowledge regarding dementia and the effects of its progression, little information is available regarding the impact of dementia on other co-morbidities, including polypharmacy, depression, incontinence and frailty (Liang et al., 2017). Each of these conditions has an additional impact on the person living with dementia, but there is currently no complete multi-domain treatment (Liaing et al., 2017).

As such, the burden of managing the requirements of all of these conditions, in addition to those characterised by the progression of dementia, often falls to caregivers and family members in the first instance.

Changes in cognition due to dementia progression may also result in increasing physical and verbal aggression, endless wandering, depression, anxiety and personality changes, which are unique to the individual and the type of dementia (Kales, Gitlin, & Lyketsos, 2015; Stokes, 2017). As their dementia progresses further, the individual may exhibit increasingly challenging physical and psychological changes that include hallucinations, combative behaviours, increasing agitation, aggression, and resistance to care (Ballard & Corbett, 2013; Hajek et al., 2016; Pini et al., 2017). The availability and affordability of continued dementia care in the home environment is often problematic for many family members and carers as community dementia care interventions are limited, and the person with dementia may not be eligible for government support and subsidisation (Chester et al., 2018; Clarkson et al., 2018; Manes, 2016).

The research literature supports the unremitting impact of prolonged care delivery of a person with dementia on family members, with many carers experiencing depression, anxiety, hostility and phobias that result in them actively distancing themselves from the person with dementia (Hopkinson, Reavell, Lane, & Mallikarjun., 2018; Landeiro et al., 2018; Omranifard et al., 2018). As a result, family members and carers may feel overwhelmed at having to continue to provide care, with many experiencing high levels of anxiety and carer burnout (M. Bauer, Fetherstonhaugh, Blackberry, et al., 2019; Bloomer, Digby, Tan, Crawford, & Williams, 2016). As the provision of dementia care within the domestic setting becomes more difficult, many individuals with mid- to late-stage dementia who are exhibiting escalating adverse behaviours will likely require admission to a Dementia Specific Care Unit for ongoing care and management (Haaksma et al., 2018; Kok et al., 2016; Srivastava et al., 2016).

Research into strategies to provide financial and social support for the individual living with dementia in the community will result in more people with dementia staying in their own homes for as long as possible (Hopkinson et al., 2018). As informal caregivers are the primary caregivers for many people living with dementia in the community, further research into management strategies for these caregivers is paramount (Hopkinson et al., 2018, O’Connell et al., 2012).

The Dementia Specific Care Unit

Specialised dementia nursing care has undergone significant changes since the 1980s when residential aged-care facilities instituted Dementia Specific Care Units for the ongoing care and safety of people living with late-stage dementia (Fleming et al., 2016; Kok et al., 2016). Prior to the development of Dementia Specific Care Units, individuals with late-stage dementia were admitted to residential aged-care facilities for care and integrated into the general patient population within the facility (Kovach, Weisman, Chaudhury, & Calkins, 1997; Maslow & Ory, 2001).

Many patients with late-stage dementia were subjected to increased use of physical and chemical restraint, with sometimes catastrophic results for the person (Gustafsson, Karlsson, & Lövheim, 2013; Riter & Fries, 1992; Sloane et al., 1991). Some suffered falls sustaining injury, others developed chest and other infections as a direct result of being sedated, and some died as a result of the administration of high doses of medications to manage their behaviours (Camicioli & Licis, 2004; Phillips et al., 1997; Ronch, 1987). In order to better manage these patients, some residential aged-care facilities decided to segregate patients with late-stage dementia into separate areas, which they called Dementia Specific Care Units (Gold et al., 1991; Mobily, Maas, Buckwalter, & Kelley, 1992; Zeisel, Hyde, & Levkoff, 1994).

Residential aged-care facilities marketed these units heavily to members of the community, espousing the significantly improved care for patients with dementia (Grant et al., 1996; Gruneir, Lapane, Miller, & Mor, 2008; Samus et al., 2008). Advocates for Dementia Specific Care Units (Berg et al., 1991; D. G Morgan & Stewart, 1999) cited the delivery of improved and specific dementia care with positive resident outcomes, but others considered its advent purely as a marketing ploy by residential aged-care facilities to increase revenue (Gruneir et al., 2008; Wells & Jorm, 1987). Some residential aged-care facilities constructed purpose-built Dementia Specific Care Units for dementia patients, but many others simply remodelled their existing buildings to manage costs and capture the growing trend for specific dementia care (Cadigan, Grabowski, Givens, & Mitchell, 2012; Gold et al., 1991; Zimmerman & Sloane, 1999).

Dementia Specific Care Units formed from remodelled spaces were often found to be unsuitable for dementia patients as they had originally been constructed for cognisant patients and offered, among other things, multiple areas for patients to spend time alone or with family members in privacy (Maslow & Ory, 2001). As patients with late-stage dementia often exhibit wandering, agitation and aggression, these remodelled units were unable to meet the specific needs of dementia patients as they allowed patients to congregate together out of sight of nurses, often resulting in patient falls and injuries (Joyce et al., 2018; Winterton, Knight, Morley, & Walters, 2018).

The effectiveness of patient care within Dementia Specific Care Units has been debated by researchers, but studies have shown that admission to a Dementia Specific Care Unit can significantly enhance patient outcomes and quality of life (Ballard et al., 2018; Mueller, Ballard, Corbett, & Aarsland, 2017; Winterton et al., 2018). Part of this specialised care within a Dementia Specific Care Unit involves the provision of various routine and familiar activities such as the completion of daily chores, group games and interactions, resulting in improved cognitive functioning, visual memory and recognition (Cohen-Mansfield, 2018; Edvardsson, Petersson, Sjogren, Lindkvist, & Sandman, 2014; Jones, Sung, & Moyle, 2015; Kok et al., 2016). As the population ages, the incidence of dementia will rise, which will increase the need for Dementia Specific Care Units and, consequently, the value of these units in the provision of quality dementia nursing care will become of growing importance to individuals and communities (Joyce et al., 2018; Winterton et al., 2018).

The Impact of the Dementia Specific Care Unit Design

As patients living with advanced dementia usually exhibit a number of physical and cognitive deficits, it is important to provide them with a safe and practical environment to support their wellbeing (Sjögren et al., 2013; Treadaway et al., 2016). Whilst the provision of individualised patient care is considered to be synonymous with quality nursing care in Dementia Specific Care Units, the role of the physical environment is often overlooked by residential aged-care facility management, largely due to cost constraints (Cooke & Chaudhury, 2017).

Research confirms that the interaction between patients and the physical environment of a Dementia Specific Care Unit can impact on patient autonomy, independence and engagement with staff and others (Cooke & Chaudhury, 2017; deBoer et al., 2018). The design and layout of well-designed Dementia Specific Care Units has been shown to improve the quality of life for patients with late-stage dementia by providing a safe environment and promoting engagement with daily activities and other patients (Joyce et al., 2018; D. G. Morgan & Stewart, 1999; R. Smith et al., 2012; Zeisal et al., 2003).

Purpose-built Dementia Specific Care Units that provide small-scale, homelike settings have been acknowledged as essential in the provision of comfort for the dementia patient and reassurance for family members that their loved one is in a safe environment and being cared for (de Boer et al., 2018; Joyce et al., 2015; Kok et al., 2016). Dementia Specific Care Units with private areas where patients can spend time with family members and a circular zone/walkway that allows patients to wander freely are regarded as preferable (Doan, Brennan, & Osada, 2018). However, poor design of Dementia Specific Care Units has been recognised as impacting on the incidence of adverse patient behaviours and to be problematic in the delivery of quality nursing care (Bowes & Dawson, 2019; Zadeh et al., 2018).

A poorly designed Dementia Specific Care unit that is characterised by a lack of comfortable, homelike patient areas can increase patient feelings of constraint and can result in increased anti-psychotic drug use, patient restraint and resultant patient injuries and hospitalisations (de Boer et al., 2018; Joyce et al., 2018; Vinoo, Vinoo, Santos, & Amin, 2018). Unfortunately, many remodelled or poorly designed Dementia Specific Care Units are characterised by long hallways painted the same colour, with resident rooms on either side of the corridor and two or more residents in each room (Gilbert et al., 2019). High levels of sensory stimulation, such as excessive noise resulting from poor building design, are common and can be overwhelming for patients with dementia (de Boer et al., 2018). Also, the lack of access to external surroundings such as sunlight and fresh air in poorly designed Dementia Specific Care Units has been shown to increase cognitive decline and disengagement of patients with others (de Boer et al., 2018). Alternatively, open-plan design, with clear and familiar cues for residents to find areas such as bathrooms and outside areas, provides a sense of familiarity and a link to their life outside of the Dementia Specific Care Unit (Gilbert et al., 2019).

Dementia Specific Care Units that facilitate patient engagement with a variety of activities and encourage mobility into external areas provide a higher quality of life for patients, with reduced incidences of falls and injuries (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013; Fleming et al., 2016). The importance of these findings was confirmed by Woodridge et al. (2018), who explored the link between the Dementia Specific Care Unit environment and patient engagement with daily activities. Findings from this research indicate that the well-designed physical dementia environment facilitates patient engagement with activities and with others. Poorly designed Dementia Specific Care Units can contribute to common challenging behaviours exhibited by individuals with late-stage dementia, such as increasing agitation, anxiety and disorientation (Van Hecke, Van Steenwinkel, & Heylighen, 2019). Well-designed Dementia Specific Care Units with outdoor areas, walkways and flower gardens provide residents with the opportunity to feel the sun and wind and have been shown to decrease the incidence of adverse patient behaviours (Calkins, 2018).

The Patient in the Dementia Specific Care Unit

Once admitted to the Dementia Specific Care Unit, patients experience a number of challenges relating to adapting to a new environment, scheduled care delivery by people they do not recognise and increased dependence on others for activities of daily living (Abbott et al., 2015; Beerens, Zwakhalen, Verbeek, Ruwaard, et al., 2015; Goldberg et al., 2018). Many patients experience feelings of isolation, uncertainty and fear as they struggle to assimilate into the unfamiliar environment of the Dementia Specific Care Unit (Mjørud, Engedal, Røsvik, & Kirkevold, 2017; Rijnaard et al., 2016). They may also experience pain or discomfort, which they are unable to communicate to nurses due to their cognitive decline and the increased stress and distress associated with their changed environment (Verbeek, Van Rossum, Zwakhalen, Kempen, & Hamers, 2009). Also, as nurses are unfamiliar with the needs of the specific individual, they may miss the subtle clues and cues displayed by the person, which results in decreased quality of nursing care and a further escalation of patient anxiety levels (Brooker & Latham, 2015; Sjögren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2015).

Often, patients within Dementia Specific Care Units struggle with large group sizes in small areas, such as lounge or dining rooms, because of the close proximity to other patients and the associated high noise levels (Kolanowski et al., 2018). High spatial density contributes to increased levels of general activity, noise and physical interaction with other patients, which results in increased patient confusion, adverse behaviours, falls and injuries (Beerens, de Boer, et al., 2016; Beerens, Zwakhalen, Verbeek, E. S. Tan, et al., 2018; Lin et al., 2018; Van Hecke et al., 2019). Many patients also experience increased agitation, physical and verbal aggression, wandering and restlessness (Laybourne et al., 2019). Aggression and assaults from other patients are common, which often result in patients sustaining physical injuries and psychological distress (Burnes & Syed, 2018; S. Johnson & Ostaszkiewicz, 2009; Lanza, 2016).

Patients living with late-stage dementia in Dementia Specific Care Units are also at significantly higher risk of experiencing malnutrition and dehydration (Bunn et al., 2016). The reduced awareness of hunger and thirst and the diminished recognition of favourite foods and fluids often occur as a result of patients' diminished cognition (Bunn et al., 2016). Strategies to encourage patients to eat and drink include altering the dining environment and food service times to meet the needs of the individual patient (Bunn et al., 2016). Introducing flexibility into established organisational routines – including meal provision, hygiene and medication administration at a time that suits the patient – can be difficult for nurses due to constraints imposed by facility management that mandate scheduled care delivery (Brooker & Woolley, 2007; Milte, Bradley, et al., 2018). Nurses can use discretion to circumvent these managerial-imposed constraints within the Dementia Specific Care Unit by providing care to meet the needs of the patient, not the organisation, such as the provision of food at all times of the day, not just at set mealtimes (Fetherstonhaugh, Haesler, & Bauer, 2019).

Challenges in Dementia Specific Care Units

Most people diagnosed with late-stage dementia in Dementia Specific Care Units develop behavioural symptoms – such as wandering, psychosis, agitation, aggression and depression – that require the administration of medications to manage these behaviours (Backhouse, Penhale, Gray, & Killett, 2018; Howard et al., 2007; Kales et al., 2015). Wandering is a behavioural symptom associated with cognitive decline and relates to the aimless process of locomotion and movement (Stokes, 2017; Wan, 2019). It has been associated with agitation, loss of spatial awareness, falls, and other injuries in the patient with late-stage dementia (Andrews, 2017; Brooker, 2003; Moser, 2019; Stokes, 2017; Wan, 2019). Over 90 per cent of patients in Dementia Specific Care Units also exhibit verbal and physical aggression and sleep disturbances (Baillon, Narayana, Luxenberg, & Clifton, 2018). These behaviours are anchored in the progressive erosion of cognition but can also be triggered by unmet patient needs, such as hunger and thirst, the presence of unrelieved pain, and various environmental factors such as cold, heat and excessive noise (Kales et al., 2015; Liljegren, Landqvist Waldö, & Englund, 2018).

Nurses have reported that dementia nursing care is exhausting, repetitive and hard work that is often characterised by frequent verbal and physical aggression from patients (Honda, Ito, Ishikawa, Takebayashi, & Tierney, 2016). Research has identified the clear link between high levels of staff stress, dementia patients' increasingly complex needs and their adverse verbal and physical behaviours (Louch, Mohammed, Hughes, & O'Hara, 2016; Maeland, Joa, & Testad, 2013; Traynor, Inoue, & Crookes; 2011). The ability of nurses to provide care to combative and aggressive patients can be a challenge (Laybourne et al., 2019; Ostaszkiewicz, Lakhan, O'Connell, & Hawkins, 2015; Pijl-Zieber et al., 2018). Dealing repeatedly with aggressive and combative patients in Dementia Specific Care Units is often considered to be part of working in dementia care but can result in physical and emotional harm, exhaustion and high nurse attrition rates (Schmidt & Diestal, 2013).

Because of the physical and psychological impact on nurses as a result of these behaviours, many Dementia Specific Care Units regularly experience poor staff-to-patient ratios (Backman, Sjögren, Lindkvist, Lövheim, & Edvardsson, 2016, 2017; Cooke, 2018; Sjögren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2012, 2017). The influence of nurse staffing levels and staffing models on the quality of nursing care provided in residential aged-care facilities has been identified and explored in a number of research studies (Backhaus et al., 2014; Edvardsson et al., 2017; McPherson, Hiskey, & Alderson, 2015; Mozley, 2017). One researcher examined the link between high Registered Nurse workloads, decreased staff numbers per shift and poor staff mix, and found these factors resulted in missed care, increased patient injuries and poor patient outcomes (White, Aiken, & Aiken, 2018). These findings were supported by Ballard et al. (2018), who discussed the influence of nurse-to-patient ratios on dementia nursing care and found a clear link between insufficient staff numbers, increased adverse patient behaviours and poor patient outcomes.

Nurses working in Dementia Specific Care Units experience competing demands when providing nursing care and may be challenged by confronting and aggressive patient behaviour (Gerritsen et al., 2018; Lood et al., 2017; Ostaszkiewicz et al., 2015). As the disease progresses and cognition declines further, nurses are required to provide increasing levels of direct patient care and utilise strategies such as distraction and one-to-one care to de-escalate adverse behaviours (Ballard, Khan, Clack, & Corbett, 2011; Clifford & Doody, 2018; Hessler et al., 2018). These behaviours can stem from unmet patient needs including hunger, thirst, pain and the need for physical contact and comfort (Laybourne et al., 2019; Sun et al., 2018).

Nurses have also identified the high levels of frustration they experience as a result of the pressurised work environment within the Dementia Specific Care Unit and the limited time they have to spend with patients and form a meaningful relationship with them (Clifford & Doody, 2018). The establishment and maintenance of interpersonal relationships with nurses and others is considered to be vital to successful care delivery and positive patient wellbeing as they help to sustain a patient's sense of self (Clifford & Doody, 2018; Sjögren et al., 2017). Nurses have also reported that the provision of comfort and familiarity with staff enables nurturing relationships between nurses and patients to be established, which results in an improved quality of life for patients with late-stage dementia (Beerens, Sutcliffe, et al., 2014; S. Lee et al., 2016; Morgan-Brown, Brangan, McMahon, & Murphy, 2019). These relationships are characterised by frequent social contact, attachment to staff members and the provision of pleasurable patient activities (Mjord et al., 2017; Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011).

Research has confirmed that nurses decide to care for dementia patients in Dementia Specific Care Units for many reasons, including obtaining permanent employment with designated shifts, the opportunity to interact and build relationships with patients, and personal gratification (S. Wang et al., 2018). For others, the desire to work with dementia patients is based in altruism, compassion, affection for their patients and the desire to make a difference to the individual as a person (Stanyon, Goldberg, Astle, Griffiths, & Gordon, 2017).

The Nursing Workforce in Dementia Specific Care Units

In conjunction with the projected increase in the number of people diagnosed with dementia is the impact on the nursing workforce of caring for these people (Gilster et al., 2018). As a result, questions have been raised by individuals and communities regarding the provision of sufficient numbers of qualified nurses to care for this group (Gilster et al., 2018). Concerns have also been raised by governments globally regarding the retention and recruitment of nurses within the healthcare workforce, particularly in aged and dementia care (Brooke & Ojo, 2018; Hickman, Neville, Fischer, Davidson, & Phillips, 2016). These concerns centre on the ageing of the nursing workforce as well as the increasing number of people who will require high-level quality nursing care in institutions such as Dementia Specific Care Units (Annear, 2018; Mayrhofer & Goodman, 2016).

In the Australian healthcare workforce, nurses are more likely to be women, with over 56 per cent aged 44 years or over (AIHW, 2019). The aged and dementia care Australian nursing workforce consists of 235,766 people (both trained and untrained), with 153,843 of these working in Dementia Specific Care Units (AIHW, 2017). Twenty-three per cent of this group were born outside Australia and 14 per cent speak English as a second language (AIHW, 2019). In order to meet the healthcare needs of the older population, it is projected that the nursing workforce in Australia will need to quadruple in size by 2050 (AIHW, 2019). The issue of the number of nurses who will be required to be employed in the aged-care system is compounded by other issues, including the fact that the younger population is growing at a slower rate than the ageing population (AIHW, 2019). Also, lower numbers of this group are in sustained full-time employment and paying taxes and are therefore generating government income to fund healthcare (ABS, 2018).

Within the residential aged-care sector, much of the direct patient care in the Dementia Specific Care Unit is delivered by untrained staff with minimal or no experience and/or qualifications in dementia care (C. Beck, Ortigara, Mercer, & Shue, 1999; Talbot & Brewer, 2016; Zimmerman et al., 2005). These staff are involved in delivering basic patient care, such as hygiene, nutrition and hydration, and are often working without the comprehension and skills required to meet the needs of patients with late-stage dementia (Estabrooks, Squires, Carleton, Cummings, & Norton, 2015; W. O’Brien et al., 2019; Simmons, Coelho, Sandler, & Schnelle, 2018; Vogel et al., 2017). The utilisation of untrained staff and cost-effective, regulated staff activities can be considered by residential aged-care facility management to be essential for the organised running of the facility (E. Beck, McIlfatrick, Hasson, & Leavey, 2017). As poor staff knowledge of dementia and the ability to manage dementia behaviours has been linked to increasing levels of adverse patient behaviours and poor patient outcomes, it is concerning that the majority of care workers in Dementia Specific Care Units have minimal or no underpinning dementia knowledge (Hazelhof et al., 2016; Tuinman, de Greef, Krijnen, Nieweg, & Roodbol, 2016).

The loss of a large number of older nurses, many of whom had worked in aged or dementia care for decades, is considered to be one of the major crises of dementia and aged care in Australia (Kagan & Melendez-Torres, 2015; Maatouk et al., 2018). This problem is not only limited to Australia; it is also having a global impact, with many other countries facing a future loss of experienced nurses from the profession (Kwok, Bates, & Ng, 2016). One issue is the fact that many nurses who have decades of clinical experience and work in aged or dementia care are also Baby Boomers, and therefore part of the ageing population, with many of them preparing for retirement by 2020 (ABS, 2018). There is also an increased number of nurses over 75 years of age who continue to work in aged care on a part-time basis as they transition to retirement (Annear, 2018). Many residential aged-care facilities struggling to obtain trained nursing staff will encourage those nurses to continue to work as long as possible as they are unable to replace them with younger nurses who are interested in dementia nursing as a career (Annear, 2018). Residential aged-care facility managers may offer flexible work practices such as regular shifts, shorter shifts, no night duty and job sharing to ageing nurses in recognition of their importance to the organisation (Clendon & Walker, 2016).

This loss of older experienced nurses who have dementia training is further compounded by the pervasive socialisation of newly graduated Registered Nurses to seek employment in high-profile and fast-paced clinical areas such as emergency departments and intensive care units instead of aged or dementia care (Cameron & Brownie, 2010; Gorman & McDowell, 2018; K. Hunter & Cook, 2018; McGilton et al., 2013; McKenzie & Brown, 2014). Many graduate Registered Nurses consider aged or dementia care to be at a lower level or of less importance, largely due to the nature of caring for older people, and associate it with low pay levels and few opportunities for professional development (Christopher, Chiarella, & Waters, 2015). Pay disparity between acute and aged and dementia care is also a major issue for many nurses, with many aged-care Registered Nurses being paid over 30 per cent less than their counterparts working in acute-care areas (C. Duffield et al., 2015). Researchers have also discussed the perception that many Registered Nurses have that aged and dementia care is where nurses go to work as they near retirement, or when they cannot cope with the challenges of acute-care nursing (Evripidou et al., 2019; Hodgkin, Warburton, Savy, & Moore, 2017; Lea, Mason, Eccleston, & Robinson, 2016).

Some graduate Registered Nurses who cannot find employment elsewhere on completion of their undergraduate degree apply for jobs working in aged or dementia care, with many moving to acute-care setting as soon as possible (Christopher et al., 2015; Elliott, Rodwell, & Martin, 2017; Willetts, Aberdeen, Hood, & Cross, 2017). Other reasons for graduate Registered Nurses leaving aged and dementia care include poor staffing levels and skill mix, with a high number of untrained staff and many Registered Nurses responsible for an inordinate number of patients, often 150 to200 in a shift (King, Svensson, & Wei, 2017). As a result, many residential aged-care facility managers struggle to recruit and retain graduate Registered Nurses in aged or dementia care for any more than limited periods of time (Ashley, Brown, Halcomb, & Peters, 2018). A cultural change within the nursing profession – characterised by wage parity, educational opportunities, clearly defined career progression, and improved working conditions – would be advantageous in changing the perceptions of nurses towards the value of aged and dementia care (Buchan, Twigg, Dussault, Duffield, & Stone, 2015). This cultural change would likely result in an increased interest in aged and dementia nursing and potentially increase the number of Registered Nurses in the aged-care workforce (King et al., 2017).

Currently, nursing degree curricula integrate dementia care into one or more courses, with often only a cursory discussion of dementia nursing care (Adewuyi, Kimble, Dormire, & Sudia, 2018; Algoso, Peters, Ramjan, & East, 2016; Garbrah, Välimäki, Palovaara, & Kankkunen, 2017; McGilton et al., 2016). There are currently no requirements that have been instituted by residential aged-care facilities or the Australian Government for nurses working in Dementia Specific Care Units to possess postgraduate qualifications in dementia care (S. Hunter & Levett-Jones, 2010; Jones & Moyle, 2013; Jones, Moyle, & Stockwell-Smith, 2013; Pulsford, Hope, & Thompson, 2007; Traynor et al., 2011). As a result, many nurses in the dementia workforce possess only their Registered Nurse qualification and do not seek to complete further education and professional development in dementia nursing (Jones et al., 2013).

Nurses have stated that they felt their basic nursing qualification has provided them with all the appropriate skills they need to work in aged care (Jenkins, 2016; Mavromaras et al., 2017). Nurses also believe that postgraduate studies are narrowly focused on acute nursing and do not accommodate training regarding the complexities of working with older people (Jeon et al., 2017). They felt that nurses with the basic practical skills could gain real-world experience when they moved into work in the aged-care sector and that this was sufficient to meet patient needs (Eltaybani, Noguchi-Watanabe, Igarashi, Saito, & Yamamoto-Mitani, 2018; Montague, Burgess, & Connell, 2015).

This limited dementia knowledge and expertise has potentially significant effects on both nursing care delivery within the Dementia Specific Care Unit and patient outcomes (M. Bauer, Fetherstonhaugh, Haesler, et al., 2018; Karlstedt, Wadensten, Fagerberg, & Pöder, 2015; Smythe, Jenkins, Galant-Miecznikowska, Bentham, & Oyebode, 2017). Given the anticipated rapid increase in the incidence of dementia throughout communities worldwide, it is of paramount importance that Registered Nurses working in Dementia Specific Care Units have sufficient dementia training. Universities need to provide increased dementia nursing care training as part of undergraduate nursing degrees to equip nurses with the requisite skills and expertise to care for dementia patients. Also, the provision of government-subsidised dementia-specific postgraduate degrees may encourage Registered Nurses working in Dementia Specific Care Units to undertake additional study and to expand their dementia knowledge and expertise.

Recruitment and retention of dementia-qualified nurses is also a major problem for rural and remote areas across Australia that struggle to attract nurses in all clinical areas, where access to healthcare is poor (Becker, 2016; Hodgkin et al., 2017). In many of these communities, nurses form the largest group of healthcare practitioners and provide multi-faceted care that ranges from paediatric to aged care (King et al., 2017). The inability to attract and retain nurses in these areas has resulted in a loss of skills and expertise that compromises the continuity and quality of nursing care for people in the community (Cosgrave, Maple, & Hussain, 2018; Lenthall et al., 2011; Russell et al., 2017). A continued decrease in the number of nurses interested in and willing to work in rural and remote areas is probable, which will further impact on the inability of these communities to care for older Australians and those with dementia (King et al., 2017; Lea et al., 2016).

The recruitment and retention of nurses in rural and remote areas is complex and often based on the relationship between work-related, personal and lifestyle factors (Francis et al., 2016; Pearson, Hegney, & Donnelly, 2018). Financial considerations have been identified as key factors in the decision-making process of nurses to work in rural and remote communities (Y. Zhao et al., 2019). Nurse remuneration and benefits – including scholarships, higher salary and additional wage allowances – are often implemented at an organisational level and so are variable. Increased funding for these incentives by the Australian Government to rural communities may prove beneficial in improving workforce supply and reducing nurse attrition rates. This situation highlights the need for decisions to be made now by the Australian Government to ensure sufficient resources and nurses are available to meet the needs of the older community living with dementia.

The Australian Government has attempted to meet the dementia nursing workforce deficit by encouraging migrants to enter the nursing profession (Kingma, 2018; Thompson & Walton-Roberts, 2018). Eligible migrants have been offered subsidised industry-based training and financial assistance, which has resulted in a marked increase in the number of these individuals entering the aged-care nursing workforce (Hajkowicz et al., 2016; Kingma, 2018). However, this may be of short-lived benefit as reports indicate that once trained, these individuals often seek better paid employment in acute-care settings instead of remaining in aged or dementia care (Dhakal, Nankervis, Connell, Fitzgerald, & Burgess, 2017; Surr et al., 2017).

The Role of the Registered Nurse in the Dementia Specific Care Unit

The role of the Registered Nurse in the Dementia Specific Care Unit is based in the provision of patient care that meets the physical and psychological needs of each individual patient (Rokstad, Vatne, et al., 2015; Smythe et al., 2017). Registered Nurses are uniquely placed to both assume direct care and leadership roles as a result of their education and understanding of the patient (Backhaus et al., 2017). They are required to supervise, support and educate Enrolled Nurses and untrained care staff within the Dementia Specific Care Unit in the provision of patient care (Smolowitz et al., 2015). They are also required to manage patient behaviours, administer medications, complete procedures (such as wound care), and ensure each patient receives sufficient nutrition and hydration (Høgsnes, Danielson, Norbergh, & Melin-Johansson, 2016; Lillekroken, Hauge, & Slettebø, 2017; Rokstad, Vatne et al., 2015). In addition to these tasks, Registered Nurses are also often required by residential aged-care facility managers to complete a variety of documentation within designated timeframes, which is linked to accreditation requirements and obtaining government funding for the residential aged-care organisation (Backman et al., 2016).

For many aged-care and dementia nurses, the focus of nursing care in Dementia Specific Care Units is to preserve patients' independence for as long as possible in the face of cognitive and physical deterioration (Greaves et al., 2018; Huber, Kleinknecht-Dolf, Müller, Kugler, & Spirig, 2017; S. Johnson & Ostaszkiewicz, 2009). Caring for older people has become more complex, largely due to increased longevity and healthcare advances, which has resulted in more elderly people living with multi-morbidities and requiring increased levels of nursing care to manage their conditions (Castellan, Sluga, Spina, & Sanson, 2016: Huber et al., 2017).

The increase in early discharge from hospital and the expectation that nurses will provide the care in residential aged-care facilities, which was once provided in hospitals, has seen an increase in the need for nurses in residential aged-care and Dementia Specific Care Units to possess and utilise a variety of clinical skills (Bray et al., 2015; Greaves et al., 2018; Jackson, Leadbetter, Martin, Wright, & Manley, 2015; Ostaszkiewicz et al., 2015). As a result, many residential aged-care facilities and Dementia Specific Care Units have been likened to "mini-hospitals", with nurses required to call on a variety of clinical skills and knowledge when caring for patients (Backhouse, Camino, & Mioshi, 2018; Digby, Lee, & Williams, 2017; Godfrey et al., 2018; Hazelhof et al., 2016; Houghton, Murphy, Brooker, & Casey, 2016). These skills and knowledge incorporate not only knowledge of the ageing process but also knowledge and skills in managing a wide variety of healthcare needs such as wound care, physical assessment, palliative care, and emergency response (Burns & McIlfatrick, 2015; S. Karlsson et al., 2015; Lalic et al., 2016; McLean, 2017).

Of all these skills, the ability of nurses to assess dementia patients quickly and accurately is paramount in Dementia Specific Care Units. Registered Nurses need to be able to identify and differentiate between changes that are part of the normal ageing process and those that are clinically significant (Davison et al., 2016; Griffiths, Bridges, Sheldon, & Thompson, 2015; Monroe, Parish, & Mion, 2015). This process needs to be rapid and accurate as clinical changes in the older person may not be as discernible as in a younger person and may have more serious consequences for the patient if not detected early (P. Griffiths et al., 2015). Also, older people do not respond as quickly to clinical interventions and may need hospitalisation sooner to prevent severe complications (Monroe et al., 2015). The number of skilled nurses, such as Nurse Practitioners, has increased in aged and dementia care in recent years to support nurses in the delivery of quality nursing care, but these numbers are limited; again, affected by the disparity of wages and the perceived lower status of aged-care nursing (Hanson et al., 2017; Jennings et al., 2017).

Registered Nurses are essential in the delivery of quality nursing care in the Dementia Specific Care Unit because their unique expertise equips them to not only deliver direct patient care but also to act as a role model, fulfil management requirements, supervise and educate other staff members in the delivery of holistic patient care, and act as innovators in the Dementia Specific Care Unit (Backhaus et al., 2017). Understanding what nurses perceive to be quality nursing care in the Dementia Specific Care Unit is critical as this information can provide rich and detailed knowledge regarding current clinical practice in this setting. This information can then be used by politicians and decision-makers to implement strategies to improve the nursing care for late-stage dementia patients residing in Dementia Specific Care Units.

Quality Nursing Care

Much remains unclear regarding what constitutes quality nursing care but what is known is that it is poorly defined. Quality has been defined as “a personal attribute, a trait, a feature of a person’s character” (Oxford English Dictionary, 2018). The World Health Organization considers that quality care is based in the provision of healthcare services that are safe, effective and result in improved health outcomes (WHO, 2017b). As this view considers healthcare services in general, and not specifically nursing care, it fails to discuss or define quality nursing care.

Registered Nurses, nurse managers, educators, researchers, healthcare organisations and policymakers appear to have differing views of just what constitutes quality nursing care, and they are unable to agree on a definition that satisfies the needs of all (Aitken et al., 2012; Backhaus et al., 2014; Department of Health, 2017; McGilton et al., 2016; Nursing and Midwifery Board of Australia, 2018; V. Parker et al., 2019). What is apparent from a review of the current research literature is that quality nursing care is complex, multidimensional and subjective to the perceptions of patients, healthcare practitioners, organisations and researchers (Cho et al., 2016; Falk & Wallin, 2016; Koy, Yunibhand, Angsuroch, & Fisher, 2015; Monsen, Acosta, Mani, & Wann-Hansson, 2015; Mozley et al., 2017). Also, while there is a significant amount of literature regarding dementia care and nursing care in general, no theories have been located that are specific to nurses’ perspectives of quality nursing care in the Dementia Specific Care Unit. The findings from this Grounded Theory study that has explored nurses’ perceptions of quality nursing care in the Dementia Specific Care Unit are important to inform the theoretical frameworks of future research into dementia nursing care. The next section contains a discussion of the current understandings of quality nursing care.

Theoretical Models of Quality Nursing Care

Various theoretical models have been used by researchers and clinicians to explain quality nursing care (Hogston, 1995; S. Mitchell et al., 2007). These models include Donabedian’s Quality of Care, the Quality Health Outcomes model and the Process of Care and Outcomes model (Gardner, Gardner, & O’Connell, 2014; Hogston, 1995; S. Mitchell et al., 2007). Donabedian (1966) considers quality care to be the balance between benefit and harm to an individual. He has identified three elements of quality care: structure, process and outcomes. Structure has been identified as the presence and use of healthcare providers, resources and tools (Donabedian, 1966). Process involves the delivery of healthcare services and the impact those services have on a patient's outcomes (Donabedian, 2003). Outcomes have been identified as the changes in a patient's condition as a direct result of the healthcare service delivery they have received (Donabedian, 2003). This model appears to consider the impact on the relationship between the patient and healthcare delivery but fails to provide depth to the discussion regarding the interactions between patients and nurses during nursing care delivery and therefore does not adequately define quality nursing care in the Dementia Specific Care Unit.

The Quality Health Outcomes model that emerged in 1988 builds on Donabedian's (1966) concept and focuses on the conduct of quality outcomes research (D. Duffield et al., 2011). This model of care specifically examines the relationships between structure, process and patient outcomes, but, as it does not consider the perceptions and expectations of both patients and nurses, it is not able to clearly identify what constitutes quality nursing care in the Dementia Specific Care Unit (D. Duffield et al., 2011). The Process of Outcome Care model also expands on Donabedian's (1966) work, where it examines the relationship between structural characteristics of both healthcare and nursing organisations and how they form the basis of quality care (Wandelt & Stewart, 1975). Whilst providing a foundation for the exploration of quality nursing care, none of these models considers the real-life experiences of nurses and patients, and, therefore, they are unable to provide clarity regarding what constitutes quality nursing care in a variety of clinical settings including the Dementia Specific Care Unit.

Over recent decades, the focus on healthcare safety and quality by healthcare organisations and researchers has become apparent (D. Allen, Braithwaite, Sandall, & Waring, 2016; Baxter, Taylor, Kellar, & Lawton, 2016; Fotaki, 2015; Waring, Allen, Braithwaite, & Sandall, 2016). In America in the 1970s, the Quality of Patient Care Scale emerged, which focuses on patient safety as the principal measurement of quality care (Ball, Murrells, Rafferty, Morrow, & Griffiths, 2014). This process involves an acute medical or surgical ward being assessed by trained nurses and awards a grade of *poor, failing, acceptable, good* or *very good* to reflect the safety of the area reserved for patients (Pearson & Chalmers et al., 2004). As this method of scoring fails to incorporate consideration of the elements of care that patients receive, not just the safety of the area, this model also fails to provide clarity in relation to quality nursing care what constitutes quality nursing care in the dementia setting.

Other traditional models of care have been utilised over the past decades in an attempt to identify and implement quality nursing care in many clinical settings. These models of care include functional, team, total and primary nursing care (Evans & Donnelly, 2006; Fairbrother, Chiarella, & Braithwaite, 2015; Thomas, 1992). Each of these models of nursing care will be discussed in turn in the next section.

Nursing Models of Care

Nursing models of care have evolved as a method for answering the elusive question of what is nursing care. Some theorists and clinicians consider that a single unified model of nursing care should be identified that explains the intricacies that is quality nursing care. However, over time, nursing models of care have been referred to as philosophies, theories, or conceptual frameworks, but this multiplicity of views has only served to add confusion to the debate concerning what constitutes quality nursing care. Various nursing models of care are discussed in turn to evaluate their ability to identify and explain what constitutes quality nursing care in the Dementia Specific Care Unit.

Some researchers have sought to ascertain what is quality nursing care by examining the various nursing models of care, including the nursing process and patient-centred models of care (Beck et al., 2017; Cherry & Jacob, 2016; Slatyer, Coventry, Twigg, & Davis, 2016). The nursing process emerged in the 1950s and is a work method based in the problem-solving aspect of nursing care. It is a systematic and logical method for planning and delivering individualised patient care and consists of five separate but interrelated steps – assessment, diagnosis, planning, implementation and evaluation (Long & Day, 2018). However, nurses considered it ignored the intuitive aspects of nursing care by disregarding the value of their clinical experience and expert opinion (Bowman, Thompson, & Sutton, 1983). This model of care is intrinsically autocratic, with the nurse making decisions regarding the care to be delivered to the patient and making judgements regarding the effectiveness of that care (Lewis & Tamblyn, 1987). The nursing process has limited applicability in Dementia Specific Care Units due to the presence of few Registered Nurses and a large number of untrained staff members who have insufficient knowledge and skill to assess and diagnose patient conditions. The assumption can be made that these staff members are task focused and primarily concerned with meeting a patient’s physical needs without the requisite skills to provide holistic dementia-specific patient care (C. Miller, 2018). The nursing process represents an important step in the debate regarding quality nursing care but fails to epitomise all aspects of quality nursing care in the Dementia Specific Care Unit.

Functional or task-based model of care.

The functional or task-based model of care evolved in the 1940s and involves dividing nursing care into tasks, which are assigned to nurses and untrained staff, based on the complexity of each task (Winslow et al., 2019). The Registered Nurse completes complex patient care tasks, with untrained staff completing the routine patient care tasks (D. Duffield et al., 2011). This model is inherently ritualistic, with priority placed on a strict adherence to procedures and protocols in an "assembly line" approach to patient care (Fairbrother et al., 2015; Fishman, 2018). This model of care has long been in use within residential aged-care facilities and Dementia Specific Care Units (Bianchetti, Benvenuti, Ghisla, Frisoni, & Trabucchi, 1997). Its use is largely due to managerial cost management strategies, where cheaper, largely untrained staff constitute the bulk of the nursing workforce with few Registered Nurses required (Beck et al., 1999; Bianchetti et al., 1997).

Whilst being economically attractive for many residential aged-care facilities, this model of care's assembly line approach to caring for dementia patients has been associated with low levels of patient satisfaction and poor patient outcomes (Fowler, Howarth, & Hardy, 2006). This model of generic care exercised by staff with little understanding of dementia can result in a lack of individually tailored meaningful activities for patients, decreased autonomy, and decreased patient wellbeing (Bowes & Dawson, 2019; Gilster et al., 2018). It does not provide holistic dementia patient care because each staff member is only required to focus on the tasks they need to complete and not on the overall needs of the patient, and, therefore, this model does not provide a complete definition of quality nursing care within the Dementia Specific Care Unit.

In order to understand the functional model of nursing care, it is necessary to discuss the roles of each of the members of the healthcare team. The nurse manager directly delegates responsibility for patient care to both trained and untrained staff members, depending on their designated scope of practice. Registered Nurses undertake the complex aspects of patient care, including intricate wound dressings, physical assessment and medication administration. Enrolled Nurses provide less complex care, such as simple wound dressings, observations and documentation. Patient Care

Attendants, who are usually untrained staff members, perform many of the basic care tasks that relate to hygiene, nutrition and hydration. By working together, each staff member contributes to the complete care of a designated group of patients for the shift. This model of nursing care is common in Dementia Specific Care Units due to its low overall cost and dependence on large numbers of untrained staff but, due to the fragmentation of patient care, does not fully explain quality nursing care in the Dementia Specific Care Unit.

Figure 1 illustrates the functional or task-based model of care, which entails the allocation of nursing tasks to different members of the nursing team, based on the complexity of the task. The nurse in charge of the clinical area delegates responsibility for tasks, such as patient assessment, documentation and medication administration, to the Registered Nurse and tasks involving hygiene and the measurement of vital signs to the Patient Care Attendant.

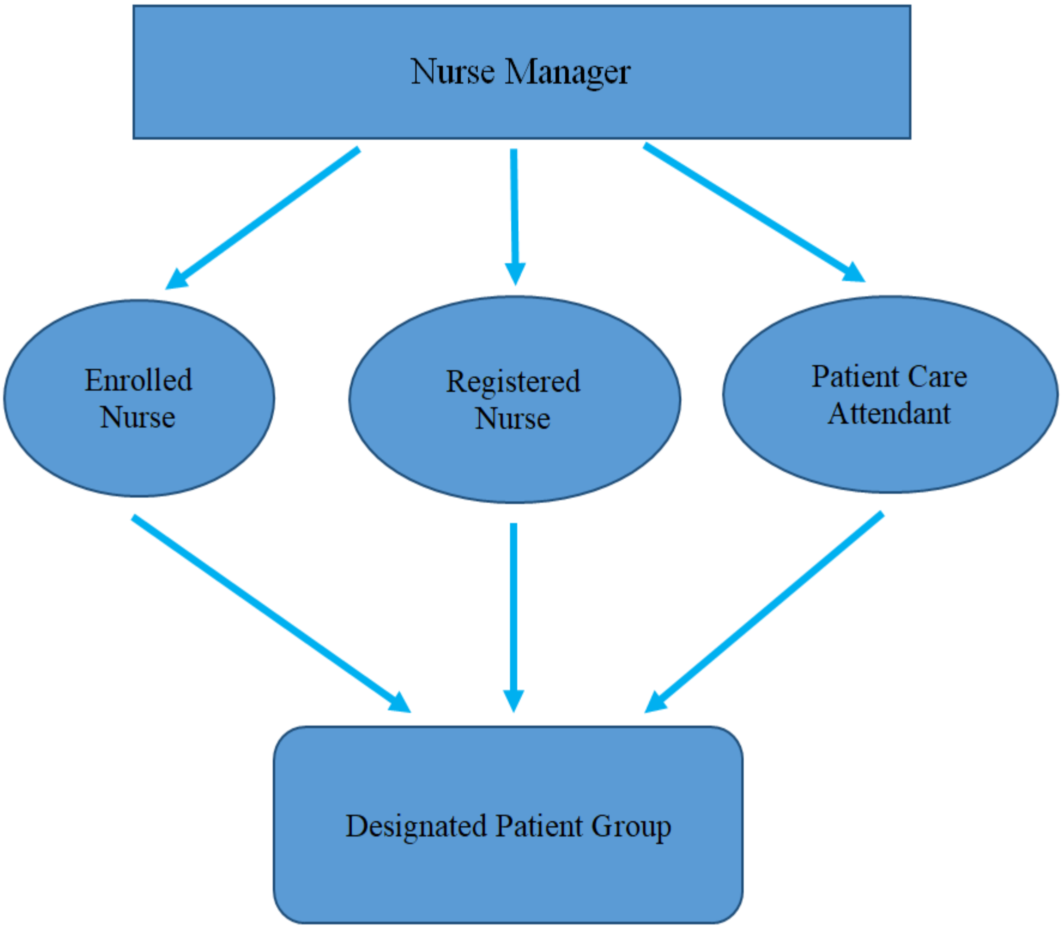


Figure 1. Functional or task-based model of care. Adapted from “Evaluating Organizational Change in Health Care: The Patient-Centered Hospital Model,” by C. V. Fiorio, M. Gorli, and S. Verzillo, 2018, *BMC Health Services Research, 18(1)*, p. 95.

Medical model of care.

The medical model of care denotes an ontological view of disease and is based in the diagnosis, the determination of a single cause, and the recommendation of a specific cure for a disease (Engel, 1977). It focuses on the disease process without consideration of the change in the psychological, social or physiological conditions of the patient, which occurs as a result of the disease process (R. Anderson, 1995). As such, the medical model of care is a process of medicalisation and dehumanisation, where the focus shifts from the person to treating the person's symptoms and ignores the benefits of health promotion and illness prevention (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009).

Many Dementia Specific Care Units are characterised by the predominant use of the medical model of care, which focuses on treating the physical and biological elements of dementia and not the individual (McGreevy, 2016; Peri et al., 2015; Stokes, 2017; Theurer et al., 2015). Researchers have confirmed that the medical model of care that has been applied to dementia care has resulted in a technical approach to treating symptoms of dementia that does not consider the human side of the condition and the person living with dementia (Hanson et al., 2017; Laver et al., 2016; McGreevy, 2016; Peri et al., 2015; Smit, De Lange, Willemse, Twisk, & Pot, 2016). As the medical model of care focuses only on the dementia disease process without any consideration of nursing care, it fails to identify what constitutes quality nursing care in the Dementia Specific Care Unit.

Team nursing model of care.

The team nursing model of care evolved in the 1950s and is based in the need to mentor and support novice nurses due to a shortage of experienced, trained nurses (Ciofffi & Ferguson, 2009). It is based in tradition and hierarchy and is characterised by decentralised communication and care delivery amongst the members of the team (Fairbrother, 2010). The team nursing model is similar to the functional or task-based model of care and involves the nurse in charge of the ward or facility pairing nurses with diverse skills and expertise (Tiedermann & Lookinland, 2004). These nurses then work collaboratively to provide patient care and share the responsibility for nursing care delivery based on patient acuity and need (Hall & Doran, 2004; Hoffart & Woods, 1996).

Its use is based in the premise that a group of nurses, under the guidance of an experienced nurse leader, can provide patients with a better level of care than if the nurses worked alone (D. Duffield et al., 2011). This model of nursing care enables each nurse to utilise their diverse skills, experience and qualifications and has been associated with increased levels of staff support, collaboration and patient satisfaction (Fernandez, Johnson, Tran, & Miranda, 2012). It is not widely used in acute clinical settings due to the high numbers of Registered Nurses who provide individualised patient care, but it is widely used in the aged-care and dementia settings (Fernandes & Mathai, 2019). Due to the small number of Registered Nurses working in Dementia Specific Care Units, it is a cost-effective model of nursing-care delivery as it enables the Registered Nurse in charge of the facility to delegate patient care to the untrained staff members (Røsvik, Brooker, Mjorud, & Kirkevold, 2013). As this model of care involves each nurse completing specific nursing activities, it does not provide the patient with holistic care and so does not provide an adequate definition of quality nursing care in the Dementia Specific Care Unit.

Figure 2 illustrates the team nursing model of care. The team nursing model of care is a modified form of functional nursing that is characterised by a team leader who has the responsibility for co-ordinating a number of trained and untrained staff to provide patient care to a small group of patients. Each staff member is assigned tasks based on their competence and training. In this model of nursing care, the nurse manager delegates responsibility to the Registered Nurse who takes on the role of team leader and has overall responsibility for the care each designated patient receives and the supervision of all staff members in the team. Within each team are also Enrolled Nurses and untrained Patient Care Attendants who perform the less complex aspects of patient care under the supervision of the Registered Nurse.

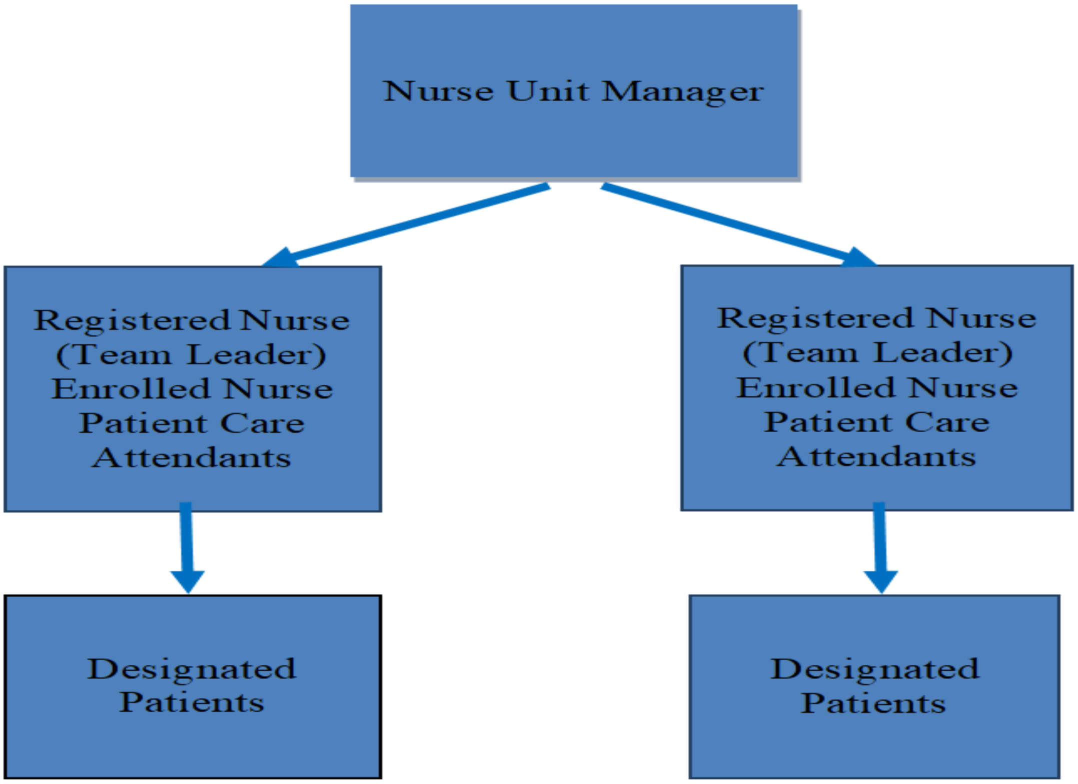


Figure 2. Team nursing model of care. Adapted from “The Impact of Primary Nursing Care Pattern: Results from a Before–After Study,” by A. Dal Molin et al., 2018, *Journal of Clinical Nursing*, *27*(5-6), p. 6.

Total nursing model of care.

The total nursing care model is the oldest model of nursing care, believed to have originated with Florence Nightingale (Shukla, 1983). It is patient centred and relies on Registered Nurses planning, organising and delivering individualised patient care (Dubois, Gauthier, & Cummings, 2013; Song, Daly, Rudy, Douglas, & Dyer, 1997). The quality of nursing care is high as the Registered Nurse completes all patient care activities by utilising their skills, knowledge and expertise and provides continuity of care each shift (Polis, Higgs, Manning, Netto, & Fernandez, 2017). It is an efficient model of care delivery as it improves communication between the nurse and the patient, requires less supervision by nurse managers to ensure care is provided, and one Registered Nurse can complete various tasks simultaneously (Aiken, Clarke, Sloane, Lake, & Cheney, 2008). It is commonly utilised in clinical settings, including Intensive Care and Coronary Care Units, where one Registered Nurse has the responsibility for the provision of care for acutely unwell patients (Aiken et al., 2017). It is uncommon in residential aged and dementia care, largely due to the high cost and lack of Registered

Nurses and so does not adequately explain quality nursing care in the Dementia Specific Care Unit (Davy et al., 2015; Dubois et al., 2013).

Patients typically respond favourably to total patient care delivery as their needs are attended to promptly and they feel supported in their recovery by the nurse (Aiken et al., 2017; Needleman, Buerhaus, Mattke, Stewart, & Zelevinsky, 2002). Registered Nurses reportedly enjoy the autonomy that total nursing care provides them but many experience burnout as a result (Laschinger & Fida, 2015; Shamian, Kerr, Laschinger, & Thomson, 2016; Woodhead, Northrop, & Edelstein, 2016). As the Registered Nurse assesses the patient then delivers patient care that is centred on the needs of the patient, this model of nursing care may provide clarity around a definition of quality nursing care.

Figure 3 illustrates the concept of the total nursing model of care. Within this model of nursing care, one Registered Nurse takes responsibility for providing every aspect of nursing care for a designated patient including planning, organising, delivering and evaluating the care that is to be provided.

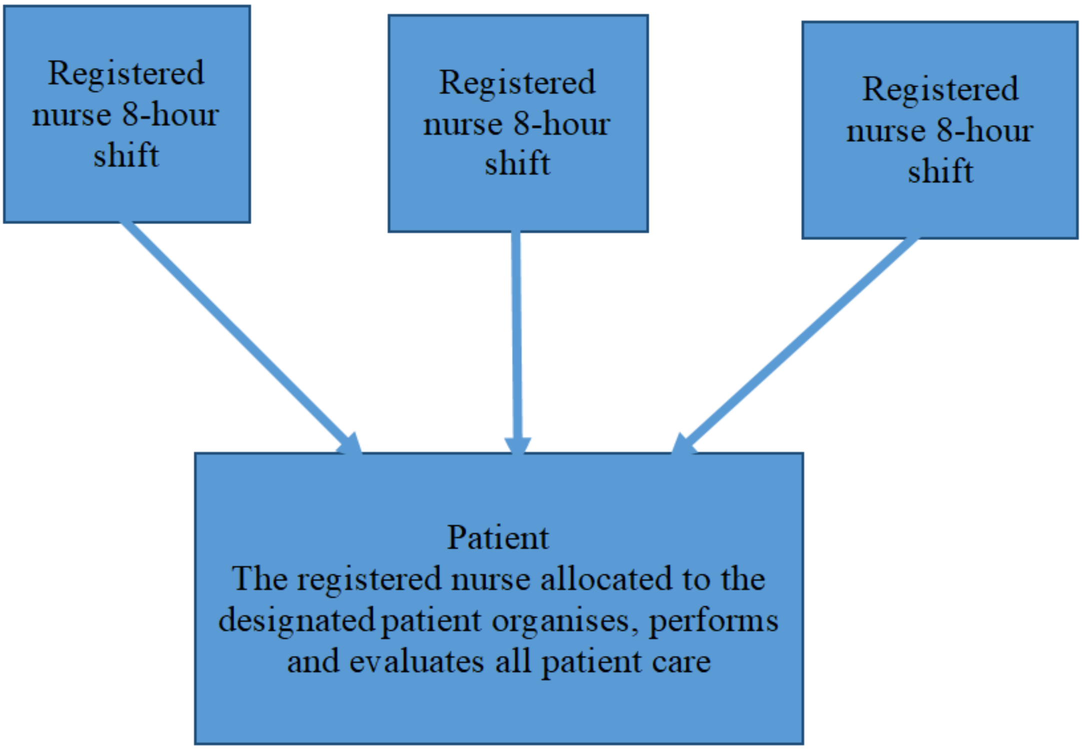


Figure 3. Total nursing model of care. Adapted from “Perceptions of a Primary Nursing Care Model in a Pediatric Hematology/Oncology Unit,” by K. Nadeau, K. Pinner, K. Murphy, and K. M. Belderson, 2017, *Journal of Pediatric Oncology Nursing*, *34*(1), p. 6.

Primary nursing model of care.

The primary nursing model of care was developed in the 1970s and became popular throughout healthcare facilities for both addressing the shortcomings of the functional and team-nursing models of care and meeting the needs of patients with complex conditions (Felton, 1975; Teresi, Holmes, et al., 1993). Primary nursing care involves one Registered Nurse being assigned patients and being responsible for their nursing care throughout their admission to hospital and, if possible, continue to care for them should they be readmitted (Dunphy et al., 2015; Klaasen et al., 2016). During this period, the Registered Nurse has the responsibility of assessing the patient and planning, organising and implementing the necessary nursing care activities followed by the evaluation of that nursing care in conjunction with the patient and their family (Smolowitz et al., 2015). The decision-making regarding the nursing care to be delivered is decentralised and is based in the judgement and skill of the Registered Nurse (Dunphy, Winland-Brown, Porter, & Thomas, 2015). This model of nursing care has proven to be popular with patients as it provides them with a sense of continuous nursing care from a knowledgeable nurse (Dossett et al., 2017).

The primary nursing model of care requires an increased number of Registered Nurses, which is problematic within aged and dementia care due to cost constraints and difficulty in recruiting and retaining Registered Nurses (Wubker et al., 2015). It is not a feasible model of nursing care within Dementia Specific Care Units due to the large patient numbers and limited number of Registered Nurses rostered on each shift. Primary nursing care provides Registered Nurses with autonomy and high levels of job satisfaction but a lack of hard data regarding its effectiveness limits its efficacy in defining quality nursing care (Davidson & Everett, 2015).

Figure 4 illustrates the primary nursing model of care. This model of nursing care involves one Registered Nurse providing continuity of nursing care through a one-to-one relationship with each patient. The Registered Nurse plans, organises, delivers and evaluates nursing care throughout the duration of a patient’s admission to provide holistic nursing care.

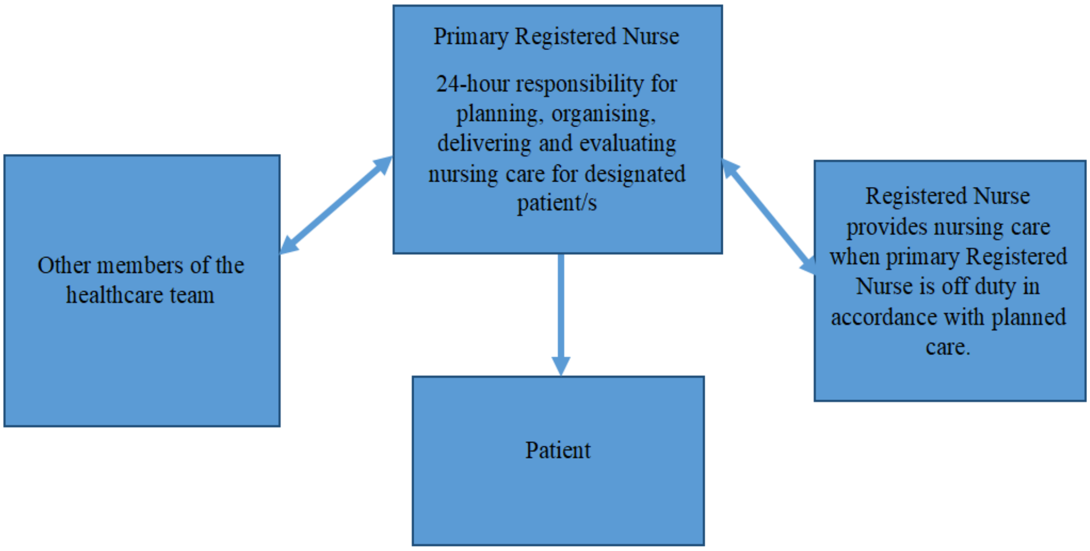


Figure 4. Primary nursing model of care. Adapted from “Role of the RN in Primary Care: Implications for Nursing Education,” by A. J. Barton, 2017, *Journal of Nursing Education*, *56*(3), p. 9.

A shift in focus to nursing care centred on the dementia patient.

In recent decades there has been an increasing interest in the development of a more sociological approach to dementia care, where the person is the focus and nursing-care interventions are based in patient preferences and needs, not in a prescribed regime of treatment (Brooker, 2003; Brooker & Latham, 2015; Epp, 2003). As a result, the focus of nursing care delivery in many Dementia Specific Care Units has shifted from that of a problem to be met as expedientially as possible to one characterised by the interaction between healthcare professionals and patients with dementia that focuses on the person’s capabilities and not their deficits (Dupuis et al., 2012; Nolan, Davies, Brown, Keady, & Nolan, 2004; Scerri, Innes, & Scerri, 2019). This approach to dementia care, particularly in the Dementia Specific Care Unit, puts the person at the centre of their care and can be considered to be an essential component of quality nursing care.

The shift from task-based care and a roster of activities to person-centred care in some Dementia Specific Care Units has resulted in the growth of communities within this setting, where individuals are valued as a unique person and the preservation of identity is a priority (Andersson, Dellkvist, Bernow Johansson, & Skär, 2019; Brannelly et al., 2019). These communities are characterised by the use of reminiscence to prompt patients’ memories, continued verbal communication with non-verbal patients, and the use of stimuli that includes pet therapy and familiar music (Allison, Balbino, &

Covinsky, 2019). This focus on the patient as an individual involves nurses spending time with each patient, speaking to family members, involving them in the patient's care and treating the patient with care and respect at all times (Brooker & Latham, 2015; Livingston et al., 2017; Suhonen, Charalambous, Stolt, Katajisto, & Puro, 2013).

Person-centred model of care.

Another model of care that developed in the 1990s was that of person-centred care, which sought to move beyond the traditional paternalistic model of care, where the person was considered to be "not fully human", to one that embraced the personal relationship between all healthcare professionals and the patient (Delaney, 2018; Fotaki, 2015). This model placed the patient at the centre of all considerations by other members of the healthcare team and encouraged the patient to be an active participant in the decision-making regarding their care (Graham, 2018). Inherent in this model of care is consideration of the patient's preferences, values and beliefs regarding their wellbeing, which is an important element in the delivery of quality nursing care (Delaney, 2018). Person-centred care has been recognised internationally as being synonymous with holistic dementia care (Fazio, Pace, Flinner, & Kallmyer, 2018). It is a philosophy that considers each person as an individual and attempts to see the world from their view (S. Kim & Park, 2017). Person-centred care is particularly relevant to dementia care as it encompasses the concepts of comfort, attachment, inclusion and occupation (Kitwood, 1997). Person-centred care is particularly relevant to dementia care as it encompasses the concepts of comfort, attachment, inclusion and occupation but has proven difficult to implement due to cost constraints and lack of Registered Nurses in the Dementia Specific Care Unit (Kitwood, 1997).

The concept of person-centred dementia care is supported by the work of Kitwood (1997), who considers that dementia care is based in the recognition and respect shown to the patient by nurses, and that each person has value and deserves to be treated with respect at all times. Kitwood (1997) also identifies the depersonalisation of the person living with dementia as a result of the use of the biomedical model of care and the associated need to provide a social and psychological environment that supports the person with dementia. This approach to patient care is based in the conviction that the person with dementia retains their personhood throughout the progression, and despite the impact of the disease, requires individually tailored support and interventions to enhance their coping mechanisms. Kitwood (1988) uses the term "person-centred care" to describe a patient care approach that is characterised by effective communication and nurturing relationships between nurses and patients. He particularly discusses how person-centred care can be effectively used in dementia settings where consideration is given to the individual’s cognitive function and psychosocial factors, with an emphasis on their general health, environment, personal experiences and social abilities (Kitwood, 1988).

Kitwood’s (1988) work has had a significant impact on the discussion concerning dementia nursing care, where he advocates for the person with dementia to be positioned at the centre of their world, confirming both their identity and value as an individual. It has signalled a significant shift in dementia care away from a focus on the biological deficits associated with a diagnosis of dementia to the creation of social and psychological environments that both support the person with dementia and promote personhood. Kitwood’s concept of person-centred dementia care is supported by B. McCormack and McCance (2010), who consider the use of a nursing framework that emphasises valuing and respecting the individual as paramount.

Kitwood and Bredin (1992) further expanded on Kitwood’s (1988) seminal work on person-centred care, concluding that quality dementia care is based on trust and respect for the patient as well as their identity and experiences. They discuss how important it is for nurses to provide comfort and contact for the dementia patient when they are feeling lost or disconnected from others by involving them in past and current interests and activities that have meaning for them. The provision of person-centred, flexible dementia nursing care, where staff get to know residents and their family members, has been linked to decreased patient stress, distress and adverse patient behaviours and quality nursing care (Elvish et al., 2018; A. Jensen et al., 2018). The social element of these interactions has significance in the preservation of self and cognition for patients living in Dementia Specific Care Units who have limited contact with society and the outside world and so provides a basis for understanding quality nursing care in the Dementia Specific Care Unit.

Person-centred care and quality nursing care appear to share fundamental similarities, but it could be argued that quality nursing care also involves the presence of a supportive nurse–patient relationship that is characterised by patient feelings of belonging, security and being cared for (Ballard et al., 2018; Evripidou et al., 2019; L. Miller, Whitlatch, Lee, & Caserta, 2018; Stokes, 2017). Whilst this model of care brought the focus back to the patient and their needs and expectations, it failed to consider the nurse and the impact of their interactions with patients in explaining quality nursing care. Also, as nurses differ in how they perceive patient needs, engage with patients and manage their care, this model of care presents a unilateral view of nursing care and does not provide a complete definition of quality nursing care within the Dementia Specific Care Unit (Graham, 2018; Ogden, 2017).

Figure 5 illustrates the person-centred model of care. It involves the nurse considering the patient’s preferences, values and beliefs, and viewing the patient as the focus of care delivery. It is underpinned by the values of mutual respect and dignity for all individuals and the individual’s inherent right to self-determination regarding the healthcare they receive.

Figure 5. Person-centred model of care. Adapted from *Person-Centred Practice in Nursing and Health Care: Theory and Practice* (p. 12), by B. McCormack and T. McCance, 2016, Oxford, UK: John Wiley & Sons.

What Nurses Say about Quality Nursing Care

Nurses form the largest group within the healthcare profession and are legally responsible for the delivery of the majority of patient care, so understanding quality nursing care from their perspective is important. As the literature relating to the meaning and definition of quality nursing care from the perspective of nurses is limited, it is imperative that the knowledge, views and values of nurses are explored in order to identify and define what quality nursing care means to them.

Nurses have described quality nursing care as meeting patients' physical, psychological and safety needs in a timely manner, but this view does not fully explain quality nursing care (Fazio et al., 2018). Nurses have also linked quality nursing care to the objective measurement of infection and fall rates, and patient morbidity and mortality rates but, as it does not consider the perceptions of patients receiving nursing care, this view is limited (Aiken et al., 2018; Loft et al., 2019). In many Dementia Specific Care Units, quality nursing care is measured by the recording of incidents such as patient falls, injuries and infections, which facility managers equate to quality but do not necessarily equate to quality nursing care (Aiken et al., 2018; Amador, Sampson, Goodman, & Robinson, 2019; Bail & Grealish, 2016; Fazio et al., 2018).

Nurses play a crucial role in the delivery of healthcare and in assisting the patient to understand the healthcare experience, with many nurses considering that quality nursing care equates to competent care (Eriksson & Granerud, 2018; Moss & O'Neill, 2019; Ostaszkiewicz, O'Connell, & Dunning, 2014). Some nurses believe that quality nursing care is more than just competence and efficiency; it includes having a genuine relationship with the patient (Tobiano, Bucknall, Marshall, Guinane, & Chaboyer, 2015). Others consider that quality nursing care is based in patient advocacy when patients are vulnerable (Owens & Koch, 2015). These views of quality nursing care are particularly relevant to dementia care, where patients are vulnerable but, again, they are limited and do not fully define quality nursing care.

The analysis of the literature relating to quality nursing care has revealed that the views of nurses are under-represented and that the relevant research does not accurately reflect the lived meaning of quality nursing care from the perspective of nurses. The current literature predominantly explores the use of tools by organisations to measure quality care, with little evidence of input from nurses themselves on both the development, suitability and use of the tool (Burhans & Alligood, 2010; Fox, Sidani, Butler, & Tregunno, 2017). What is apparent is that many nurses equate quality nursing care to the achievement of clinical goals, with a focus on positive patient outcomes, but as this view is limited, it remains uncertain if this is sufficient to define quality nursing care (Frankel, 2008; Jarrar, Minai, Al-Bsheish, Meri, & Jaber, 2018).

What Patients and Their Families Say about Quality Nursing Care

Understanding how patients view their healthcare experiences contributes to the continued evaluation and development of healthcare services and patient safety (Richter, McAlearney, & Pennell, 2016). Patient satisfaction surveys are commonly used by healthcare organisations to evaluate healthcare cost, quality and patient satisfaction with nursing care. Often, patients perceive quality care differently from that of healthcare practitioners as they relate their experience to the things they understand and have experienced previously, so patient satisfaction surveys have limited usefulness as a tool to evaluate the quality of nursing care patients receive (Foster et al., 2016).

For many patients, quality nursing care is based in the nurse–patient therapeutic relationship, their previous life experiences, interactions with healthcare professionals and the context in which nursing care is delivered (Aiken et al., 2018; Moss & O'Neill, 2019). This relationship is considered to be the foundation of nursing care, incorporating the interpersonal relationship developed over time between the nurse and the patient (Aiken et al., 2018). It is characterised by effective communication and the development of trust between the patient and the nurse within the context of caring (Aiken et al., 2018). Patients also place significance on a clean environment, positive interpersonal encounters and the absence of mistakes in their care, with many considering that nurses meeting these requirements are delivering quality nursing care (Dubois et al., 2017; Edvardsson, Watt, & Pearce, 2017). Others consider that nurses knowing and catering to patient preferences is quality nursing care (Milte, Ratcliffe, et al., 2018). It should be noted that these findings only explore the perceptions of patients in relation to quality nursing care in acute healthcare settings and therefore present a unilateral view and not a definition of quality nursing care in the dementia setting.

Debate continues regarding the validity of patient perceptions of quality nursing care that is subjective and based on their personal experience of illness and acuity (Suhonen, Stolt, & Papastavrou, 2019). Edvardsson et al. (2017) explored the relationship between patient evaluations of patient-centred care and perceived caring to quality nursing care. Findings from this research indicate that patient perceptions of person-centredness and caring interactions with nurses influence patients' experiences of quality nursing care. Patients' perceptions of nursing care have been shown to be based in their confidence in nurses and few episodes of missed care but as these perceptions are subjective and unproven, they are limited in identifying and defining quality nursing care

(Aiken et al., 2018). Following a review of the current literature, it is apparent that the patient perception of quality nursing care is subjective, complex, multifaceted and differs from that of nurses.

The perceptions of family members regarding quality nursing care appears to differ again from that of patients and nurses. For many family members, seeing their loved one in hospital has been identified as being particularly distressing and has resulted in family members focusing on the cleanliness of the environment instead of the actions of nurses (Delaney, 2018). For others, support from nurses for shared decision-making, empathy and specific communication regarding their loved one's condition was considered to be quality nursing care (Hinkle, Bosslet, & Tork, 2015). For family members who have made the often difficult decision to admit their loved one to a Dementia Specific Care Unit, feelings of guilt, anxiety and failure commonly influence their view of quality nursing care (Nikmat, Al-Mashoor, & Hashim, 2015). As a result, some family members focus on the physical environment in the Dementia Specific Care Unit and link this to the quality of nursing care being delivered (S. Lee et al., 2016). Other family members value the ability and opportunity to be involved in delivering patient care in Dementia Specific Care Units and gauge the quality of nursing care according to the frequency of opportunities they are given to be involved in caring for their loved one (Reid & Chappell, 2017).

What Healthcare Organisations Say about Quality Nursing Care

Quality improvement is frequently lauded by healthcare organisations as a method for both measuring and ensuring quality nursing care is delivered, but its effectiveness as a tool to explain quality nursing care has received mixed reviews (Berman, Raval, & Goldin, 2018; Dixon-Woods & Martin, 2016; Mitra, 2016). For many organisations, quality improvement was considered to be the magical solution for any healthcare problem, regardless of the context (Dixon-Woods & Martin, 2016). As quality improvement examines situations retrospectively and is limited to measurable outcomes, it fails to provide a complete definition of quality nursing care (Aragona et al., 2016; J. Johnson & Sollecito, 2018; Kaminski et al., 2017).

Research relating to quality nursing care in residential aged-care facilities has found that the tools used to measure quality do not necessarily correlate to care delivery or quality nursing practice (Burke & Werner, 2019). The tools often focused on the measurement of elements linked to government subsidies such as food quality, the standard of cleanliness of the organisation environment, and nurse response time when answering patient call bells (Bollig, Gjengedal, & Rosland, 2016; Leff, Carlson, Saliba, & Ritchie, 2015; Shield, 2018).

Residential aged-care organisations use other tools such as patient satisfaction surveys to try to capture information about the quality of care delivered (Pomey et al., 2015). Patient surveys are used to identify what people value about the residential aged-care organisation and for the organisation to be eligible for government subsidies and funding, which are often directly linked to patient satisfaction and outcomes (G. Roberts et al., 2015; Singh & Prasher, 2017). This information is subjective and often excludes components of nursing-care behaviour, so it is likely to not be accurate and reflective of the actual delivery of quality nursing care (Pomey et al., 2015). In the contemporary healthcare setting it is important for organisations and individual healthcare practitioners to understand the criteria that patients use to judge the care that they receive in order that services can be evaluated and improved (Mohammed et al., 2016). Consequently, clarity regarding what constitutes quality nursing care remains elusive.

What Researchers Say about Quality Nursing Care

Some researchers consider quality nursing care to be care that meets the needs of patients through caring and compassionate interactions (Burhans & Alligood, 2010; Cooper, Marston, et al., 2018; Laschinger, Read, Wilk, & Finegan, 2014; Morrison & Korol, 2014; Slatyer et al., 2016). Others view quality nursing care as an ambiguous, context-specific term based in the perceptions of both patients and nurses (Ellis, 2019; Hands et al., 2018; James, Nelson, & Ashwill, 2014; Ke, Hu, Takemura, & Lin, 2019; Lindquist, Tracy, & Snyder, 2018). It is interesting to note that researchers have identified that the majority of nurses deliver nursing care without a clear understanding of what the term quality nursing care means, adding further layers to the complexity surrounding the definition of quality nursing care (Connor, Mott, Green, Larson, & Hickey, 2016; Grimley, 2017; Koy et al., 2015; Sherwood & Barnsteiner, 2017).

Researchers have explored the relationship between the nurse–patient relationship and quality nursing care and found that nurses often equate meeting the patients' expectations to quality nursing care (Cho et al., 2016; Feo, Kitson, & Conroy, 2017; Kutney-Lee, Sloane, & Aitken, 2015; Norouzinia, Ahmadi, & Seidabadi, 2016; Tobiano et al., 2015). One researcher discussed the importance of trust in the establishment of the therapeutic relationship, which would result in nurses delivering individualised patient care, but fell short of confirming this to be quality nursing care (Charalambous et al., 2016). Wiechula et al. (2016) also explored the importance nurses place on the caring relationship between nurses and patients and found that in the absence of this relationship, care provision may be sporadic and generic. This relationship has been described as a key component of quality nursing care but in isolation is insufficient to explain quality nursing care (Wiechula et al., 2016).

One study examined nurses' perceptions of quality nursing care in acute healthcare and identified professionalism, best practice, competence, and nursing skill as essential elements of quality nursing care (Amiri, Ebrahimi, Vahidi, Asghari Jafarabadi, & Namdar Areshtanab, 2018). Another researcher included the personal characteristics and values of nurses, their attitude and understanding of the individual's condition, together with acknowledgment of the person as an individual, as important elements of quality nursing care (Zamanzadeh, Valizadeh, Rahmani, Cingel, & Ghafourifard, 2018). This view, whilst providing further insight into nursing care, also fails to clearly define what constitutes quality nursing care.

A growing body of literature has highlighted the importance of organisational factors in the delivery of quality nursing care (C. Cheng, Bartram, Karimi, & Leggat, 2016). These factors include the link between the support nurses receive from organisations, their feelings of being valued, their level of job satisfaction, and their rating of quality patient care but was not able to identify what quality nursing care entailed (Charalambous et al., 2016; C. Cheng et al., 2016; Cho et al., 2016; Laschinger & Fida, 2015). The importance of these elements has been reinforced by researchers who consider that quality nursing care is based in patients being consulted regarding the care they have received and nurses involving them in decisions regarding their care (Al-Hussami, Al-Momani, Hammad, Maharmeh, & Darawad, 2017; Lu, Zhao, & While, 2019).

Research findings indicate that patients also value the presence of knowledgeable and friendly nurses and the timeliness of assistance when required, with many considering this to be quality nursing care (Ballard et al., 2018; Beerens, Sutcliffe, et al., 2014; Edvardsson et al., 2017; Milte, Ratcliffe, et al., 2018). Whilst the literature has identified some of the elements that nurses consider constitute quality nursing care, a clear picture of quality nursing care from the perspective of nurses remains elusive, which reinforces the importance of this Grounded Theory study that explored nurses' perceptions of quality nursing care in Dementia Specific Care Units.

Evaluating Quality Nursing Care in Practice

The difficulty in defining quality nursing care is likely to be based in a lack of clarity around how quality nursing care is evaluated. The clinical tools used by many healthcare managers to measure the achievement of “quality” have not always been clearly delineated or reflective of patient care delivery, often having been focused, instead, on funding-based outcomes (Moorhead, Johnson, Maas, & Swanson, 2018; Mohammed et al., 2016; Mozley et al., 2017). Healthcare organisations routinely utilise tools that measure staff turnover and poor patient outcomes to evaluate and continuously improve the quality of care delivered (Nakrem, Vinsnes, Harkless, Paulsen, & Seim, 2013). As these tools focus on particular measurements associated with specified outcomes, they are limited in their efficacy in defining quality nursing care (Mohammed et al., 2016).

Nakrem et al. (2013) attempted to identify a quality nursing care measurement tool in acute healthcare by using surveys that focused on the relationship between individuals’ need for social interaction, high-quality nursing care and standardised organisational routines. This research was unable to identify a specific tool that measured quality nursing care but identified a clear link between the nurse–patient interaction and patient satisfaction (Nakrem et al., 2013). Standardised patient satisfaction surveys have gained increased focus in recent decades as a quick, effective tool to measure quality for healthcare organisations (L. Miller et al., 2018). As they are inherently subjective, being based on the perceptions of individual patients, the use of patient surveys may not reflect actual nursing care quality (Rokstad, Vatne, et al., 2015; Voutilainen, Pitkäaho, Kvist, & Vehviläinen-Julkunen, 2016). Consequently, ambiguity and debate continue to besiege the identification and definition of quality nursing care, which reinforces the need for additional research into this topic (Aiken et al., 2017; Lindquist et al., 2018; Mozley et al., 2017; Tyler et al., 2017).

Chapter 2 has presented a review of the literature relevant to nurses’ perceptions of quality nursing care in Dementia Specific Care Units. The chapter has discussed the characteristics of dementia, the risk factors for developing dementia, and the issues that relate to living with dementia. In order to provide context for this discussion, information regarding the ageing population, caring for older Australians, the impact of the ageing population on the healthcare system, and the cost of dementia care were also presented. I have outlined the current knowledge regarding quality nursing care from the perspectives of nurses, patients and researchers in addition to models of care and the evaluation of quality nursing care. Discussion regarding the impact of the Dementia Specific Care Unit design on the provision of quality nursing care was also provided in addition to dialogue regarding the patient in the Dementia Specific Care Unit. The inherent challenges relating to the delivery of quality nursing care in the Dementia Specific Care Unit were also discussed as well as issues relating to the current dementia care workforce and the role of the Registered Nurse in the Dementia Specific Care Unit. The next chapter, Chapter 3, introduces and discusses the methodology and research methods used in this research study.

Chapter 3

Methodology and Method

This chapter describes how Grounded Theory methodology was used in this research study to explore nurses' perceptions of quality nursing care in Dementia Specific Care Units. It begins by discussing qualitative research before providing a brief history of Grounded Theory and discussing the rationale for choosing Grounded Theory for this study. The ethical considerations relevant to this study, the study setting, the participant recruitment process, the data collection phase, and the use of the constant comparison data analysis process are then described. Table 2 provides a glossary of terms.

This research question is anchored in the constructivist paradigm. The ontological and epistemological assumptions of this paradigm are that perceived reality is mentally constructed by individuals and that findings are revealed through an interactive process between the researcher and participants. This research study seeks to determine what reality regarding quality nursing care in a Dementia Specific Care Unit means to the participants via the interaction and rapport formed during the interview process. Subjectivity of experiences and personal values were considered to be essential in determining themes within this research (Polit & Beck, 2012; Corbin & Strauss, 2008). These assumptions formed the basis for the choice of a Grounded Theory approach to this research – to explore the nurses' perception of quality care within a Dementia Specific Care Unit.

Table 2

Glossary of Terms

Term	Definition
Coding	A method of categorising data by its relationship to other data, concepts and categories (Gibbs, 2007).
Constant comparison	Part of the data analysis process and consists of the researcher comparing data with data, data with codes, codes with codes, codes with categories and categories with categories (Charmaz, 2014).
Theoretical sampling	Selecting participants for research based on specific characteristics (Charmaz, 2006).
Data saturation	The point in data analysis where no new information has been identified from the data (Glaser, 1967).
Validity	The soundness of the research and how accurately the findings represent the data (Glaser, 1967).
Rigour	The quality of the research process (Charmaz, 2006).
Reflexivity	The process of reflecting on the relationship between the researcher and the research process (Glaser, Strauss, & Strutzel, 1968).

Qualitative Research

The literature confirms that qualitative research is appropriate for nursing studies as it can facilitate an explanation of a phenomenon and is based in both the participants' information and the researcher's interpretation of that information (R. Allen et al., 2018; Berger, 2018; Borraccino, Pera, & Lima, 2019; Cooney, 2011; Green & Thorogood, 2018; Haigh & Miller, 2018; McEwan & Wills, 2017; D. L. Morgan, 2018; Moser & Korstjens, 2018; Reay, Rankin, & Then, 2016; Renolen & Hjalmhult, 2015; Richards, Killian, Graber, & Kern. 2019; Sanders, 2019; Spreadbury & Kipps, 2019). This is important for nursing research as not only can data regarding the patient experience of healthcare be identified but this information may also serve to modify clinical nursing practice (Buetow, 2019; Green & Thorogood, 2018; G. D. Smith et al., 2018). Qualitative research is therefore appropriate for this study.

History of Grounded Theory

Grounded Theory methodology is a qualitative research method that is "grounded" in data. The data is logically and systematically gathered, continually compared and analysed, and culminates in the generation of a substantive theory that is used to describe and explain the phenomenon (Bryant & Charmaz, 2019; Charmaz, 2006; Flick, 2018; Lambert, 2019; Timonen, Foley, & Conlon, 2018). In order to provide context for the use of Grounded Theory in this study, a short discussion regarding the emergence and development of Grounded Theory as a methodology is presented.

Grounded Theory was developed as a qualitative methodology in the 1960s within the field of social science by Barney Glaser and Anselm Strauss (Glaser & Strauss, 1967). Strauss was an advocate for qualitative research, particularly the use of symbolic interactionism, which involves individuals seeing themselves from the perspectives of others and adapting their behaviour to a situation as a result of those perspectives (Glaser & Strauss, 1967). In contrast, Glaser was a quantitative researcher who advocated for traditional quantitative research methods of reviewing the literature and planning all stages of the research process (Glaser, 1992). Together, their research into the awareness of dying was used as a basis for the development of their new methodology, Grounded Theory (Glaser & Strauss, 1967). Grounded Theory is of particular value when researchers seek a fresh perspective on a familiar situation; it provides systematic guidelines for the obtaining, analysing and conceptualising of data to generate a theory to explain the situation (Glaser, 1992).

From Grounded Theory's inception, Glaser and Strauss (1967) have held divergent views of Grounded Theory methodology (Hallberg, 2006; S. N. Khan, 2014; Lingard, Albert, & Levinson, 2008; Pandit, 1996). Strauss (1967) considers that the researcher needs to go out into the field to be able to understand what is happening, with the emergent theory being "grounded" in the data, the participants' experiences and their interrelationships. In contrast, Glaser's (1967) approach remains true to the original concept of Grounded Theory methodology. Glaser (1967) focuses on an evolving methodology, where a theory is developed inductively from data and steps are incorporated in the process to code and test hypotheses generated from the data.

The major differences in the two approaches to Grounded Theory are based not in ontological and epistemological variances, but in the methodological process of data analysis (Walker & Myrick, 2006). Glaser (1992) believes that the participants' stories would naturally emerge as data analysis proceeded and felt that it was important to allow this to happen without the process being forced by the researcher. Alternatively, Strauss (1967) considers that data analysis needs to be measurable, replicable and able to be verified (Babchuck, 1997). These two approaches can be summarised as Glaser exhorting the researcher to allow the data to tell the story of the phenomenon, and Strauss instructing the researcher to ask “what if” and consider the value of abstract concepts (Annells, 1996; Melia, 1996; Thornberg, 2012).

Ethical Considerations

Prior to the commencement of this study, ethics approval was obtained from LaTrobe University’s Ethics Committee in 2012 (see Appendix A). The regional manager for the residential aged-care organisations where the Dementia Specific Care Units were located also granted ethics approval for the research to be conducted (see Appendix B). Following the receipt of ethics approval, the Director of Nursing from each residential aged-care facility was contacted and the proposed research project was outlined. Each Director was then provided with written information about the research, including the research question, what the research entailed, the Participant Information Sheet (see Appendix C), and the Consent and Withdrawal of Consent forms (see Appendix D).

The Research Setting

Each of the two Dementia Specific Care Units in this study was located on the Gold Coast in Queensland, Australia, owned and operated by a non-profit organisation and part of a multi aged-care facility chain. The researcher contacted a number of residential aged-care facilities on the Gold Coast requesting permission to conduct this research in their facilities, but only this one non-profit organisation responded and granted permission for the research to be conducted. The total likely sample of Registered Nurses in each Dementia Specific Care Unit was identified by the State Manager of the organisation as being between 10 and 12 individuals.

Each of these Dementia Specific Care Units housed 16 residents and included both permanent and respite beds for individuals living with dementia. These sites were physically located at either end of the Gold Coast and represented each end of the socioeconomic spectrum, which I considered to be important in obtaining information regarding what constituted quality nursing care in different socioeconomic environments. I sought to identify differences and similarities regarding quality nursing care in two units characterised by variations in funding and physical and human resources.

Both of the residential aged-care facilities were accredited with the Australian Aged Care Quality Agency, the independent body responsible for managing the accreditation and ongoing supervision of Commonwealth-funded aged-care facilities.

They ranged in size between 100 and 130 beds, including the Dementia Specific Care Units. Both residential aged-care facilities advertised services including respite, permanent and dementia care with Registered Nursing staff available on each shift.

Both Dementia Specific Care Units had been modified from pre-existing structures in 2000. These structures had both previously been used for equipment storage, not patient accommodation. They both consisted of single-storey, standalone structures with outdoor areas and gardens that were surrounded by high, solid-metal security fencing. Each Dementia Specific Care Unit was significantly smaller in size in comparison to the other buildings in the residential aged-care facility.

Both Dementia Specific Care Units were configured in the same way: each consisted of one long central corridor with patient bedrooms and living areas opening off the corridor. Patient rooms were locked when not in use and did not have room numbers or patient names on the doors. The walls in each Dementia Specific Care Unit were painted pale grey and the carpeting was dark grey. The only windows in each Dementia Specific Care Unit were in each patient’s room, but these did not open. The one entry-and-exit access point for each of the Dementia Specific Care Units was via a locked and number-coded door. Only staff and visitors were given the code. Each Dementia Specific Care Unit had one glass sliding door, which provided access to the outside garden areas, but it was routinely kept locked by order of the facility manager of each residential aged-care facility.

The Recruitment of Participants

As recommended by Charmaz (2014), selective sampling was used to identify appropriate participants who could provide relevant data for this study. Selective sampling involves the identification of research populations and settings regarding the specific characteristics of either individuals or groups possessing the knowledge or experience relevant to the research question (Corbin & Strauss, 1990; Coyne, 1997; Engward, 2013). Registered Nurses were selected as the research population as they were considered to be the most knowledgeable in relation to the delivery of quality nursing care in the Dementia Specific Care Unit (Foley & Timonen, 2015; Glaser & Strauss, 2017).

Once ethical approval for the research study had been obtained, I contacted each Director of Nursing from the two residential aged-care facility sites to outline the proposed research project and asked for consent to conduct the research on their site. They were provided with written information about the research, including the research question, what the research would entail, the research participant information sheet, consent and withdrawal of consent forms. They were then asked to disseminate the research study information by email to all Registered Nursing staff who worked at least two shifts a week in the Dementia Specific Care Units in their facilities.

The email contained a plain language statement (see Appendix D) that outlined what the research involved, the aims and process of the study and what was required of participants. Email recipients were informed that participation in the study was voluntary and all participants were offered the opportunity to withdraw from the study at any time without penalty. Potential participants were provided with the opportunity to ask questions about the research and voice any concerns regarding the research they might have. Given that potential participants were from diverse cultural and educational backgrounds, written information relevant to their comprehension, in plain English, was provided. In this email, potential participants were asked to contact the researcher if they were interested in participating in the study. It was initially anticipated that 20 participants would be recruited, 10 from each of the aged-care facilities.

The Director of Nursing from each residential aged-care facility was then asked to disseminate the research study information by email to all the Registered Nurses who worked in the Dementia Specific Care Units in their facilities. In this email, potential participants were asked to contact me if they were interested in participating in the study. Nurses who contacted me were informed about the research study, that participation in the study was voluntary, and that they could withdraw from the study at any time without penalty. They were provided with the opportunity to ask me questions about the research and voice any concerns they might have regarding the study.

However, there was only limited interest generated initially, so I contacted the Directors of Nursing in each facility and requested their assistance in recruiting further participants.

I interviewed nine participants from both sexes, with diverse ages, clinical experience and cultural backgrounds and provided them with the participant Information Sheet (see Appendix B) and Consent and Withdrawal of Consent Form (see Appendix C and Appendix D). Participant experience varied from one year to over 40 years' experience as a nurse in a variety of clinical settings. The distribution of the participant sample was skewed towards females, which I felt reflected the workforce within residential aged care and particularly dementia care.

Participation information sheet and consent form.

Nurses who contacted me were emailed the Participant Information Sheet and Consent forms and invited to attend an interview at a mutually agreed time and venue. They were asked to read the information, complete the Consent form and return this to me prior to the interview.

Nine Registered Nurses working in separate Dementia Specific Care Units within the two identified residential aged-care facilities offered to participate. The participants' ages ranged between early 20s to mid-70s; one participant was male and eight were female. The first four participants interviewed had between one and 12 years of experience working as a Registered Nurse, with a mean of six years. The remaining five participants had between 12 and 40 years of experience working as a Registered Nurse, with a mean of 32 years. The distribution of the participant sample was skewed towards females, which reflected the current profile of the workforce within residential aged-care facilities and particularly in Dementia Specific Care Units across Australia (Pierce, Perry, Gallagher, & Chiarelli, 2017).

Data Collection

Grounded Theory methodology provides the researcher with flexibility regarding data collection methods, which can include participant observation, interviews or memos (Flick, 2018; Glaser & Strauss, 2017; Thornberg, 2017). Charmaz (2006) refers to this as collecting "rich" data and identifies this as an essential component in Grounded Theory research. Rich data has been described by Charmaz (2008) as data that is detailed, focused and full and where the participants' thoughts, feelings and actions are evident. In this study, data was collected using individual, semi-structured interviews, which allowed for a degree of flexibility in the interview process. I also wrote memos following each interview and included them as data during the data analysis process.

Confidentiality.

To maintain confidentiality, all participants were given pseudonyms (Glaser, 1992, 1998). As previously mentioned, participants consisted of one male and eight females. As there was capacity for the male participant to be identified by employees of the organisation and others, he was allocated a gender-neutral name when reporting on the data.

Participants were encouraged not to use the names of other persons (including staff or residents) or the residential aged-care facility in the interviews to maintain confidentiality. The interviews were conducted in a private setting away from the workplace, and all conversations were treated as confidential. Participants were informed that the information obtained would be shared with others in the form of this dissertation, journal articles or presentations at conferences. All research information will be kept for five years following the completion of the research project and destroyed after this time.

Risk to participants.

It was anticipated that there was a low risk of harm to participants from their involvement in this research study. It was acknowledged that some participants could experience feelings of distress following their discussions during the interview. In order to address this, participants were provided with the information contained in the Participant Information Sheet regarding counselling services they could access, including the residential aged-care organisations’ Employee Assistance Program and Lifeline. At the completion of the interview, I thanked each participant for their time and referred them to the Employee Assistance Program or Lifeline if they had experienced any distress as a result of the conversation. I also provided my mobile telephone number for participants if they wished to talk further.

The interviews.

The nurses who offered to participate in the study contacted me and arranged a time and venue for the interview. All the participants returned the Consent Form prior to their interview (see Appendix D). The interviews were conducted between September 2015 and December 2016 in a variety of settings. These settings included meeting rooms at the university, participants’ homes, the beachfront and the local library. No interviews were conducted in the residential aged-care facilities or the Dementia Specific Care Units due to the requirement for participant privacy. All participants completed one interview, with no interview lasting longer than 90 minutes.

I used the open-ended, semi-structured interview guide (see Appendix E), during the face-to-face interviews. The questions were deliberately open ended to facilitate the participants responding in their own terms (Glaser, 1992). Prior to the commencement of each interview, I again explained the research purpose and what the interview entailed. I also reiterated the importance of participants discussing the issues that were important to them when describing their perceptions of quality nursing care.

Glaser (2002) does not advise the Grounded Theory researcher to use a voice recorder during interviews as he felt that the important information from each interview would be retained by the researcher. Strauss and Corbin (1990), however, advocate for the researcher to use a voice recorder to ensure the accuracy of the data during transcription and to enable the researcher to replay the interviews as many times as needed throughout the data analysis process. Following consideration of these different perspectives, I decided to record the interviews so the data could be reviewed for both clarity and veracity during the data analysis phase. All participants agreed for their interviews to be audio recorded, so when the interview was about to commence, the small digital voice recorder was placed in clear view and in close proximity to both the participant and me during each interview. The use of a voice recorder was important as it allowed me to record data and develop a rapport with the participant as well as encouraging an easy conversation without the distraction of having to make notes during the interview (Olson, 2016).

During each interview, I sat diagonally across from the participant to maintain eye contact and reduce any perception of being confrontational (Licqurish & Seibold, 2011). I also utilised active listening and positive body language to show interest in the participant’s conversation and promote an atmosphere of engagement and trust in order to encourage discussion (Dworkin, 2012). The interviews were kept as conversational as possible to allow participants to identify and discuss information that was meaningful to them (Lambert, 2019; Thornberg, 2017). Words were used that would make sense to the participant and have meaning in the context of the Dementia Specific Care Unit. I was also careful to ask just one question at a time in order to make it easier for participants to interpret the question and provide their answer (Charmaz, 2006). As soon as possible after each interview, I wrote a memo to record my impressions and thoughts regarding the interview and the participant’s conversation.

Following each interview, I listened to each audio recording within 24 hours to review the content (Bryant & Charmaz, 2019). The interview recordings were then transcribed verbatim. Any identifying material relating to participants, patients or the residential aged-care facility was removed. Each transcript was then numbered and coded. All information, including consent forms, audio recordings, transcripts and memos were locked in my office at the university.

I wrote memos in a spiral-bound notebook as soon as possible following each interview, when my impressions and thoughts relating to the interview were fresh (Charmaz & Belgrave, 2012; Glaser, 1992; Stern, 1980). The use of a spiral-bound notebook enabled me to easily remove a memo in order to group it with other data during data analysis and as codes, subcategories, categories and themes developed.

In the memos, I recorded information that included the interview setting, participants' actions, body posture, eye contact and vocal tone. This information was valuable as it provided depth of detail and helped to "flesh out" the data. Some participants became emotional during their interview when discussing specific patient experiences, with some participants crying, shaking and visibly distressed at the recollection. Others appeared almost uninterested in discussing their interactions with patients, displaying closed body language with little eye contact, and using dismissive hand gestures. Still others were obviously passionate about the nursing care they provided; they leaned forward in their chair, smiling and laughing when telling me about individual patients and used animated hand and facial gestures when they were talking about their interactions with both patients and family members.

Data Analysis in Grounded Theory

Grounded Theory methodology is characterised by concurrent data collection and constant comparative data analysis (Charmaz, 2006; Glaser, 1968, 1992). The data analysis process is iterative and interactive, involving movement back and forth between codes, themes and successive data (A. Hunter, Murphy, Grealish, Casey, & Keady, 2011). Data analysis commences as soon as the data is identified (Glaser, 1992; Thornberg, 2017). The constant comparative method involves the generation of increasingly abstract concepts and theories by the comparison of data with data, data with category, category with category and category with concept (Glaser, 1992; Thornberg, 2017). In this process, data collection and analysis proceeds until *saturation* is reached where the researcher determines that the same information is continually being identified with no new information evident (Glaser & Strauss, 2017). Any differences and similarities are identified and emergent categories are used in the generation of a substantive theory (Glaser, 1992; Harris, 2015; Glaser & Strauss, 2017).

Prior to commencing this study, the use of a computerised data analysis program to assist with analysing the data was considered. Glaser (2003) considers that computerised programs are unable to cope with the often complex data that is generated from Grounded Theory studies and they keep the researcher away from the emerging theory due to the time required to learn how to use the computer program. Glaser (2003) believes that the use of a computer program fails to capture the complexity of Grounded Theory studies, which are based in inductive reasoning. Following contemplation of these comments, I decided not to use a computer software package for data analysis in this study; instead, manual data analysis was utilised to remain true to the underlying Grounded Theory principle of the researcher being immersed in the data and the emerging themes. A rigorous process of data analysis was used. Data analysis commenced with the coding of the data. Codes were allocated to recurrent words used by the participants; the codes were then compared with all codes and categories. The categories were then compared to each other for commonality and relevance to the data and were then combined to form three themes: Caring at the Coalface, Labour of Love, and The Business of Dementia Healthcare. The three themes formed the theory: *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding*.

Use of memos in data analysis.

In Grounded Theory studies, memos are one of the most useful and powerful tools for researchers during data analysis (Charmaz, 2017; Levy, 2016). Memos can be in the form of a sentence, a paragraph or a page of information and link the individual pieces of data into one recognisable category (Lempert, 2007). Writing memos enables the researcher to move with the data, identify the main categories and the relationship each category has with the others to support the emergence of a theory (Engward, 2013; Glaser, 1978). Glaser (1978) considers memo writing and reflective practice to be essential in the generation of theory from the data and to allow replication of the research by others. He feels so strongly about the importance of “memoing” that he considers if the researcher omitted writing memos, then Grounded Theory research had not been conducted.

Memo writing served a variety of functions during this study, including being incorporated into the data as essential information. Memos were written throughout the data analysis process, using data from memos in analysis, theorising and theoretical sampling. Data contained in the memos was very helpful in identifying gaps in the data and focused my attention on the emerging categories and themes. The memos both constituted data and informed the data and so were coded accordingly. They identified information that might have been missed through the audio recording and transcription of each interview and highlighted the links between categories and themes, becoming data in their own right (Charmaz, 2017; Mey & Dietrich, 2017). The memos were also constantly reviewed during the data collection and analysis phases, which enabled different aspects of the theory emerging from the data to be identified (Glaser, 1992; Lempert, 2007; Mruck & Mey, 2019; Thornberg, 2017).

Reflecting on and revisiting the memos allowed me to challenge any assumptions where necessary – for example, the assumption that nurses in the Dementia Specific Care Unit received support from their facility managers. They also assisted in the definition and delineation of theoretical categories and the recorded emerging categories, which ensured that the emerging themes and theory were indeed “grounded in the data”.

Data coding and constant comparison data analysis.

Constant comparative data analysis was utilised in this Grounded Theory study as illustrated in Figure 6.

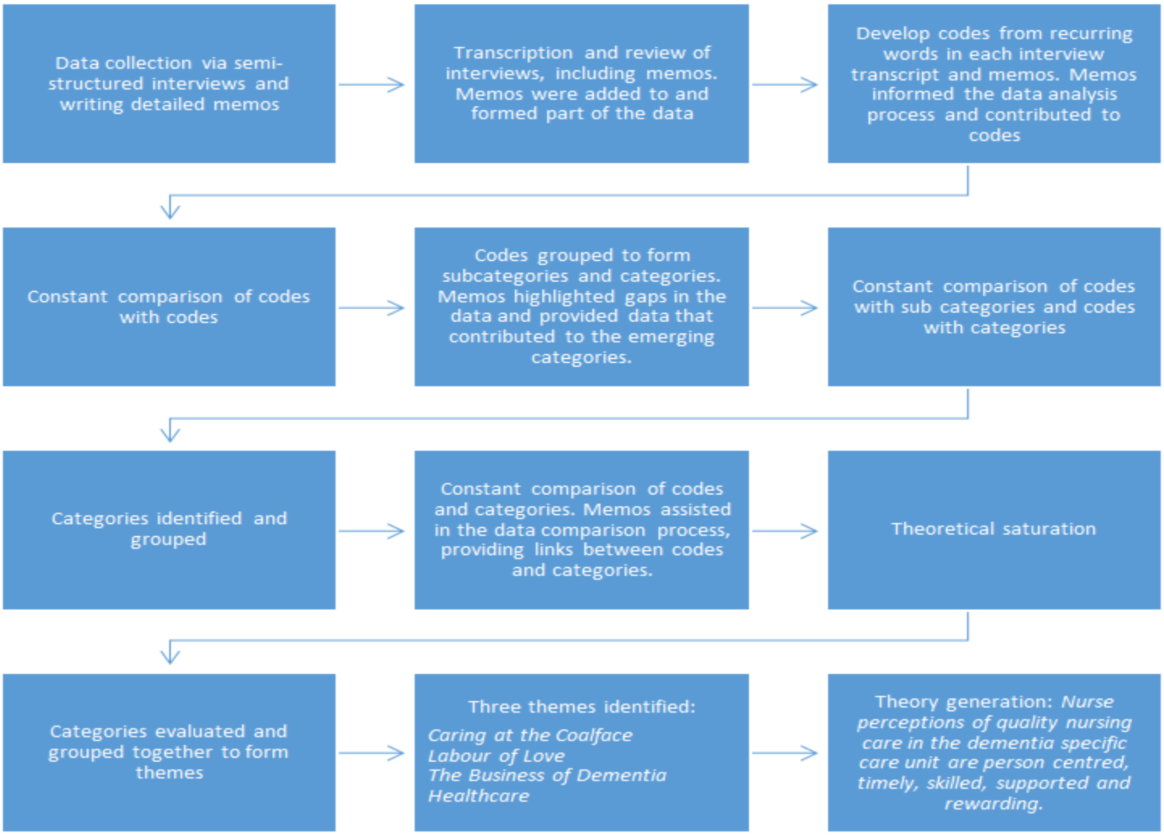


Figure 6. Constant comparison data analysis process used in this study. Adapted from “Constructivist grounded theory,” by B. G. Glaser, 2002, *Qualitative Social Research,(3)*3, p. 6.

Coding.

Coding is the initial phase of data analysis in Grounded Theory research that enables the researcher to transfer from the transcripts of data to the emerging theory by identifying as many ideas from the data as possible (Glaser, 2002). During coding, data is divided into as many categories as possible to identify the connection between the categories and the incidents identified by the participants (Charmaz, 2006). It has been defined as the process where data is named with a label that simultaneously categorises, summarises and accounts for each piece of data (Charmaz, 2003). Charmaz (2006) identified the importance of coding during data analysis in Grounded Theory research, stating that it forms the link between the collected data and the emerging theory. Three levels of coding in this form of research have been identified.

Level 1 coding occurs in the first stage of data analysis when codes develop word by word and line by line (Corbin & Strauss, 1990; Kendall, 1999). During this level of coding, the researcher highlights the exact individual participant's words and is encouraged to code the data in as many ways as possible and write additional memos that identify any further ideas that have emerged from the data (Glaser, 1978). Level 2 coding involves the researcher comparing codes and grouping them together to form categories (Glaser & Holton, 2004). This process involves the comparison of Level 1 data codes, grouping them together with similar codes and checking that each resultant code is mutually exclusive (Payne, 2007). Level 3 coding occurs when the researcher moves from data that is purely descriptive to a theoretical level. This involves the researcher identifying clear relationships between the Level 1 and 2 codes and categories that have evolved to form the substantive theory (Charmaz & Belgrave, 2007).

In the initial coding process following the first few interviews, I found that a large amount of data had been accumulated. Initially, I read each interview transcript multiple times and coded freely, considering anything and everything that might match information. Significant words, or series of words, were identified, and participant words and phrases in the transcripts that kept recurring were circled – for example, “tasks”, “jobs”, “hard work”, “pressure”, “the coalface”, “relentless”. Different-coloured texta pens were used to circle each word or phrase and comments were written in the margin of each transcript regarding how many times each word or phrase appeared. Additional memos were written regarding the context used by the participant, a code was allocated and the memos were stapled to the relevant transcripts. An example of such a memo is as follows:

(Memo 18 September 2015).

> *I am still seeing lots of emphasis on completing tasks in the interviews. They also talk time and time again about the speed in doing tasks and following designated schedules for care delivery. I have compared the codes for completing tasks with codes allocated to the new data relating to these discussions. These new codes are* pressure, workload, working at the coalface. *Together with* jobs, *this forms the subcategories* ticking things off a list *and* task-based care. *I have looked at all the data and the resultant codes and evaluated them for the things they have in common and made the category* task-based, scheduled care.

Task completion in the provision of quality nursing care seemed very important to all participants and they talked about it in many ways. As it was discussed often in the interviews using various terminologies, I allocated the code *jobs* and wrote it in the margins of the interview transcripts in pencil (Charmaz, 2014). Other codes identified from the transcripts included *patient behaviours, pressure, tasks, working at the coalface* and *documentation*. These codes were evaluated for commonality; grouped, separated, or renamed as necessary; and then combined to form the subcategories of *ticking things off a list* and *task-based care*. The subcategories were, in turn, evaluated for commonality, relevance and their relationship to other data, and combined to form the category *task-based, scheduled care*. This category contained information related to the many tasks participants said they completed every day. Participants discussed the hard, physical and demanding tasks that they perceived to be quality nursing care. This category was reviewed for relevance, combined with relevant data and evolved to form the first theme, Caring at the Coalface.

All the participants discussed how they interacted and engaged with patients in the Dementia Specific Care Unit. Some participants discussed their close and intimate relationships with patients and how important these relationships were to them. The words “joy”, “loving”, “caring”, “persistence”, “compassion” and “trust” were used often and in different contexts, conveying the importance of these relationships to the participants. These words were allocated the code *loving care*. Other codes identified were *job satisfaction*, *love, caring*, *persistence, compassion*, *engagement*, *humour, advocacy* and *empathy*. These codes captured both the information identified from the transcripts and the elements of quality nursing care that the participants considered essential. The following memo reflects these sentiments:

> (Memo 28 December 2015)
>
> *They talk about how much they love their patients, how they care for them as people, as individuals. They are highly cognisant of this. They talk about "going the extra mile" and "whatever it takes", even at the expense of their health and wellbeing. Even when they are exhausted, they come in every day because they want to care for their patients.*
>
> *It is amazing what they do for their patients – bringing in food they know the patients like, advocating for them against general practitioners and others when necessary and providing kindness and comfort for a dying patient and her daughter. This is extraordinary. The codes* compassion, love, caring *and* engagement *reflect their judgement, clinical experience and degree of empathy for their patients.*

The codes were grouped into the subcategories *therapeutic touch* and *the patient as an individual*, which reflected the relationships between the information and the data. They were then evaluated and redefined to form the categories of *warm, loving care* and *making a difference*. These categories clearly illustrated how the participants felt about their patients and the lengths that they would go to provide what they considered to be quality nursing care. Following evaluation of the relevance to, and links between this data, these categories evolved to form the second theme, Labour of Love.

Participants also repeatedly identified the impact of managerial directives and poor organisational culture on their ability to deliver what they perceived to be quality nursing care. Words and phrases used repeatedly included "audits", "poor culture", "no resources", "keep the costs down", "increasing documentation", "threats", "bullying behaviour", "high workloads" and "no training". These words and phrases were evaluated for relevance and commonality, grouped and allocated the codes *documentation completion*, *timeframes*, *management stress* and *cost containment*. The following memo reflects these sentiments:

> (Memo 12 January 2016)
>
> *They all talk about how they are treated by the facility managers. They repeatedly talk about excessive workloads, feeling abandoned, not valued and under constant threat of punishment for the smallest of errors. Some have been very upset, crying and trembling when they talk about it. They say there are no opportunities for dementia-specific training and development, and that the focus for managers is keeping costs down and generating income through documentation completion. Every participant says that these factors impact on their delivery of quality nursing care.*

These codes were assessed for commonality, and grouped together to form the subcategories *meeting managerial goals and expectations* and *cost management*. The subcategories were evaluated for relevance to the other data and refined to form the categories *keep your head down* and *stressed, diminished and devalued*. These categories contained detailed information regarding the stressors the participants believed impacted on their ability to deliver quality nursing care. These categories were again evaluated for relevance and commonality and evolved to form the third theme, The Business of Dementia Healthcare.

Saturation occurred when gathering more data on a category did not contribute any additional insights into the category (Charmaz, 2014). Saturation was not just about obtaining substantial amounts of data but was also related to the “richness” and depth of the data. The identified codes and categories accurately represented and reflected what the participants discussed and so became rich data. This rich data formed the basis for the robust theory: *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding.*

Confidentiality.

To maintain confidentiality, all participants were given pseudonyms (Glaser, 1992, 1998). As previously mentioned, participants consisted of one male and eight females. As there was capacity for the male participant to be identified by employees of the organisation and others, he was allocated a gender neutral name when reporting on the data.

Participants were encouraged not to use the names of other persons (including staff or residents) or the residential aged-care facility in the interviews to maintain confidentiality. The interviews were conducted in a private setting away from the workplace, and all conversations were treated as confidential. Participants were informed that the information obtained would be shared with others in the form of this dissertation, journal articles or presentations at conferences. All research information will be kept for five years following the completion of the research project and destroyed after this time.

Risk to participants.

It was anticipated that there was a low risk of harm to participants from their involvement in this research study. It was acknowledged that some participants could experience feelings of distress following their discussions during the interview. In order to address this, participants were provided with the information contained in the Participant Information Sheet regarding counselling services they could access, including the residential aged-care organisations' Employee Assistance Program and Lifeline. At the completion of the interview, I thanked each participant for their time and referred them to the Employee Assistance Program or Lifeline if they had experienced any distress as a result of the conversation. I also provided my mobile telephone number for participants if they wished to talk further.

Reflexivity, validity and rigour.

In qualitative research, the term *validity* refers to the accuracy with which the findings precisely reflect the data and the reliability of the data analysis process (Markey, 2018). For validity in Grounded Theory research, the categories and themes that emerge from the data must accurately reflect what the participants believe is their reality. Grounded Theory methodology requires the researcher to draw on their prior knowledge and experience, keeping an open mind to the emerging theory (Glaser, 1998). This prior knowledge forms sensitising concepts, which provides the researcher with the background information forming the inquiry into the research topic (Charmaz, 2006; Glaser, 1992, 1998).

I was conscious throughout the data analysis phase to not make my pre-existing concepts "fit" the data and drive the emergence of the substantive theory. Memos and reflection were utilised to ensure that data was truly identified by participants. I was also aware of the importance of the relationship between myself and the participants during each interview and how the identification of common meanings could influence the construction of the substantive theory.

Rigour in Grounded Theory is supported by the researcher's use of constant comparison to allow a core category or theme to emerge from the data (Glaser, 1998). Glaser (1998) considers rigour to be significant in Grounded Theory research as it provides information regarding the strength of the research design. He identified four criteria – work, relevance, fit and modifiability – which he felt confirmed validity and the presence of rigour in Grounded Theory studies (Glaser, 1998).

The first criterion – work – explains how participants vary their behaviour in attempts to explain the identified issue (Glaser, 1998). In this study, quality nursing care was primarily identified and interpreted by participants as the tasks they completed each and every day in the Dementia Specific Care Unit. Participants talked about the work they did and how they would adjust task completion, depending on external factors such as managerial directives and conflicting priorities.

The second criterion – relevance – relates to the fit between the emerging concepts and the issues identified by the participants, reflecting that the researcher has accurately identified and described what is happening in the participants' world (Gelling, 2015). In order to ensure that the issues identified by the participants were accurately identified, I allowed them to guide the inquiry process and explore the issues they considered important during each interview. When a participant identified an issue or concept during an interview, I also added it to the interview guide in the form of questions to be used in subsequent interviews (Charmaz, 2006). One example of this was that when task completion was identified by participants in the initial interviews, I added the question "what do you mean by the term task completion" to the interview guide for use in subsequent interviews. Modifying the interview guide in response to participant information validated the relevance and accuracy of this information and satisfied the criteria of relevance (Glaser, 1992, 1998).

The third criterion – fit – refers to the validity of the research and has been defined as "the accuracy of the information about the true variable being examined" (Cooney, 2011, p. 17). The emerging codes should "fit" the data instead of the reverse, reflecting the issues important to participants (Glaser, 1998). I was aware that there was potential for the participants' meaning of a word or relationship to be distorted when using isolated data following their interview. I ensured that I used the participants' own language during each level of coding to further Grounded Theory construction and enhance credibility of the research findings. The meanings of words or relationships identified by the participants were supported by excerpts from the interview data and clearly delineated for clarity, ensuring fit.

The final criterion – modifiability – refers to the modification of the theory as new data is collected and analysed and new ideas emerge (Bluff, 1997; B. Roberts, Walton, & Viechtbauer, 2006). The modification of the theory in the face of new data reflects the changes people experience every day and the value they attribute to these changes (Rose & Webb, 1998). I was aware that my thoughts and constructions relating to quality nursing care in the Dementia Specific Care Unit could affect the credibility and form of the emerging theory. As a result, I used memos and reflective practice to limit the influence of any pre-existing views on the substantive theory. The use of memos formed the basis of a self-monitoring tool, which enabled me to maintain both an open view and theoretical sensitivity, thereby satisfying the criteria of modifiability.

In this study, trustworthiness and credibility were achieved through checking the procedures and interpretation of the data with my supervisors (Chenitz & Swanson, 1986). I was also able to reflect on my experience in aged-care and dementia nursing in conjunction with reviewing the current literature as the research process evolved and categories and themes emerged (Richards, 2014). Rigour was attained by regularly checking with my three supervisors and providing details of the research process so it could be replicated by others to obtain consistent results. In conjunction with the memos, I recorded the major decisions I made regarding the direction of the research together with versions of the theory as it developed.

Reflexivity, as described by McGhee, Marland, and Atkinson (2007), is a continual process of critiquing gathered information and improving the researcher's self-awareness during the data analysis process. Urquhart (2007) considers it likely that a researcher would have some experience in a specific area that they have chosen to research. As a Registered Nurse of considerable clinical experience, including aged and dementia care, I could not avoid some knowledge and preconceptions regarding quality dementia nursing care. I considered that my experience of working within residential aged-care and dementia care informed the research process in the sense that all researchers bring pre-existing knowledge to their research.

Reflexivity occurred as I thought about the evolving theory, reflecting on myself as a researcher and my personal beliefs and how this influenced the emergence of the theory (Charmaz, 2014). I facilitated reflexivity through the writing of memos, then revisited and rewrote them as necessary as the categories emerged. I was careful to represent the nurses as experts in this area. I also reflected on the need to avoid preconceived ideas, which I found difficult early in the research process. I found that frequent reviewing of each memo assisted me to refocus on just what the participant had said and not what I thought they had said. This ability to appreciate the data from the participants' perspective became easier with time and with ongoing reflection of the interview and data.

Summary

This chapter has presented the Grounded Theory research process that was used in this study. It has explained the methods and processes that were applied including the origin, development and application of Grounded Theory methodology. The specific methods used in the conduct of this study – including data collection and analysis, which led to the identification of the three themes – were discussed. In this chapter the selection of the study sites, participant recruitment and selection, discussion regarding the research setting, and the ethics approval process were also presented. In addition, the interview, data coding and constant comparison analysis process were addressed. Chapter 4 presents the participants’ stories and the three identified themes: Caring at the Coalface, Labour of Love and The Business of Dementia Healthcare.

Chapter 4

The Participants’ Stories

Chapter 4 presents the rich personal accounts of the participants in response to the research topic: *Nurses’ perceptions of quality nursing care in the Dementia Specific Care Unit.* This chapter presents the three themes that emerged from the study and provides a discussion on the findings. Many of the participants’ responses presented in this chapter are confronting and surprising; however, all are the honest, considered reflections of nurses working and delivering what they perceive to be quality nursing care in a Dementia Specific Care Unit. Selected excerpts from each interview are presented in the next section to provide context.

The Dementia Specific Care Units

As mentioned previously, this study was conducted in two separate Dementia Specific Care Units located in two different residential aged-care facilities in Queensland. Every participant identified that the Dementia Specific Care Unit they worked in was not specifically built for dementia patients. Each of the two Dementia Specific Care Units had been adapted from existing buildings that had been used for equipment storage in 2000. Each unit was considerably smaller in size than the other buildings in the residential aged-care facility.

Both Dementia Specific Care Units had the same configuration, consisting of one long corridor painted pale grey with dark grey carpeting. Each of the units had two communal lounge and dining room spaces, one small television area with limited seating and individual patient rooms, which were kept locked when not in use. There were small windows (non-opening) in each patient’s room but no other windows in any of the communal areas to provide a view of the outside world. Entry and exit from each of the Dementia Specific Care Units was via a heavy, locked, coded access door, to which only staff and visitors had the code. In each unit there was one sliding door that opened out into the enclosed and secure garden areas bounded by high, solid metal fencing. Participants all confirmed that these doors in both the units were routinely kept locked by order of the facility manager, which prevented patient access to this area.

The Participants

The nine participants in this study came from diverse backgrounds and had a range of clinical nursing skills and life experiences. The participants' age, gender and years of work experience as a Registered Nurse was recorded to provide context for their responses. The average participant age was 46 years, the average years of working as a Registered Nurse was 22 years and the average interview length was 65 minutes. This information is provided in Table 3.

Table 3

Participant Demographics

Participant pseudonym	Age	Years working as a registered nurse	Gender	Facility	Length of interview
Lee	27 years	1 year	Male	1	60 mins
Daisy	34 years	2½ years	Female	2	70 mins
Dahil	36 years	5 years	Female	2	60 mins
Phyllis	42 years	20 years	Female	1	75 mins
Laura	53 years	28 years	Female	1	60 mins
Cheryl	54 years	33 years	Female	1	60 mins
Jane	55 years	35 years	Female	2	70 mins
Wendy	60 years	40 years	Female	2	75 mins
Mary	65 years	40 years	Female	2	60 mins

The Interviews

Semi-structured interviews were used in this study. They are congruent with Grounded Theory methodology, which enables the researcher to ask key questions in the same way and provides flexibility in the sequence of asking the interview questions (Glaser, 1978, 1992; Charmaz, 2006). The interview guide contained the key questions critical to the enquiry (see Appendix E) and was the primary data collection tool for this research. The questions within the interview guide were deliberately open-ended questions to allow the participants to respond in their own terms (Glaser, 1992).

The Themes

The three themes to emerge were:

Caring at the Coalface

In this theme, all the participants described quality nursing care in the Dementia Specific Care Unit as hard, heavy, task-based and scheduled care. They repeatedly mentioned the myriad of tasks they were assigned and were required to complete within designated timeframes. The words and phrases they used when discussing what they perceived to be quality nursing care included “hard work”, “relentless”, “pressure”, “working at the coalface”, “tasks” and “jobs”. All the participants aligned task-based care with their perceptions of quality nursing care, but some argued that quality nursing care was much more than this. All of them talked about the impact delivering this task-based, scheduled nursing care in the Dementia Specific Care Unit had on their physical and psychological health and wellbeing.

Labour of Love

This theme defined quality nursing care in relation to the participants’ relationships with patients in the Dementia Specific Care Unit. The participants mentioned the pleasure and satisfaction they received when they could reach the person “within the disease” and make a difference to their quality of life. They used the words “love”, “joy”, “care”, “patience”, “persistence” and “humour” when discussing how they cared for their patients. The participants also talked about the joy they felt when they were able to provide truly individualised care to patients and how they loved doing this. It was evident from this theme that the participants loved their patients and, despite the obstacles they faced every day, they did not want to work anywhere else. It was also obvious that, regardless of fatigue, physical assault and aggression from patients, they would present every day, just because they wanted to care for these patients.

The Business of Dementia Healthcare

In this theme all the participants mentioned the impact of managerial directives and the poor organisational culture on their ability to deliver what they perceived to be quality nursing care. They repeatedly used the words and phrases “audits”, “poor culture”, “no resources”, “high workloads”, “keep the costs down”, “increasing documentation” and “no training”. It was evident that the participants believed that these

Dementia Specific Care Units operated as a business that was not focused on caring for patients. The participants highlighted that there were few opportunities for dementia-specific training, which impacted on the way the nurses performed their caring duties.

As the interviews progressed, some aspects of the participants' conversations concerned me, which prompted me to delve deeper into what they had said in an effort to identify the essence of the issue. One example of this was when all the participants told me that patients were denied access to the outside garden areas as the one door leading to these areas was routinely kept locked by order of the facility manager. These conversations led me to probe more deeply into the existing literature on patient access into secured areas within Dementia Specific Care Units. It also allowed me to reflect on my own clinical experience working in other Dementia Specific Care Units, where patients had access to all areas, and what impact this had had on patient experience and wellbeing. The Business of Dementia Healthcare theme clearly illustrates that nurses perceive prescriptive management practices, including a lack of resources and the focus on scheduled task-based care, significantly inhibit their ability to provide what they consider is quality nursing care in the Dementia Specific Care Unit.

The three themes provide insight into the complexity and multidimensional reality of nurses' perceptions of delivering quality nursing care in the Dementia Specific Care Unit. Excerpts of participant interviews have also been provided to provide context. Within each of the three themes there are identified subthemes, which, again, provide context. Each of the themes and subthemes is discussed.

Theme 1: Caring at the Coalface.

The theme Caring at the Coalface recognises that the nurses consistently related task completion to their perceptions of quality nursing care. They used a number of terms to describe the tasks they completed, the most evocative being "working at the coalface". The term "coalface" resonated with me as a theme title as I listened to how the participants described what they did every day in the Dementia Specific Care Unit. Their descriptions evoked images of hard, back-breaking toil as they described what they did on each nursing shift. I was reminded of workers at the coalface of a mine – performing hard manual labour, heads down, backs bent, focused on just the task at hand. Researchers have previously used the term coalface to refer to where the work is "really done" in nursing, which is at the patient's bedside and includes shift work and excessive workloads as well as dealing with daily violent behaviour from patients and family members (Bogossion, Winters, Chang, & Tuckett, 2014; Lo et al., 2017) and the following subtheme emerged.

Subtheme: Unrelenting, hard work.

All the participants discussed how providing quality nursing care in the Dementia Specific Care Unit was hard, physical work. They used words and phrases such as “consistent”, “hard work”, “unrelenting” and “relentless”. They all identified that in order to provide what they perceived to be quality nursing care, they had to work at “the coalface”. The participants also linked quality nursing care to the process of task completion within designated timeframes and according to a predetermined schedule. They all stated the priority they gave to completing each task and “ticking things off a list”. They also said that to achieve this level of nursing care, they had to invest significant time and energy. The problem identified by all the participants was that doing this had a potential consequence on their own health and wellbeing.

One participant, Laura, said:

> *Every day, day after day, the same thing...unrelenting...consistent...never ending…just ticking things off a list.*

Laura discussed how fatigued she became due to the repetitiveness of the hard, manual task-based care every shift, and the impact this had on her family and her life in general. She talked about how tired she was every day and the insomnia, depression and continual joint and muscle pain she had experienced for over three years. Laura said she felt sure it was the result of the hard work involved in providing physical and emotional nursing care to patients in the Dementia Specific Care Unit day after day. Research has confirmed the adverse impact that unrelenting work-based pressure often has on the physical and psychological health of nurses (Bronkhurst, 2015; M. Cope, 2016; Digby et al., 2017; Yang, Lv, Zhou, Liu, & Mi, 2017).

Laura went on to discuss how sometimes she felt disheartened by the hard, physical task repetition, especially when she already felt tired. She also said that despite the hard, physical work, she experienced comfort and satisfaction when she delivered the care each patient needed, and this to her was quality nursing care. As Laura said:

> *Some days, I am tired...worked a double shift the day before or a late-early; it’s all I can do to get here...just get the job done…then I have to face the same things as yesterday...very stressful…but then I also feel so*

> *good at the end of the shift when the patients are happy, sitting together and smiling, no behaviours…just great. …that's quality care.*

Resilient nurses are increasingly likely to report delivering higher levels of nursing care and increased levels of patient engagement (Jennings et al., 2017). The literature confirms the importance of resilience for nurses caring for patients with dementia so that they can balance the emotional and physical challenges inherent in dementia nursing care (Benadé, Du Plessis, & Koen, 2017; Jennings et al., 2017; McPherson et al., 2015; Spenceley, Witcher, Hagen, Hall, & Kardolus-Wilson, 2017).

Attending to basic tasks was also identified as a priority by the participants and described as being back breaking and tiring. Basic care needs have been identified as the physical and psychological needs of an individual and include adequate nutrition and hydration, hygiene, comfort, rest, sleep and safety (Al Danaf et al., 2018; Beavis et al., 2018; Duffy et al., 2018; Røsvik et al., 2013). Phyllis, who had worked in the Dementia Specific Care Unit for over 20 years, discussed the importance she placed on meeting just the basic needs of patients, such as showering, toileting and ensuring each patient had sufficient nutrition and hydration. She stated very clearly that she considered that this was quality nursing care and represented being a good nurse. She also identified that these jobs required time and planning, and that to complete them, she needed to work at a fast pace. As Phyllis said:

> *I do the basics…feed them, wash them, give a drink when I can…I have to work fast as there is so much to do…that's quality nursing care…that means I am a good nurse.…Personal hygiene, I think that's quality…nutrition and hydration.*

Phyllis talked about how prioritising adequate nutrition and hydration was quality nursing care. Phyllis's comments confirmed that her focus was on meeting just these basic patient needs and that doing so made her feel as if she was doing a good job.

The participants all identified and discussed the frequent personal and physical attacks they experienced when completing patient care tasks in the Dementia Specific Care Unit, and how hard it was to provide quality nursing care as a result. One participant, Jane, said:

> *Challenging behaviours – screaming, spitting, being punched or slapped if you get too close when they are being showered…happens every day…day after day.*

The participants repeatedly used the words “spitting”, “kicking”, “punched”, “slapped” and “screaming”, and as they said these, again, I had the mental image of coalminers hard at work, head down, just trying to get the job done as noted in my memo.

Memo 20 December 2015.

> *This is hard work, head down every day, day after day is how she describes it. I have a mental picture of a donkey on a treadmill, round and round...a miner in a coalmine, covered in dust, head down, past caring about themselves, just focusing on getting through the job, no thought of anything else. It is interesting that even though this is obviously taking a toll on her, Laura would turn up every day just so she could care for these patients.*

Aggression, violent and destructive behaviour is one of the most challenging aspects of dementia nursing care (Jutkowitz et al., 2016; S. S. Khan, Ye, Taati, & Mihailidis, 2018). Close patient proximity and the completion of tasks have been identified as common contexts in which nurses experience high levels of verbal and physical abuse in the Dementia Specific Care Unit (Gillis et al., 2019; Lanza, 2016). As a result, physical and verbal aggression from patients during care task completion can be considered to be “part of the job” in dementia settings and so is often under-reported by nurses (Lanza, 2016; McFarlane & O’Connor, 2016; Ostaszkiewicz et al., 2015; Scales, Bailey, Middleton, & Schneider, 2017).

Continued exposure to verbal and physical aggression during care task completion can result in physical and emotional exhaustion, dehumanisation of interactions and withdrawal by nurses (Franchi, 2016; Stokes, 2017; Tible, Riese, Savaskan, & von Gunten, 2017). It appeared to me that the nurses in this study were resilient to the hard-labour component inherent in working in the Dementia Specific Care Unit. They appeared able to withstand long hours of physical manual labour and physical aggression from patients and still come to work day after day despite the impact on their health and wellbeing.

All the participants talked about the phenomena of “feeling pressured” to get the jobs done and complete required daily tasks. “Pressure” was a consistent term used by participants and the data analysis yielded rich descriptions of the pressure they said they experienced in the course of every day. They discussed the pressure to get everything done by the end of the shift, to hurry up and push things along, to complete each task as quickly as possible, and then move on to the next one. All the participants talked about experiencing two types of pressure: the pressure from the facility managers, who expected specific tasks to be completed within a designated timeframe; and the pressure they applied to themselves to provide more than this in order to meet *all* the needs of the patients given that this was their belief of what constituted quality nursing care. Again, these comments caused me to think of miners at the coalface, head down, chipping away, bone tired but trying to get it all done, as detailed in the following memo:

> Memo 4 January 2016.
>
> *They talk a lot about the need to get everything done, keep it moving, get it done. Again, I can see the miner at work in the coal mine, head down, chip, chip, get it done and move on. They say they have to hurry all the time, getting things done quickly is the priority for many of them. What impact does it have on them long term, and on the patient?*
>
> Also, as Phyllis said:
>
> *Go, go, go…get it all done, then move on to the next one and do it all over again…so much pressure, I have to get it all done* or else.

The theme Caring at the Coalface has provided a glimpse of the complex reality of delivering quality nursing care in the Dementia Specific Care Unit. It has explored the reality of scheduled task-based care, managing challenging patient behaviour every day, and the impact this has on the health and wellbeing of nurses working in the Dementia Specific Care Unit. This theme has also identified the ways in which nurses meet these challenges, often at the expense of their health and wellbeing.

The second theme, Labour of Love, explores the personal connection between the participants and patients in the Dementia Specific Care Unit.

Theme 2: Labour of Love.

All of the participants raised the significance of their relationships with the patients in the Dementia Specific Care Unit, and this emerged as the second theme (the largest) from the data, Labour of Love. Quality nursing care was described by six of the participants as a labour of love. These participants conveyed the personal reward and sense of engagement they received when interacting with their patients. They talked about the rewards they received from making a difference to patients and the joy they received from providing care for each patient. These participants repeatedly discussed their feelings of fulfilment and job satisfaction, which they said was more important than just completing tasks and, to them, was quality nursing care, and, consequently, a number of subthemes emerged:

Subtheme 1: What if that was me?

Six participants discussed repeatedly and in depth their feelings of compassion and empathy for their patients. They said that they made the time and effort to view each patient as an individual. Empathy can be described as the ability to understand another person's thoughts, feelings and a given situation from that person's perspective (Bickford et al., 2019; Pulsford, 2016; Pulsford et al., 2016). The nurse working in the Dementia Specific Care Unit who practises empathy is able to put themselves in the patient's situation and experience the situation from the patient's point of view, not their own, which then forms the basis for the ensuing nurse–patient relationship (Bickford et al., 2019).

Jane talked about how she felt empathy for patients in the Dementia Specific Care Unit every day, and how she viewed them as unique individuals. She discussed how upset she had been when she had observed staff entering a patient's room when the patient was asleep and start washing them without speaking to them. Jane talked at length about how distressing and frightening it must have been for the patient. She said she always tried to understand the situation from the patients' perspective, made the time to show the patients kindness and to treat them as individuals as this was, to her, quality nursing care. As she said:

> *I think, "What if that was me?" Everything is unfamiliar...this is not my home...you are not my family….treat them with kindness and as individuals…that to me is quality nursing care.*

Jane continued:

> *That person is an individual and what you have to look at is the whole person, and you can't compare that whole person with this whole person because their needs are completely different.…What is it that they need? What matters to them? That is quality nursing care.*

Jane was clearly able to look past the dementia disease and imagine what life was like for these patients. She also talked about treating each patient as she would like to be treated herself, or how she would like her family members to be treated, and how she considered that this was quality nursing care. Empathy is a crucial element in person-centred care for dementia patients and has been shown to enhance both nurse satisfaction and patient wellbeing (Brooker, 2008; Brown, Agronin, & Stein, 2019; Digby et al., 2016; Park, 2018). Research has also confirmed that nurses who use empathy when caring for patients with dementia have increased understanding of the disease and its progression, focus more on the patient experience, and provide patient-centred care (Camp & Camp, 2018; Fischer, Landeira-Fernandez, Sollero de Campos, & Mograbi, 2019; May, Edwards, & Brooker, 2009; Weaver, 2015).

Daisy discussed how she used empathy, compassion and patience during her interactions with patients by sitting with them and using therapeutic touch to engage with them as individuals. She spoke passionately during the interview, leaning forward in her chair and using animated hand gestures. She said that the essence of quality nursing care for her was the provision of the best care possible:

> *It doesn't matter to me what their behaviours are; I just hold out my hands, look them in the eyes and smile…sometimes it takes a while but I'm patient, most times they come and sit with me.…I think, "What would I like someone to do for me?"…provide the best care they can, that's what…that is quality nursing care.*

Laura spoke about how she considered being flexible in her practice was quality nursing care. She spoke about her usual practice of persistence and creativity:

> *If I can't get him to have a shower by the time they want, I just sit with him for a while, holding his hand. I'll say to him…I can see you laughing at me. Yes, I can, and before you know it, he is laughing, and I can get him into the shower.*

Laura identified that she was being more than just flexible in her work but was actively seeking to connect with the patient, engaging with them as an individual and trying to work with them instead of just making the patient do something she wanted them to do. This concept of quality nursing care was explored further by Daisy who discussed her ability to interact with a patient who refused his oral medications. She said that although she was under extreme pressure to complete tasks, she made time to adapt a routine activity to meet the needs of the patient, and that she considered this to be quality nursing care. She spoke about being flexible and "bending the rules" when necessary:

> *If he won't take his medication, that is okay.... I just come back later...sometimes you have to come back three or four times or try when they having a meal.... I know we are supposed to give the meds at the set time, but I would rather give it when the patient will take it, even if it is an*

> *hour late….I'm happy to bend the rules if I need to; it doesn't bother me, as long as he gets what he needs.*

Daisy confirmed that there were limitations when patients refused to have certain care. She spoke about recognising that there was only so much she could do at any one time but that she was willing to be flexible in her practice to provide the best possible patient care as this was what constituted quality nursing care.

Both Jane and Daisy identified and discussed at length the importance they placed on establishing an intimate and deep relationship between themselves and the individual patient and that they considered that this was quality nursing care. They talked about how these relationships were based in their knowledge of the patient as an individual and the respect they showed to each patient (Brooker, 2012; Fazio et al., 2018). As Daisy said:

> *I get out their pictures and sit with them…what is this?...what is your dog's name?…getting to know everything about their life is so important….I love it that when he sees me, he breaks into a big smile, holds out his hands so I sit down with him and just talk…to me that is quality care.*

Four participants discussed the importance they placed on communicating with their patients and how this could facilitate engagement and defuse difficult situations. Wendy spoke about how she loved spending time with each patient throughout the shift, speaking to them about their family or pets, and how she valued the smiles and hugs she received from patients. She said that this was quality nursing care:

> *Sitting with the patients, interacting with the patients, just talking to them, asking them about their families, pets, anything really that means something to them...the patients do like that little bit of staff interaction where it is fun....You can get the patients laughing…makes them forget why they are angry…stops their behaviours…this is quality nursing care.*

Dahil also discussed how she loved to sit with a patient and look through pictures of the patient's family and their pets and engage with them in conversations as she believed this was part of quality nursing care. She was cognisant of the importance of connecting each patient's past life with their current situation. Dahil also talked about how she had always had animals in her life and that this gave her an affinity with patients who had also owned animals and how this rapport also formed part of quality nursing care:

> *Also pet therapy, music therapy, and interactive activities where patients are encouraged to sing or play a musical instrument are quality.*

> *Sometimes just sitting with them, looking at photos.... I ask them, "Who is this?" "What a lovely dog."...and they tell me all about them. I have always had dogs…I know what it means, so I can relate to my patients…this is quality nursing care.*

I reflected on these conversations and how much these interactions seemed to mean to both Dahil and Wendy in the following memo:

> Memo 10 January 2016.
>
> *It is so great that they make the time to sit with patients and talk to them about their lives and what matters to them, especially when the unit is so busy and they are under such pressure. They both seem happy doing this and it seems to be just part of their day; not a job, not a chore, but something they enjoy. Wendy was obviously happy to share this with me. She was very animated, laughed out loud a few times, and smiled a lot. She said a number of times how much she enjoys it and this was quality nursing care.*

Laura also spoke about the importance she placed on communicating with patients as individuals and how this helped her to engage with them. This was obviously very important for her and she said this was quality nursing care. As she said:

> *Yes, the thing is we get to know them. We talk to the family, talk to other staff members to know more about the particular dementia patient – if they are aggressive at 5 or 6 o'clock; if the patient doesn't want to get up because they were used to working the night shift – so that the more you know, the more you can look after them.... Looking at the person…know them, really know them…communication is part of quality nursing care.*

Dahil also spoke about how she felt it was important to take every opportunity to engage with patients in the Dementia Specific Care Unit on an individual level as this constituted quality nursing care. The ability to link the patient's career, personality, past experiences, interests, culture and social status to the present was obviously important to her:

> *What was their job, things they used to do when they were younger...did they look after children, did they enjoy gardening…Take the time to engage with them on every level…that is quality nursing care.*

Wendy also made similar comments regarding the importance of engaging with each patient as part of quality nursing care, stating:

> *In an ideal world, my ideal world for dementia care would be never mind the bits of paper, go and sit and talk to the patient…just be with them…that's quality nursing care*

Wendy articulated that "being with" the patient and engaging with them constituted quality nursing care. The notion of "being with the patient" was clearly considered by her to be more important than the task of completing the organisational paperwork within a set timeframe. Again, her comments confirmed her intrinsic need to engage with the patient as an individual and meet their needs.

Jane also spoke about how important she felt it was to engage with patients as individuals and how she loved to spend time with them:

> *When the patient is happy, they are smiling…I love it.…I've noticed with some of the patients that they don't want to go to some carers...if you are good to them and they can see that, they take a likening to you, really. They are more relaxed even if they are doing some challenging behaviours....if they can relate to you as they see you as somebody nice...they will calm down....that's quality care right there*

Daisy talked about how she loved to spend time with individual patients in the Dementia Specific Care Unit, talking about things that happened that day and trying to involve the patients in conversations:

> *It's great when the same people are on shift... you're able to form a relationship…talk about the things they did…what happened today…that's quality nursing care.*
>
> *They have done so much in their lives…everything is important to them...their kids, pets, work.... I just want to know about what was important to them and try and connect…the connection is important and is quality nursing care.*

I found it quite interesting to listen to these participants talk about the importance they attached to understanding the patients' situations, knowing about the patients' life stories and engaging and connecting with their patients at every opportunity in the Dementia Specific Care Unit. They all talked with passion about how much they valued these interactions, and that they believed quality nursing care was represented by patient engagement.

Jane spoke about the closeness and love she felt for her patients and the tenderness and warmth she experienced as a result of spending time with them. She said it was important to her that she could interpret a patient's situation and feelings by looking into their eyes and noting their facial expressions and body movements. She talked about the delicate process of interpretation of cues from each patient and how this affected the delivery of quality nursing care. Jane identified that each patient’s facial expressions and behaviour indicated to her if they were fearful, anxious, happy or in pain, enabling her to intervene if necessary to relieve any discomfort. The ability to do so was obviously important for Jane and she said this was quality nursing care. As she said:

> *I love it…makes me feel warm all over and this intense feeling of joy…just spending time with them is everything.…I can pick up the cues and clues if there is anything wrong just by touching them and spending time with them…things that others might miss, I can pick up because I touch their hand, give them a hug, then I can do something about it. To me that is a big part of quality nursing care.*

I recorded my impressions of this conversation with Jane in the following memo.

Memo 13 March 2016

> *Jane seems so happy when she talked about spending time with her patients, laughing, smiling and very animated. I find it interesting that she can look beyond the surface and pick up the nuances of a patient’s behaviour and allow this to influence their care. Is this because of her clinical experience or life experience? Or is it something else? It seemed to me she genuinely enjoyed the company of these patients.*

L. Kelly and Adams (2018) explored the presence of engagement, satisfaction and joy in nurses. They consider that nurses work on a continuum that ranges from burnout to engagement, choosing to generate satisfaction and meaning from interactions with patients. Jane also shared during her interview how these patient interactions made her feel and identified that she felt she was able to make a difference to the individual patient by providing comfort for them:

> *I don’t need a box of roses…if I can make a difference to one patient then I have done a good job…makes me feel happy and warm inside…to me that is quality nursing care.*

Jane said she was realistic about the dementia disease process and was able to see the individual beyond the confusion and behaviours and focus on that person and this constituted quality nursing care. The influences on how nurses engage with dementia patients at various levels has been documented by Digby et al. (2016) who identified that dementia care is complex and requires nurses to engage with patients on different levels such as during the completion of everyday activities.

Research has confirmed that nurses' job satisfaction is based in the subjective feelings and the emotion they experience in performing their duties (Atwood & Hinshaw, 1977; Elipoulos, 2015; Geritsen et al., 2018; Hoan & Ngo, 2019; Liu, Aungsuroch, & Yunibhand, 2016; P. Spector, 1985). These findings echo the comments expressed by the participants in this Grounded Theory study, validating the importance the participants placed on patient engagement in the provision of quality nursing care.

The ability of the participants to provide therapeutic interactions and engage with patients as individuals within the confines of the Dementia Specific Care Unit was remarkable. Laura spoke about a situation where she was asked by a patient's family member to go beyond her usual role as a Registered Nurse to provide comfort and individualised care for a dying patient and the patient's daughter:

> *I saw her daughter come towards me and I thought, "Oh no, not now" and wondered if I could run away. We knew her mother was dying. Her daughter said, "My mum wants a glass of gin". I said, "Well, I don't have any, but there might be some in H Wing", and sent a carer over to see. They came back…no gin… so I got $20 from my purse and sent the carer to the bottle shop down the road to buy some….She comes back and Mum dies with a glass of gin in her hand and the daughter has one, too….I felt so good that she had her last wish granted….It's nothing special, just what I do…that's quality nursing care.*

Laura's actions, when she went far beyond what is commonly expected of a Registered Nurse and cared for both the patient and her daughter to the best of her ability, demonstrated what she considered to be quality nursing care. Laura talked about how she wanted to provide comfort and understanding, to meet a patient's needs in a kind and loving way. She said it was important to her to provide this care with tenderness and closeness. Making a difference to both the patient and her daughter was identified by Laura as being important, and she said it gave her great pleasure. She said it was a labour of love and was quality nursing care.

I was touched on a personal level and not a little amazed at hearing this story, recording my thoughts in the following memo:

> Memo 23 February 2016.
>
> *This is extraordinary. I cannot imagine the stress she must have been feeling when she was faced with this situation. It is interesting that she talked about wanting to run away, I can relate to that feeling. I could feel the tears well up in my eyes when I heard the story, how she did what she*

> *could, used her own money to buy gin and tried her hardest to make this woman's death as comfortable as possible for her and her daughter.*

Dahil spoke about how she felt it was important to build a rapport between herself and each patient and how she considered that this was part of quality nursing care. She described the reward she experienced reaching the person within the disease and said:

> *For me it's an achievement already when you are able to take care of a person who trusts you and then lets you take care of them even though to others they're very challenging but to you it's just okay…quality care.*
>
> *Staff sing along if we get the time. It's very enjoyable; they laugh, smiling, enjoying themselves…there's that connection, a rapport, that's quality nursing care.*

Dahil went on to discuss how she felt knowing information about individual patients and their lives could help her engage with them as individuals and that this was quality nursing care. She talked about her interaction with one patient and his wife:

> *I said to him, "Can you come with me to the dining room for dinner?" He said, "No." I remember that his wife had said he used to be a semi-professional piano player and loved an audience. So, I said to him, "They are all waiting for you"...He gets up, straightens his clothes, head up, shoulders back and walks to the dining room…I felt tears in my eyes.…That is making a difference to them as an individual; that is quality nursing care.*

During this conversation Dahil smiled broadly, clearly enjoying telling me about this interaction. She said that it made her feel happy and content that she had been able to reach this patient, connect his past with his present and make a difference to both him and his wife. She clearly articulated how important this was to her and repeatedly said how this was quality nursing care.

Wendy also spoke about how finding out information about an individual patient, who she had observed to walk endlessly up and down the Dementia Specific Care Unit corridor, helped her to engage with him. She became emotional during the interview, crying at times, and was self-deprecating regarding the impact of her actions on the patient. She described the reward she felt from making a personal connection and feeling needed by the patient and that she considered this was quality nursing care:

> *So I sat with him and said, "Why do you walk up and down the corridor?" He said, "Well, I am the supervisor for the biscuit factory and have to watch everything." I thought about what he must be experiencing back at*

> *that time, so I found my old lab coat from uni and brought it in for him. He wore it proudly and every shift I made sure we sat together to discuss how the shift at the factory had been, and I told him he was doing a great job. It is nothing, really…an old coat, but to him he is back there, in charge.…That is quality nursing care, connecting his past to now.*

Tak, Kedia, Tongumpun, and Hong (2015) and Jones et al. (2015) discuss how the engagement of individual dementia patients by nurses in various social activities that remind the patients of their previous life experiences can increase patients' quality of life and wellbeing. Wendy continued:

> *I asked him, "So how was your day at the factory? What happened? You are doing such a great job." Making that connection is important to me….quality nursing care.*

Wendy stated that her continued interactions with this patient were a source of great joy to her and gave her insight into the meaning of quality nursing care. She talked about how she reflected on the impact of such simple actions on the patient and her interpretation of the patient experience. My thoughts are reflected in the following memo:

> Memo 24 February 2016.
>
> *I am just blown away by this story. Her ability to see beyond a patient's behaviour that to someone else might be just annoying, or part of the dementia progression, was amazing. Her joy at these interactions was palpable. She cried, laughed, was very animated but humbled at the same time. I wonder if the joy she felt came from the actual interactions with this patient. Or is it from making a connection with the patient and making a difference? Or is it more?*

From the discussions with these six participants, there is no doubt that providing care for patients in the Dementia Specific Care Unit was difficult at times. Even in the face of adversity they were able to meet these challenges by going above and beyond what is commonly expected of a Registered Nurse. The importance of engaging with an individual with dementia in social relationships through strategies such as these was supported by Grandner, Li, Chang, Jungquist, and Porock (2017), who found that meaningful activities and social interactions assisted patients with dementia to relax.

Subtheme 2: Moments of happiness.

The use of humour during their interactions with patients was discussed by four participants. They all talked about the moments of satisfaction they experienced when they could make a patient happy, and how this in turn made them more understanding and patient in their ways. They all said that this was an important part of quality nursing care.

Jane commented that sharing humour with the patients was quality nursing care and said:

> *Smiles – if you see the smiles on the faces of those patients and they do react to your face….I love to make them smile…I tell them jokes, get them laughing…quality nursing care right there.*

Wendy also described the rich, sometimes humorous, experiences she had with patients when she engaged with them on an individual basis – some made her laugh and others stopped her in her tracks. She was very animated during this conversation, smiling broadly and occasionally bursting into laughter. She talked about the "personal high" she experienced from these interactions. She said she loved her patients and considered this was part of quality nursing care:

> *Bill always calls me "Sal", who was his wife….I was really pleased until a family member told me that he didn't get on with her and hadn't spoken to her in 20 years…. LOL.*
>
> *Sometimes they come out with things that just stop you in your tracks….One patient told me every day that he loved me, another that he knew I had taken all his money….You just never know what they are going to say…I just love it…this is part of quality nursing care.*

Subtheme 3: The normal everyday things.

Dahil discussed how she used the completion of day-to-day activities familiar to patients, such as washing-up and folding clothes, to engage with patients as individuals. She talked about how the modelling of appropriate behaviour when completing these daily activities within the Dementia Specific Care Unit could increase nurse–patient engagement and that she thought it was part of quality nursing care:

> *Quality care is encouraging patients to do the normal everyday things they were used to doing – washing the dishes, caring for a baby, gardening, folding clothes – and measuring the response from the person*

> *to determine if it is a quality activity for them….It makes them feel needed, engages them…this stuff is very important…quality care.*

De Boer et al. (2017) explored the impact of completing day-to-day activities, engagement in completion of the activity, and the level of social interaction during the activity for individuals living with dementia. It was evident that these participants valued both making each patient comfortable and content and the feelings of satisfaction they experienced as a result.

Subtheme 4: When they have no one, they have us.

As their dementia progresses, many patients will lose their legal capacity to make decisions, necessitating others to act on their behalf. Once admitted to a Dementia Specific Care Unit, the individual may be deprived of the opportunity to make decisions due to their loss of cognition. As a result, family members and nurses may advocate for and act to support the person with dementia in making decisions. Advocacy can be described as protecting individuals' and other people's rights, challenging barriers and discrimination and ensuring people are treated with respect by healthcare providers (Dixon, Laing, & Valentine, 2018; Gilster et al., 2018; Winterton et al., 2018).

Six of the participants talked about how advocating for their patients in the Dementia Specific Care Unit was sometimes difficult but, was for them, a labour of love. Mary talked about how she wanted to support patients within the Dementia Specific Care Unit when they could not speak for themselves and that this was quality nursing care:

> *When they have no one, they have us.... I just want to help if they can't speak for themselves…that's quality care….Difficult at times, I guess you could say it was a labour of love.*

Oliveira and Tariman (2017) explored the role of nurses as patient advocates, identifying that nurses needed to understand all aspects of advocacy to be effective patient advocates. Dahil talked about how she integrated advocacy into her daily interactions with patients in the Dementia Specific Care Unit as she loved doing it and considered it to be part of quality nursing care:

> *Advocacy is part of what we do every day...what they would do…quality nursing care…I love being able to do this for them…a labour of love; yes, that is what it is.*

Taylor, Marjanovic, Nolte, Pollitt, and Rubin (2015) explored the tendency for nurses to advocate within the dementia setting and found that it was a key element of quality nursing care. Pierre and Conley (2017) agree with these findings in addition to acknowledging that nurses can act on behalf of dementia patients to promote their rights and promote the delivery of quality nursing care. Wendy discussed how she considered advocacy to be much more than just a part of basic care:

> *It's so much more than the basics; it is what they would want if they could speak for themselves…that's quality nursing care.*

Mary spoke about the importance she attributed to knowing patients' rights and their preferences when advocating on their behalf and that she considered this to be quality nursing care:

> *I know Billy so well – what he likes to eat, when he likes to go to bed and get up – all his moods.…He should be able to have this now; his likes and preferences are important, too.…It's important to protect them, to know their likes, their right to be treated well and looked after as well as we can…that's quality nursing care.*

Dahil talked about how she focused on advocating for and protecting the rights of patients in the Dementia Specific Care Unit and that she considered this is quality nursing care:

> *It's also about keeping them safe, giving them the best care we can. They still have rights, even if they can't tell us what they want. We can use what we know about them, talk to the family and together a decision is made…that is quality nursing care.*

Advocacy clearly played a key part in the patient care Dahil provided and was important to her.

Three of the participants talked about how the relationships they had built with patients meant so much to them and how advocacy seemed like a natural extension to their care because they knew them so well. They said that knowing the patient well was quality nursing care. Laura said:

> *I rely on the relationship Lennie and I have.... I feel close to him and understand what he valued...it is part of providing quality care.*

Dahil discussed and confirmed the importance she attributed to the relationships between nurses and patients, and how this assisted her to advocate for patients in the Dementia Specific Care Unit because she loved doing it:

> *He smiles when he sees me, holds out his hand and seems happy to see me…it makes me feel happy that he trusts me. I love it…I want to do what I can to help him...do what he would want…quality care right there.*

Three of the nine participants also discussed the importance of patient advocacy in relation to supporting family members, making referrals to healthcare practitioners and assisting them to make healthcare decisions. Mary said that patient advocacy included supporting family members and was part of quality nursing care:

> *You have to support the family. They don't necessarily know how the system works, so it's up to us to help them…getting to other doctors, specialists…it is hard for them, but we are here. I think this is also part of quality nursing care as it affects the patient.*

Milte and McNaughton (2016) discuss how important it is for nurses to not just tolerate family member involvement in patient care but to embrace it and support family members at every opportunity. Brooker and Latham (2015) also discuss how nurses working with family members can facilitate patient communication and advocacy that results in improved patient outcomes. These findings are clearly reflected in the participants' comments and confirm the importance of advocacy as part of quality nursing care.

Dahil discussed how important it was for her to advocate for patients in the Dementia Specific Care Unit by assisting family members when other health issues arose and the patient required additional care. She said:

> *Sometimes a patient needs to see a specialist for another health issue and the family don't know how to do it, how the system works, what is best for the patient, so we help them...discuss options, help them organise transport...just part of the job…quality of care.*

Again, the issue of family members having to navigate a seemingly bewildering healthcare system was raised and it was clearly an important matter for Dahil. She spoke about how she considered it was part of her role to assist them and advocate for her patients and that this formed part of quality nursing care.

Subtheme 5: He still needs care.

Five of the participants discussed the apparent stigma exhibited by healthcare practitioners towards patients in the Dementia Specific Care Unit. The stigma associated with the diagnosis and management of dementia is well represented in the literature (Digby et al., 2016; Gove, Downs, Vernooij-Dassen, & Small, 2016; Herrmann et al., 2018; Mukadam & Livingstone, 2012; Walmsley & McCormack, 2016). These participants repeatedly discussed their frustration regarding the apparent lack of understanding of the dementia disease process by other healthcare practitioners. These included General Practitioners and ambulance officers who denied patients appropriate palliative care or assessment and treatment following falls or other injuries. A study by Mukaetova-Ladinska et al. (2019) found that discrimination by healthcare workers towards individuals living with dementia was widespread, thereby validating these participants' comments.

Mary discussed a situation where a patient had fallen in the Dementia Specific Care Unit and sustained a deep laceration to their head. The ambulance officer who attended the facility refused to transport the patient to hospital because they had dementia. Mary discussed the situation with the ambulance officer but to no avail. She said that she then contacted the facility manager for assistance and was successful in advocating for the patient to be transported to hospital for assessment and treatment. Mary became very emotional when discussing this occurrence, bursting into tears and shaking. She spoke about how ensuring the patient received the best of care was, for her, quality nursing care and a labour of love:

> *The ambos wouldn't even take him to hospital for care…just refused. "He's got dementia." "Yes he has, but he still needs care." That is quality nursing care.*

The following memo records my thoughts regarding her conversation:

Memo 14 February 2016.

> *What a dreadful situation. Mary was very upset when talking about this – crying, shaking, arms crossed, eyes closed at times. I wondered what would have happened to that patient if Mary had not been there to advocate for him? Would he have been treated? Why is this allowed to happen?*

Laura said she considered that other healthcare practitioners seemed to struggle with preserving the rights and personhood of dementia patients. She discussed how she advocated for a palliative care patient within the Dementia Specific Care Unit when they were refused analgesia by their General Practitioner because they had lost cognition and "didn't know if they had pain". Laura said that she felt honoured to have been able to help the patient and she loved doing it. She said this was part of quality nursing care. During this discussion she began to cry, saying:

> *She was palliative, in pain and the GP…he wouldn't even order her morphine…said he didn't want her to become addicted…she's dying!*
>
> *Said to me, "She doesn't know if she has pain…why does she need morphine?"*

Laura confirmed the challenges nurses in Dementia Specific Care Units faced from other healthcare providers whom they expected to support them in the delivery of appropriate care for patients. The comments from both these participants also confirmed for me that these were likely not to have been isolated incidents in the Dementia Specific Care Unit.

Subtheme 6: I know she likes the pink dress.

The opportunity for patients to have involvement in decision-making was important for four of the participants. They discussed how they regularly advocated for each patient to make the decisions they could make for themselves because they loved doing it and they considered this was quality nursing care. They talked about how they loved selecting clothes the patient wanted to wear because this meant so much to the patient. These four participants spoke about how important it was to them that they could ensure patient decisions were respected and communicated to other staff. As Daisy said:

> *It might take longer, but I just take the time to ask them what they want to wear…sometimes they can say…other times they just smile when they are wearing something, so I know they like it…this is important – to them and to me – quality nursing care.*

In relation to another patient, Laura shared:

> *I don't make her have a shower when it suits the nurses…When she is going to the toilet or to the bathroom to comb her hair, I ask her then if she would like a shower…most of the time she does.*

Jane also spoke about how she loved to advocate for patients by making the time to involve patients in decision-making. She identified that she loved doing this and it was quality nursing care:

> *If I am working a late shift, I make the time to ask him what he wants to wear the next day and get out the clothes for the next morning and leave them over a chair for the nurse the next day…this is important for him, he likes to be well dressed.*

Jane also talked about how she made the effort to know what a patient liked to wear and advocate for her with other staff to ensure she was dressed in her favourite clothes when possible. She said this was an act of love and quality nursing care:

> *I know she likes the pink dress and matching cardigan, so I make sure she is asked and wears it if I can…to me it's an act of love…quality nursing care.*

Research conducted by Fetherstonhaugh, Tarzia, Bauer, Nay, and Beattie (2016), found that respect exhibited by nurses for a person's ability to participate in decision-making is central to the delivery of quality nursing care. Mariani, Vernooij-Dassen, Koopmans, Engels, and Chattat (2017) support these findings, adding that patient advocacy and involving patients in decision-making also promoted social health and wellbeing.

Subtheme 7: The patients are more important.

Three of the participants identified methods they used to advocate for themselves and their patients with facility management to optimise the safety and effectiveness of patient care. Successful strategies identified by these participants included discussion and negotiation with the facility manager for additional time to complete assigned tasks. They also frequently requested additional staff each shift, especially overnight when patient wandering and adverse behaviours escalated. These participants identified that these strategies were not always successful and discussed how they often felt frustrated at the response from facility management to their requests. Despite their requests being refused, they continued to advocate for their patients because they said they loved them and it was part of quality nursing care. As Mary said:

> *Never mind the bits of paper, go and sit and talk to the patient.... I just tell the manager that the patients are more important…sometimes it works, sometimes it doesn't…I just keep trying because it is important for the patients to have enough people to look after them at night. I think this is part of quality nursing care.*

The Labour of Love theme has explored the connection between participants and patients in the Dementia Specific Care Unit, which included the impact of nurse advocacy and flexible practice on the delivery of quality nursing care. It has also explored the intention and commitment of nurses to care for each patient by consciously engaging with and forming a meaningful relationship with them or to consciously disconnect with patients.

Theme three, The Business of Dementia Healthcare, explores the impact on quality nursing care when residential aged-care facilities and Dementia Specific Care Units use strategies common in a business model in order to enhance efficiency and rationalise costs.

Theme 3: The Business of Dementia Healthcare.

The third theme, The Business of Dementia Healthcare, emerged when all the participants identified and discussed the adverse impact of a number of organisational practices on their ability to deliver what they believed was quality nursing care. These factors included a poor organisation culture, inadequate communication, hostile management practices, an adherence to strict, scheduled patient care routines, ever-increasing workloads, inadequate staffing levels and mix, and lack of dementia-specific training. All participants said it was very difficult to provide what they considered to be quality nursing care when confronted by these constraints. As identified by Downs and Collins (2015), ineffective communication, high facility management expectations and an inappropriate staff skill mix impact on the level of quality care nurses can provide.

All participants identified that the high workloads and the continued lack of resources made it particularly difficult to meet more than just basic patient needs. Aligned to the participants’ statements, further studies (V. Cope & Murray, 2017; Zarowitz, Resnick, & Ouslander, 2018) indicate that aged-care facility managers who focus on task completion can promote a culture of staff disempowerment and disengagement that impedes the delivery of quality nursing care. Research has confirmed that standardised organisational routines, lack of resources and high staff workloads combine to inhibit patient care delivery within the Dementia Specific Care Unit (Bains, Singh, Kaur, & Singh, 2018; Bassal, Czellar, Kaiser, & Dan-Glauser, 2016; Gilbert et al., 2019; Hazelhof et al., 2016; P. Hunter, Hadjistavropoulos, & Kaasalainen, 2016; Kilroy, Flood, Bosak, & Chênevert, 2016; Nuñez, & Chana-Cuevas, 2018; Woodhead et al., 2016). These findings are certainly reflected in the stories and experiences of the nurses who participated in this study.

All the participants identified management-imposed stress from ever-increasing workloads and documentation was one of the key issues for them each day. They stated that the increased stress they worked under had a profound impact on their ability to cope with and provide quality nursing care in the Dementia Specific Care Unit. Daisy discussed how facility managers seemed to her to increase workloads every week by increasing the documentation she had to complete in order to generate more money for the facility. She also talked at length about the increasing complexity of documentation evident in recent months, which had impacted on her ability to complete her workload during the shift, as it took more of her time. She said:

> *We used to have to complete six patient care plans a month, but now it is up to 12…and they keep changing the forms…more information needed, put it in a different place…if you don't you are in trouble…no time for the patients…I can't give them quality nursing care.*
>
> *I just feel overwhelmed sometimes…. I can't spend time with my patients, just no time to do anything but paperwork…more money for them…it's the bottom line every time.*

Measurement of what nurses do every day when delivering patient care is common practice in healthcare organisations, typically through the completion of audits or other monitoring processes (Alghamdi, 2016; Berkowitz, 2016; Petrucci, Calandro, Tresulti, Baldacchini, & Lancia, 2015; Reynolds, 2017). Six of the participants specifically discussed how they were pressured by managers to complete patient care plans and audits in preference to other duties. The completion of this documentation was, to them, clearly linked to generating government funding and facility revenue. They also said that it was clear that the facility managers used completed documentation to confirm the delivery of nursing care and so generate even more income for the organisation. These participants said they were sceptical that the completion of the audits measured the quality of nursing care received by the patients in the Dementia Specific Care Unit. Whilst they understood the need for access to funding to support the facility, they discussed how this was in conflict with their desire to provide what they considered to be quality nursing care in the Dementia Specific Care Unit. As Mary said:

> *Care plans...documentation that's what we do…day to day…paperwork every day…generate that money…that's not quality nursing care.*

The importance placed on the bureaucratic management model that is characterised by documentation completion within designated timeframes was explored by Holahan, Jacquart, and Moos (2019), who found that forced documentation completion to generate income was directly linked to low nurse satisfaction and poor nursing care. Bach and Ellis (2018) question the validity of documentation completion in the delivery of nursing care, finding that managers who force staff to complete documentation to generate income adversely impacts on patient care delivery.

Cheryl talked about the pressure she had experienced from facility managers to complete clinical audits each shift. She said that these audits involved assessing aspects of individual dementia patients' care such as weight, infection and fall rates, then documenting the results:

> *They look at all the statistics for falls, infections, weights and then just overall satisfaction of family as an indicator of care...more and more every shift…get them done…or else…have to keep that money rolling in for the bosses.…I can't give the patients quality nursing care as I have to cross the t's and dot the i's.*

Dahil spoke about having to complete patient audits every shift as part of her daily routine. She said she was aware of the dichotomy between what facility managers considered to be care and what quality nursing care meant to her:

> *We do all the audits every day, day after day for funding but what about the care we give? The audits don't measure that, what I think is quality care…they just don't do it.*

The use of evidence-based evaluation of care for dementia patients in residential aged-care facilities is linked to government-funding initiatives and is underpinned by the assumption that if care is not documented, it did not occur (O'Connor et al., 2018). Despite the completion of patient care audits in Dementia Specific Care Units, there remains uncertainty if this information accurately reflects the quality of nursing care received by dementia patients (Tropea, LoGiudice, Liew, Gorelik, & Brand, 2017).

Laura also spoke about having to complete patient audits every shift in order to secure funding for the organisation. She said that she valued patient care over completing the audits:

> *I don't mind doing audits if they measure care but not just for funding...patient care is what I am here for…but I can't because I have to get that money for the bosses.*

All the participants discussed that they were aware of management expectations and the prioritisation of the completion of tasks, including audits and documentation, over patient care delivery. Laura went on to say that, despite being aware of these expectations, she chose to provide nursing care that was based on the needs of the individual patient at the time they needed it because that was quality nursing care:

> *They tell us...showers all done by 10 am, then care plans, then audits...quality care is not just filling in forms.... I'll get to them after I look after the patients...they are more important…that's quality nursing care.*

Sykes, Nipah, Kalra, and Green (2018) conducted a systematic review into whether audit completion by nurses resulted in improved care of dementia patients. Findings from this review indicated that due to limitations in the audit tools themselves, and the often sporadic completion of audits by nurses, it cannot conclusively be demonstrated that the completion of audits is of benefit to the care delivered to dementia patients.

Subtheme 1: Stressed, diminished and devalued.

All the participants discussed the ever-present threat of punitive action by managers for even the smallest of errors, making them feel stressed, diminished and devalued and preventing them from providing quality nursing care. Research has confirmed the use of punishment by managers to staff to enforce the social norm of the work environment and change employee behaviour (de Kwaadsteniet, Kiyonari, Molenmaker, & van Dijk, 2019; Killett et al., 2016; Kinley & Ben-Hur, 2015; Kras, Dmello, Meyer, Butterfield, & Rudes, 2019). Findings from these studies confirm there are often significant ramifications for staff that do not follow management directives. Woods, Phibbs, and Severinsen (2017) agree, adding that the implied punitive threat of disciplinary action and continual cost-cutting measures from managers results in increased staff stress, high nurse attrition rates and substandard nursing care.

Five of the participants in this study identified and discussed how they felt bullied and discriminated against by managers, with the ever-present threat of punitive action if they requested additional physical and staff resources to complete tasks within the Dementia Specific Care Unit. The implications of negative workplace behaviour on nursing practice has been explored by researchers, with reports that bullying, intimidation and humiliation from managers results in job dissatisfaction and poor standards of patient care (Hampton, Tharp, Barrie, & Kay Rayens, 2019; Lindy & Schaefer, 2010). As Jane said:

> *Staff need affirmation that they believe...not "you've done a great job". They don't believe that because on the other hand, at the other side of it, "if you don't do this, there may be disciplinary procedures against you."…They bully us and threaten us…at one time one of the letters came in.... I think there were five in a row who didn't do this…disciplinary*

> *procedures…how are you supposed to deliver quality care then?…. It is so intimidating.*

Feeling silenced, punished and disillusioned by managers is common in the socio-political context in which nurses practise, and this situation appears to have prevailed in the Dementia Specific Care Units that were the settings for this study (Kay, Evans, & Glass, 2015; Yarbrough & Davis, 2019).

These participants' comments clearly indicated that there was a widespread perception of a lack of managerial support for the work undertaken by the nurses in these units. It was apparent that all the participants felt they had no choice but to abide by the managerial directives in order to avoid retribution. Lawrence, Fossey, Ballard, Ferreira, and Murray (2016) explored the impact of poor managerial support and behaviour on the provision of nursing care. Findings from their research indicate that contextual factors including staff morale, feelings of being valued and interpersonal relationships are essential in the provision of long-term quality patient care.

Subtheme 2: Why can't you get it all done?

Four of the participants discussed their perceptions that facility managers had little understanding of the needs of patients within the Dementia Specific Care Unit as patients were "hidden behind doors" and often appeared physically well. As Cheryl said:

> *They don't even know what we do...their focus is on documentation to make money…not on the needs of our patients.*

Mary agreed that there appeared to be little understanding by managers of patient acuity in the Dementia Specific Care Unit and this meant she could not provide quality nursing care:

> *Just because they walk around doesn't mean they can do anything for themselves... I don't think management get it…. They are not the same as the other patients…. I can't give them quality nursing care.*

These participants also discussed how this was in contrast with patients in the other areas of the facility who might have multiple co-morbidities impacting on their mobility and functionality and were considered by management to have higher acuity. The validity of these perceptions was confirmed by O'Connor et al. (2018), who found that stigma and discrimination of dementia patients by facility managers was widespread globally.

Jane spoke about how it appeared to her that the needs of the patients within the Dementia Specific Care Unit were deemed by managers to be less important than those of other patients in the facility:

> *They don't see them as high-care patients...no additional staff, even when there is chaos…She said to me, "You only have 12 patients in there…why do you need more staff?" "Why can't you get it all done?"...I just can't give them quality nursing care.*

Subtheme 3: How do I do that?

The issue of ever-increasing workloads arose frequently in the participants' discussions, particularly the supervision of other staff and the impact of poor staff numbers and skill mix on nursing care delivery. Three of the participants identified and discussed how they struggled to complete tasks with insufficient staff numbers and the inappropriate staff number and skill mix provided by management. As Phyllis said:

> *I look at the staff on the shift and go, "Oh no, we won't get it all done."...I have to work hard and fast, or I can't get it all done – watch the care staff, watch the ENs – I don't have time for quality nursing care.…How am I supposed to do it all?*

The importance of these participants' comments are supported by C. Duffield, Roche, and Merrick (2006), who found that Enrolled Nurses and care staff are valued members of the healthcare team but require close supervision, which significantly adds to the Registered Nurse's workload. Other findings from this research included that whilst skill mix did not impact on basic care provision (showers, toileting), it significantly impacted on task completion and the provision of complex nursing care. The need for residential aged-care organisations to provide safe nursing care within budgetary restrictions continues to be a challenge in the future for an ageing population and increased dementia diagnoses.

All of the participants identified that they faced conflicting priorities every day and that as a result, they could not provide what they considered to be quality nursing care. They talked in detail about the frequent interruptions they experience every day such as answering telephone calls, talking to relatives, arranging medical officers' visits and managing patient falls and injuries, often simultaneously. Seven of the participants spoke about how the lack of clerical support in the Dementia Specific Care Unit meant that they also had to undertake these duties, further adding to their workloads, which prevented them from delivering quality nursing care.

All participants discussed the pressure they were under from facility managers to complete complex and time-consuming tasks for patients both within and outside the Dementia Specific Care Unit, often with just two staff for 50 or more patients. They said this stopped them from being able to deliver quality nursing care. Two of the participants spoke about how, at the commencement of their shift, they would often be told by the facility managers that they were required to care for additional patients outside of the Dementia Specific Care Unit and complete tasks including patient audits, care plans and evaluations in addition to their normal activities during the shift. Both participants discussed the anxiety they experienced as a result of these directives. They talked about how they frequently experienced nausea, headaches and abdominal distress as a direct result of the often-escalating internal pressure they felt to complete all of these tasks within the designated timeframe. As Phyllis said:

> *Someone outside in B Wing is off sick, no replacement staff, so I have to give her meds as well as the ones in the unit…all due at the same time…how do I do that?.... I feel sick all the time, terrible headaches every shift.*

Wendy identified and discussed the conflicting priorities that she felt arose when trying to meet the needs of patients inside and outside the Dementia Specific Care Unit because of insufficient staff numbers. She said she was unable to deliver quality nursing case as a result:

> *Patients in the wing outside complaining they haven't got their sleeping pill…I'm dealing with an aggro patient in the unit…no staff around…. Where is the priority?*
>
> *It's just go, go, go…hit the floor running…flat out going from one area to another…can't keep tabs on the patients in the unit as well as being outside because someone is off sick and hasn't been replaced…so stressed…no meal break…late off…. I can't give my patients quality nursing care.*

Lee discussed how he felt it was difficult to administer medication in other facility areas whilst completing other duties within the Dementia Specific Care Unit and this was not quality nursing care:

> *You're thinking while you're out there giving pills, "Please don't let anything happen in that unit" because you've got to run back.*
>
> *"Their medications are ready to be done; please don't have a fall, please don't do this, I've got so much to do."*

The importance of a compassionate work environment in aged-care facilities was explored by Sjögren, Lindkvist, Sandman, Zingmark, and Edvardsson (2015). The findings from their cross-sectional quantitative research confirm that a supportive work climate results in higher levels of person-centred care and reduces staff stress, which validates these participants' comments.

Subtheme 4: Keeping the unit calm.

Daisy discussed the pressure she experienced from the facility management to quickly administer sedation and other medications to patients in the Dementia Specific Care Unit who had frequent challenging behaviours to "keep the unit calm". She said this was not quality nursing care:

> *We cannot just go straight to the tablet even though management says, "Give this first, then that, then this." This is not quality nursing care…I won't do it, I look at the patient and just give something if he needs it.…What does he need?...not just give him everything ordered, just if he needs it.*

Daisy said that this management directive was reinforced by an organisation-based designated medication administration schedule, and there was the perceived threat of punitive action by facility management if it was not complied with. Antipsychotic medications have limited efficacy and have significant, common side effects, including falls and increased mortality, yet these medications are frequently, and often routinely, administered to patients in Dementia Specific Care Units to control adverse behaviours (Backhouse, Killett, Penhale, Burns, & Gray, 2014; Maust et al., 2015).

Bangash et al. (2017) also discuss the association between antipsychotics, sedation and adverse patient outcomes in dementia settings and identified a number of possible outcomes from excessive medication use, including increased risk of cardiovascular events, falls and death. These findings are supported by Reese, Thiel, and Cocker (2016), who recommend that the smallest effective dose of antipsychotic medications be given for the shortest possible time to reduce the likelihood of adverse effects for dementia patients. H. Shin et al. (2016) explored the incidence of antipsychotic medication administration in Dementia Specific Care Units and found that high rates of medication administration and the long-term use of concurrent antipsychotic and dementia medications was common practice. Further research has confirmed that the scheduled administration of antipsychotic medications is common practice in Dementia Specific Care Units and often results in poor patient outcomes, including increased morbidity and mortality (Allers et al., 2017; Backhouse, 2014; Backhouse, Killett, Penhale, & Gray, 2016).

Subtheme 5: I just watch the others and learn.

During the interviews, all the participants were asked if they received appropriate and sufficient dementia-specific training or education in order to develop and maintain their skills and be able to provide quality dementia nursing care. All of them identified that dementia-specific education was sparse in the Dementia Specific Care Units. Four of the participants talked about how they usually learnt dementia care from watching other staff, or by trial and error, because there were no dementia-specific training sessions available. They identified that progression through experience, good and bad, was how their learning occurred and that this was not conducive to the provision of quality nursing care. As Lee said:

> *I don't know enough about dementia care, so I just watch the others and learn; that's not quality care…but it's all I have got.*

In the absence of structured staff education and managerial support, the practice of just following other staff actions may result in the continuance of poor work practices and substandard levels of nursing care delivery (Testad et al., 2016; Y. Wang, Xiao, Ullah, He, & De Bellis, 2017).

Daisy expressed her frustration regarding in-service sessions provided by facility management that focused on the preparation of thickened fluids. She said that these education sessions were provided for free by the manufacturer of this product, so staff attendance was mandated by facility managers. Daisy talked about her frustration at the lack of practical in-service sessions regarding managing dementia behaviours and that this lack of education led to poor nursing care. Her comments centred on the lack of skill development sessions, which she felt would enable nurses to do their job correctly and provide what she considered to be quality nursing care:

> *Education? Pretty few and far between to my mind…what the management need to provide for funding not really what we need to know…without dementia training, how can we deliver quality nursing care? You know what? We can't.*
>
> *Thickened fluids. What about dementia care? That's what we want to know, not how to thicken water…we need dementia-specific training for everyone; that would be quality care.*

All the participants also confirmed that there was no requirement for formal training or education for nurses to work in the Dementia Specific Care Unit. They all said that they would like to have structured education sessions and be supported in achieving dementia postgraduate qualifications to assist them to give quality nursing care. Research in this field encourages education, and the support of nurses by management to manage the behavioural changes associated with the progression of dementia leads to improved levels of nursing care (Phillipson, Goodenough, Reis, & Fleming, 2016; Xu, Wang, Wimo, Fratiglioni, & Qiu, 2017). Further research into this topic would be helpful in exploring these issues further.

Subtheme 6: Nowhere to go.

The impact of the physical environment of the Dementia Specific Care Unit on the delivery of quality nursing care was identified by all the participants. As discussed previously, all the participants identified that the two Dementia Specific Care Units in this study were not purpose built but were modified from pre-existing buildings within each residential aged-care facility. They said that each building had been used for the storage of equipment and therefore was not designed for patient use. Six of the participants discussed the poor physical layout of the Dementia Specific Care Units and the impact they thought this had on patients. They spoke about how they had no control over factors such as the doors to the outside areas being continually locked, the style of furniture, and the size of the Dementia Specific Care Unit. As Phyllis said:

> *They go up the corridor, hit the door, then back down the same corridor…nowhere to go.*
>
> *The door to the outside areas is always closed and locked…they can't get outside. We are told, "Don't open the doors, don't let them out." I have no control over this.*

Mary spoke about how she considered that the layout of the Dementia Specific Care Unit was austere and not patient friendly. She specifically talked about how it appeared to her to be cold and not homelike and did not facilitate the delivery of quality nursing care:

> *Cold and unfriendly…not like a home at all…no wonder they become more confused.*

> *The furniture is cold…metal chairs because of patient soiling…metal tables to make it easier to clean…no comfy armchairs…this is not quality nursing care.*

Lee also talked about how the Dementia Specific Care Unit had a poor layout that impacted on patients’ behaviours, how it was not like a home, and how it appeared cold to him. Lee said it was not quality nursing care:

> *Looking at that unit, how that unit is so cold and unhomelike. How can this be quality nursing care? It’s not.*
>
> *The layout of the unit – that’s a frustration, especially with patients wanting to go through that access door; it’s one of the behavioural issues.*

Jane discussed how she found the Dementia Specific Care Unit small and that the furnishings were not appropriate for the patients. She also talked about the response she received from the facility manager when she asked if the furnishings could be changed to make it more comfortable for patients as she considered this was part of quality nursing care:

> *I’d love to see dementia units more homely, more friendly, more space. I find that the unit is particularly small – it’s literally you walk down one corridor you come back up the same corridor, and it is so unfriendly.*
>
> *[Management] told me that there is no money to change things – “It’s not as if they even know, so why spend the money?” – called me in, told me to focus on my job and not try to change the unit…“don’t rock the boat”…that’s not quality nursing care.*

S. Lee et al. (2015) examined the impact of the physical environment of Dementia Specific Care Units on the health and behaviours of patients and found that restricted space and unfriendly environments result in increased adverse patient behaviours and poor patient outcomes. These findings have been supported by Woodbridge et al. (2016), who found that the modification of the physical environment in Dementia Specific Care Units by management can support positive interaction between patients and staff. Nordin, McKee, Wijk, and Elf (2017) also confirm the importance of dementia patients having access to outside areas to improve activity, orientation and overall feelings of wellbeing. The importance of these findings is supported by the research literature (Campo & Chaudhury, 2012; Chaudhury, Cooke, Cowie, & Razaghi, 2018; Chaudhury, Hung, & Badger, 2013; Chaudhury & Cooke, 2014; Hung & Chaudhury, 2011; Schwarz, Chaudhury, & Tofle, 2004).

Laura spoke about her feelings of frustration at directives from facility managers to restrict patient access to all areas of what was essentially a small, confined space because they could not be observed by the small number of nurses on each shift. She said this was not quality nursing care. She also identified and discussed how she had been asked to account for her actions by the facility manager when she opened the doors into the garden for patients. Laura talked about how she continued to open the doors for patients, regardless of the consequences for herself, as she felt it was the right thing to do and was part of quality nursing care:

> *I open the doors, let them out…they need to be able to go out…that's quality nursing care…I came in the next day and had a call from the boss…come and see me…"Why did you open the doors? The patients need to stay in the unit." Letting them out is quality nursing care, not keeping them locked inside all the time.*

The ability of patients to access all areas of the Dementia Specific Care Unit was important to Laura and clearly reflected what she considered to be quality nursing care, comments that are also validated by the literature (Chaudhury, Hung, Rust, & Wu, 2017).

Dahil spoke about how she was instrumental in negotiating with facility management to have a resident cat within the Dementia Specific Care Unit. She said this met the psycho-social needs of patients and was quality nursing care. She talked about how obtaining a resident cat was a small thing and easily fixed by management but it resulted in a long and exhaustive battle between herself and the facility manager:

> *I asked at every meeting, "Why can't we have a cat? Some patients have had cats in the past, it would be good for them"…that would be quality nursing care. I was told, "No, who will feed it, clean up after it?"*
>
> *In the end I wrote to the senior management in Brisbane and asked for their help to get a cat to provide comfort for the patients. They said yes. I asked staff if they would put in for food and all of them did.*

It was evident that in the face of adversity, these participants endeavoured to provide a caring and comfortable environment for patients, which was characterised by kindness, concern and compassion that they considered constituted quality nursing care.

Summary

This study's objective was to explore nurses' perceptions of quality nursing care in the Dementia Specific Care Unit. The challenges of dementia care have been well documented in the literature, but what are largely absent are the descriptions of nurses' perceptions of quality nursing care in Dementia Specific Care Units. The nurses who participated in this study willingly provided a depth and richness of information and context regarding the complexities involved in delivering quality nursing care in this clinical setting.

Each of the three themes that have been identified discuss the challenges nurses face daily working in the Dementia Specific Care Unit. These challenges include the prioritisation by facility managers of task-based care and prescriptive managerialism, which result in a loss of nurse and patient autonomy and an organisational culture of retribution, fear and distrust. All the participants discussed the organisational contexts of a poor staff mix, inadequate staff-to-patient ratios, and the large number of untrained staff members caring for patients in the Dementia Specific Care Unit. They discussed the impact these factors had on the quality of nursing care they could deliver.

Findings from this Grounded Theory study indicate that the nurses working in the Dementia Specific Care Units that were the setting for this study identified and defined quality nursing care differently, but all considered it to be complex and multi-factorial. They defined it in relation to the daily tasks they completed each shift and they measured it through audits, and family and carer satisfaction. Methods of measuring and improving quality (medication administration, hygiene, infection control, drug counts, pressure area care, and patient weight loss and documentation audits) were also identified by the participants as part of their daily tasks and part of delivering quality nursing care. Also revealed were the many rewards nurses found in providing dementia nursing care, with many demonstrating that they really cared for patients as individuals and loved them.

The participants identified that they felt hindered in the delivery of what they believed to be quality nursing care due to the consistently high workloads, a lack of dementia care education and poor managerial support. The challenges to the delivery of quality nursing care in the Dementia Specific Care Unit were also discussed by Kay, Evans, and Glass (2018), who found that limited resources, challenging environments and increased workloads impact negatively on the ability of nurses to provide individualised care within the dementia care setting.

The ability of six of the participants to provide a caring environment, characterised by compassion, empathy, respect and dignity, appeared to be severely impacted by the physical environment and the availability of resources. The physical limitations of the Dementia Specific Care Units in the provision of individualised patient care were clearly identified by all the participants, particularly in conjunction with organisational requirements where patients were barred from accessing outside areas.

Findings from this Grounded Theory study into nurses’ perceptions of quality nursing care in Dementia Specific Care Units have made a significant contribution to understanding how nurses utilise advocacy to provide care for not only patients but also their family members. Six of the participants described the challenges of supporting and advocating for patients and their family members. Some described it as physically and emotionally draining. These findings are congruent with the study completed by Andrews (2017), who noted the importance of including family members in the care of the individual living with dementia. The lack of support by other healthcare workers, including General Practitioners and ambulance officers, to deliver appropriate care for patients was also identified by the participants as frustrating and exhausting. The participants discussed the need to advocate on behalf of patients when they were unable to communicate their needs, whilst at the same time treating them with dignity and respect that was underpinned by their existing relationships with the patients. This ability to form and maintain a relationship with patients remains the central element in the provision of quality nursing care and they described it as a labour of love.

Some of the participants expressed how they advocated and cared for their patients when they discussed how they “bent the rules” to provide a homelike environment and meaningful experiences for patients. One of the participants particularly discussed how she would allow patients outside into the garden areas despite fears of retribution from management. Some of the participants also spoke of the need to bend the rules at times to meet a patient’s needs, especially in relation to mealtimes and medication administration. This ability and willingness of nurses to adapt standardised care practices was discussed by Daley et al. (2016).

Findings from this Grounded Theory research indicate that nurses could justify bending the rules sometimes to provide comfort to the patients in the Dementia Specific Care Unit and enhance communication. Spencer et al. (2017) explored the incidence of rule adaptation in dementia care and also found that nurses often adapted facility rules in the interests of the person with dementia. This perception of “playing by the rules” is further reinforced by V. Cope and Murray (2017), whose research into management expectations of staff found that the focus on task completion results in non-holistic patient care and missed care. Zarowitz et al. (2018) confirm the importance of these findings and further explored the impact on patient care of a facility culture that is focused on task completion.

This chapter has presented the participants’ stories of their experiences working in Dementia Specific Care Units. The three themes identified and discussed from their stories and the subsequent findings have been summarised. The Grounded Theory that was developed from this research – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding* – is presented in Chapter 5.

Chapter 5

The Theory

The research study that is the subject of this thesis aimed to provide an increased understanding of nurses' perceptions of quality nursing care in the Dementia Specific Care Unit. This chapter presents the substantive grounded theory that emerged from this study, namely: *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding*.

The Registered Nurses who participated in this study identified that in order to provide quality nursing care in the Dementia Specific Care Unit, they needed a sound understanding of dementia, dementia-specific skills and expertise, patience and empathy. The nurses identified challenges that would impact on their ability to provide quality nursing care in the Dementia Specific Care Unit environment. The nurses in this study also described feeling a sense of satisfaction and personal reward in delivering quality nursing care in this environment.

Developing the Theory

Three themes were identified in this study: Caring at the Coalface, Labour of Love and The Business of Dementia Healthcare. These themes informed the development of the theory that nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding.

The key elements of the theory are unpacked in the following sections.

Person centred.

The nurses who participated in this study perceived quality nursing care in the Dementia Specific Care Unit to be person centred and based on the nurse acknowledging the personhood of the individual in every aspect of the care they provide. The nurses demonstrated that they focused on patient inclusion, attending to all the patients' needs, and "being with" the patient, physically and emotionally (Ballard et al., 2018; Kogan et al., 2016; Woodhead et al., 2016). This focus on providing person-centred care is illustrated by the comment from Jane (participant), who said:

> *They are an individual, and what you have to look at is that person, the whole person…what is it that they need? What matters to them? That is quality nursing care.*

The nurses involved in the study identified that effective communication, where information is presented in a manner that makes sense to the patient, shared decision-making, and prioritising the nurse–patient relationship over the completion of tasks is critical to the provision of quality nursing care in the Dementia Specific Care Unit (Edvardsson, Winblad, & Sandman, 2008). The importance of these comments is supported by the relevant literature (Edvardsson et al., 2017; Joyce et al., 2018; Kok et al., 2016; B. McCormack & McCance, 2006), which confirms that person-centred care is much more than just the use of techniques or skills to complete procedures as efficiently as possible.

Research has confirmed that person-centred care places the patient centrally within the care and nursing process and considers the entire person, including their preferences, values and expectations (Brooker & Latham, 2015; Kitwood, 1997; McGreevey, 2015). The concept of person-centred care is considered to be interrelated with the provision of a safe environment, involves shared decision-making, and meeting both the physical and psychological needs of patients (Kitwood, 1997; Woodhead et al., 2016). It is characterised by dignity, autonomy, caring, respect and knowledge of the person as an individual (Kitwood, 1997; B. McCormack, 2004; Ross et al, 2015).

Brooker and Latham (2015) demonstrated the strong link between person centredness and caring by exploring the centrality of concepts common to both – that of relationships between nurses and patients, shared values, the process of caring for patients, and the care environment. Stockwell-Smith, Jones, and Moyle (2011) reinforce the synergistic relationship between caring and person-centred care by concluding that caring frameworks enable nurses to deliver person-centred care. B. McCormack et al. (2006) also explored the elements of person-centred care utilising a person-centred nursing framework. This framework consists of four constructs: *prerequisites,* which focus on the attributes of the nurse; *the care environment,* which explores the context in which the nursing care is provided; *person-centred processes,* which are the activities nurses use to deliver person-centred care; and *expected outcomes*, which are the patient outcomes resulting from the provision of person-centred care (B. McCormack et al., 2006).

Person-centred dementia care has been identified as a holistic philosophy that exists across the continuum of healthcare services and is based in the interactive process, where patients with dementia are active participants in their own care through all the stages of the disease process (Brooker & Latham, 2015; Edvardsson, Fetherstonhaugh, & Nay, 2010; Edvardsson et al., 2012; Kitwood, 1997). Person-centred care is essential for the continued physical and emotional wellbeing of patients in the Dementia Specific Care Unit and its value is well supported by the literature (Brooker & Latham, 2015; Cadigan et al., 2012; Kitson, Marshall, Bassett, & Zeitz, 2013; Spilsbury, Hewitt, Stirk, & Bowman, 2011). The relationship between person-centred care and quality nursing care in Dementia Specific Care Units was explored by Edvardsson et al. (2010). Findings from their study confirm that person-centred care is based on the continuation of self for the patient; the nurse knowing the person as an individual; the provision of meaningful, flexible activities every day; and the continuity of nursing care (Edvardsson et al., 2012; Hobson, 2019). These findings reflect and validate the comments made by the nurses who participated in this study regarding what they perceived constituted quality nursing care in the Dementia Specific Care Unit.

They identified that story work, where nurses encourage conversations with dementia patients regarding their lives and families, is part of quality nursing care. As illustrated by Daisy's comment, story work is important and facilitates the continuation of self and normality for the person with dementia (Chaudhury, 2008; Edvardsson et al., 2010; Hobson, 2019; McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; Ross et al., 2015; Spilsbury et al., 2011) as it encourages dementia patients to link their life story with loved ones who hold meaning for them (Cooney & O'Shea, 2019; Edvardsson et al., 2010):

> *I get out their pictures and sit with them. What is this? What is your dog's name? Getting to know everything about their life is so important…sitting with the patients, interacting with the patients, asking them about their families, pets, anything really that means something to them.*

Story work also provides nurses with useful information regarding the life and experiences of the patient and enhances the nurse–patient therapeutic relationship, which is essential to the delivery of quality nursing care (Cooney & O' Shea, 2019; Edvardsson et al., 2010; Kontos & Naglie, 2007; McKeown et al., 2010; Vernooij-Dassen & Moniz-Cook, 2016).

The nurses involved in this study considered person-centred care to be based on the development of a loving, caring therapeutic relationship, and that this was vital to providing quality nursing care in the Dementia Specific Care Unit. The therapeutic relationship has been described as one that exists between the nurse and the patient, where it is built on trust, understanding and care, with the patient being central for the care being delivered (Brooker & Latham, 2015; Nazir, Arling, Perkins, & Boustani, 2011; Al-Hussami et al., 2017; Ross et al., 2015; Zhao et al., 2016). The importance placed on the therapeutic relationship by the participant nurses is illustrated by Wendy's comments. She spoke about the relationship she had developed and maintained with a patient who was reliving his days as a supervisor in a biscuit factory:

> *So I sat with him and said, "Why do you walk up and down the corridor?" He said, "Well, I am the supervisor for the biscuit factory and have to watch everything." I thought about what he must be experiencing back at that time, so I found my old lab coat from uni and brought it in for him. He wore it proudly, and every shift I made sure we sat together to discuss how the shift at the factory had been, and I told him he was doing a great job. It is nothing really…an old coat, but to him he is back there, in charge, reliving his life.*

The literature supports the comments from the nurses involved in this study, where they emphasised the value of the nurse knowing the patient's social context, which then sustains a therapeutic relationship that values the patient as an individual and is nurturing to both the nurse and the patient (Kitwood, 1997; Stockwell-Smith et al., 2011; B. McCormack & McCance, 2016; van Kooten, van der Wouden, et al., 2017; Wiechula et al., 2016; Willemse et al., 2015; Zhao et al, 2016).

The nurses who participated in this study linked person-centred care and quality nursing care in the Dementia Specific Care Unit to a homelike atmosphere, the presence of patients' personal belongings, and a shared philosophy of care, love and support for patients. The validity of these comments is supported by the literature (Amiri et al., 2018; Anderson et al., 2016; Backman et al., 2016). Person-centred and quality nursing care have been shown to include the provision of care services that are delivered in an integrative, collaborative and mutually respectful manner and within an organisation-wide, person-centred philosophy of care (Brooker, 2003; Brooker & Latham, 2015; Epp, 2003; G. Mitchell & Agnelli, 2015).

The nurses involved in the study identified that a person-centred philosophy of care is particularly important for patients in the Dementia Specific Care Unit who have lost the ability to clearly express their needs, wants and desires. The person-centred philosophy of care encourages patients to engage in meaningful activities, programs and daily rituals that provide feelings of comfort and normality such as the enjoyment of meals, physical exercise, mental stimulation and comfortable personal hygiene when they want it, not when the nurse decrees it will occur (Alonzo, 2017; Amiri et al., 2018; Anderson et al., 2016; Chenoweth et al., 2019; Farlow, Borson, Connor, Grossberg, & Mittelman, 2016; Hobson, 2019; P. Hunter, Hadjistavropoulos, & Kaasalainen, 2016; McGreevey, 2015; Stokes, 2017). Meaningful activities identified by the nurses who participated in this study included one-on-one activities such as cooking, folding laundry or washing-up, where the nurses would actively engage with patients to ensure the activities were personal to the patients. The nurses acknowledged that being able to continue activities that the person enjoyed throughout their life was important for patients in the Dementia Specific Care Unit as it could provide stimulation and help to maintain the person's functional abilities and quality of life. Dahil spoke about how she used completion of everyday activities, such as washing-up and folding clothes, to engage with patients in the Dementia Specific Care Unit on an individual level:

> *Quality care is encouraging patients to do the normal everyday things they were used to doing – washing the dishes, folding clothes …it makes them feel needed…engages them.*

Some residential aged-care organisations describe their patient care as being person centred, but this was not reflected in the comments expressed by the nurses involved in this study nor the real-life situation present in many Dementia Specific Care Units (Davis, Morgans, Birks, & Browning, 2016; Field, 2015; Kirkley et al., 2011). The organisational structure and culture of many residential aged-care facilities, which are characterised by a task-based model of care, appear to be in conflict with the practice of compassionate and person-centred nursing (Backman, Sjögren, Lovheim, & Edvardsson, 2018; A. Griffiths et al., 2019; Labrague, McEnroe Petitte, Leocadio, Van Bogaert, & Tsaras, 2018; Sharma & Dar, 2016). In order to provide quality nursing care, the literature confirms that residential aged-care facilities need to move from an institution based on the completion of scheduled routines and procedures to one of person-centred care (Jeon et al., 2017; Kulig et al., 2018; Low, Fletcher, et al., 2015).

The second key element in the theory to explain nurses' perception of quality nursing care in the Dementia Specific Care Unit is that care is timely, which is discussed in the next section.

Timely.

The nurses who participated in this study perceived that the provision of timely care was a crucial element of quality nursing care in the Dementia Specific Care Unit. Timely care has been conceptualised as the rapid provision of appropriate patient care at the right time for the individual patient and when a need has been identified (Andersen & Bengsston, 2019; Kovach, Logan, Simpson, & Reynolds, 2010) and is recognised in the research literature as being a core component of clinically competent, quality nursing care (Bartfay, Bartfay, & Gorey, 2016; Browne, Roseman, Schaller, & Edgman-Levitan, 2010; Henning-Smith, Gonzales, & Shippee, 2016; Nembhard, Yuan, Shabanova, & Cleary, 2015; Orrell, 2016; Robinson, Tang, & Taylor, 2015).

Timely nursing care has also been shown to include the nurse regularly and accurately observing and assessing a patient’s health status, detecting any changes in the patient’s condition, and initiating rapid and appropriate action to address the changes (P. Jensen, Fraser, Shankardass, Epstein, & Khera, 2009; Kirsebom, Hedström, Wadensten, & Pöder, 2014; S. Miller et al., 2017; Orrell, 2016; Stokes, 2017; Stutte et al., 2017; Sullivan et al., 2017; Trahan, Spiers, & Cummings, 2016). The nurses who participated in this study considered that individuals living with dementia were at increased risk of injury and poor outcomes as a result of decreased cognition, and the provision of appropriate and timely nursing care in the Dementia Specific Care Unit was a vital element of quality nursing care (Surr et al., 2017; Tuomola, Soon, Fisher, & Yap, 2016; van de Ven et al., 2012).

As raised by the nurses, the process of providing timely nursing care within the context of fluctuating patient needs and the complexity of the Dementia Specific Care Unit is a major challenge. The dementia disease process itself is unique to the individual and is dependent on the form of dementia and its presentation and progression (Henning-Smith et al., 2016). This heterogeneity can make it difficult for the nurse to determine if detected changes in the person’s condition are due to the progression of the dementia disease, or if they reflect an underlying physical problem such as pain, injury, ongoing constipation or urinary incontinence (Laske & Stephens, 2018). Also, as their dementia progresses, the patient may lose the ability to self-report symptoms of illness or infection, and the development of a significant condition may be missed or mistakenly attributed to worsening dementia (McConnell & Meyer, 2019; Smalbrugge, Zwijsen, Koopmans, & Gerritsen, 2017). As a result, the patient may rapidly develop an overwhelming infection or other health problem, which then impacts on their health and wellbeing (Robinson et al., 2015; Yamakawa, Suto, Shigenobu, Kunimoto, & Makimoto, 2012). The nurses involved in this study identified that the ability to perform an accurate and timely assessment of a patient was therefore imperative to recognise early changes in their condition, develop baseline data from which any further changes could be determined and institute appropriate and timely treatment – all essential elements of quality nursing care (Barry et al., 2006; C. Carter et al., 2018; Pinkert et al., 2018; Silvester, Mohammed, Harriman, Girolami, & Downes, 2014).

Nurses also recognise that timely nursing care in the Dementia Specific Care Unit includes ensuring patients receive appropriate nutrition, hydration and hygiene care when necessary. As a result of cognitive deterioration, patients with dementia may not identify that they are thirsty or hungry, or may not be physically able to access a drink or food by themselves (Allison et al., 2019; Leggett et al., 2019; Morgan & Stewart, 1999; Rheaume, Riley, & Volicer, 1988; Spilsbury et al., 2011). This can result in dehydration, increased confusion and falls, so the nurse in the Dementia Specific Care Unit must offer food and fluids at regular intervals and ensure that each patient receives sufficient nutrition and hydration in a timely manner (Nazir et al., 2011; Spilsbury et al., 2011).

Nurses involved in this study considered that timely medication administration was an important component of quality nursing care in the Dementia Specific Care Unit (Nelson & Flynn, 2015). As acknowledged in the literature, many patients with late-stage dementia require various medications to manage co-morbidities, including depression, anxiety or psychotic disorders (Azermai et al., 2012; Byrne, 2005; Deeks et al., 2012; El-Saifi, Moyle, & Jones, 2018; Lim & Sharmeen, 2018; Sadowsky & Galvin, 2012). In addition, medications are often required to manage adverse behavioural problems such as aggression, agitation and wandering (Azermai et al., 2012; Deeks et al., 2012; Lim & Sharmeen, 2018; Moyle et al., 2017). As discussed by J. O'Brien et al. (2017) and Conn, Snowdon, and Purandare (2017), for maximum efficacy, psychotropics and other medications must be administered at correct time intervals and the effect on the patient monitored and doses adjusted by the nurse if necessary.

The nurses who participated in the study recognised that as their patients' dementia progressed, many of them experienced significant generalised pain as a result of the associated neuropathological changes that were impacting on the medial pain system (Achterberg et al., 2013; Corbett et al., 2012; Ezzati et al., 2019). The literature confirms that patients in the Dementia Specific Care Unit are at higher risk of suffering unrecognised and unrelieved pain; again, due to cognitive deterioration, which may have impaired their ability to both recognise and communicate the presence of pain (Hadjistavropoulos, Voyer, Sharpe, Verreault, & Aubin, 2008; Karki, 2018; Kolonowski et al., 2015). As a result, pain is often poorly managed in the Dementia Specific Care Unit, which results in many patients suffering unrelieved pain for extended periods of time (Husebo, Achterberg, & Flo, 2016; Malara et al., 2016; Tang, Wollsen, & Aagaard, 2016).

As unrelieved pain can cause escalating adverse patient behaviours, falls and subsequent injuries, nurses feel it is important that patients in the Dementia Specific Care Unit are regularly assessed for pain, administered analgesia in a timely manner, and the effect of the analgesia evaluated (Karki, 2018; Nakashima, Young, & Hsu, 2019; Parsons, 2017). Pain may be evaluated by the use of a pain scale, such as the Abbey Pain Scale, although this method has been found to be less successful in patients with significant cognitive decline who are unable to understand or communicate their pain rating to the nurse (Cipriani, Nuti, & Di Fiorino, 2018; Louro et al., 2018; Rostad et al., 2018). Nurses who participated in this study identified that the evaluation of pain was usually made by the nurse observing the patient’s facial and body language and knowing what was normal behaviour for the patient in the Dementia Specific Care Unit. These observations are supported by the relevant literature (Brooker, 2003; Cipriani et al., 2018; Husebo et al., 2016; Karki, 2018; McGreevy, 2015; Zamanzadeh et al., 2018).

The third key element identified in the theory explaining nurses’ perceptions of quality nursing care in the Dementia Specific Care Unit is the presence of skilled nursing care, which is discussed in the next section.

Skilled.

The nurses involved in this study identified the importance of skills and appropriate clinical knowledge in the delivery of quality nursing care in the Dementia Specific Care Unit. Appropriate skills and sound, relevant clinical knowledge have been shown to underpin dementia nursing practice, which validates the comments of the participant nurses (Langhammer et al., 2019; S. Sharp et al., 2018; J. Shin, 2013; Simmons et al., 2018; Smit et al., 2016; G. E. Smith, 2016; Tan et al., 2017).

In addition to possessing a wide range of clinical skills, the nurses who participated in this study identified that they needed to develop and maintain effective communication skills in order to provide quality nursing care. The research literature has identified that effective communication skills include the ability to listen, to speak slowly and clearly, maintain eye contact and provide the patient with sufficient time to respond to questions (Burgio, Allen-Burge, Stevens, Davis, & Marson, 2018; Jootun & McGhee, 2011; Hopkins, 2017; Machiels, Metzelthin, Hamers, & Zwakhalen, 2017; Riesch, Meyer, Lehr, & Severin, 2018). Effective communication skills are important in quality nursing care as dementia progression can lead to deterioration in the ability of the patient to communicate with others, resulting in social isolation and a reduced quality of life for patients in the Dementia Specific Care Unit (Burgio et al., 2018; D'Onofrio et al., 2017; Stanyon, Griffiths, Thomas, & Gordon, 2016; Teri, McKenzie, & Coulter, 2016).

As discussed by the nurses involved in this study, quality nursing care in the Dementia Specific Care Unit was delivered in the context of increasing patient acuity and often escalating behaviours. As a result, they identified that the development and maintenance of dementia specific skills and expertise to meet the changing needs of patients were essential elements of quality nursing care (Langhammer et al., 2019; Tan et al., 2017). The reality of providing nursing care in the Dementia Specific Care Unit is evident in Laura's comment:

> *Every day, day after day, the same thing...challenging behaviours, being spat at, punched or slapped if you get too close when they are showered...unrelenting...consistent...never ending.*

The research literature confirms that requisite skill and knowledge are essential for nurses to adapt their practice, using a systematic, evidence-based approach, to meet the needs of the individual patient (Smolowitz et al., 2015; Spenceley et al., 2017; Stutte et al., 2017).

Currently there are no legal requirements for nurses working in Dementia Specific Care Units in Australia to possess postgraduate dementia-specific qualifications (Dreier, Thyrian, Eichler, & Hoffmann, 2016). As a result, nurses working in Dementia Specific Care Units have identified that many nurses possess basic nursing skills and learn dementia nursing care by observing other nurses and copying their actions (C. Carter et al., 2018; Chang & Lin, 2005; Traynor et al., 2011). The practice of nurses with insufficient dementia knowledge and skill watching and copying what other nurses do is evident in Lee's comment:

> *I don't know enough about dementia care so I just watch the others and learn.... I do what they do.*

This has significant ramifications for the provision of skilled, quality nursing care in Dementia Specific Care Units when some nurses are only able to provide basic nursing care. The research literature recommends the continued engagement of nurses with education and professional development in order that sound clinical competence and skilled nursing care is delivered in all clinical areas, including the Dementia Specific Care Unit (C. Carter et al., 2018; C. C. Chang & Lin, 2005; Dreier et al., 2016; Scerri et al., 2019; S. Sharp et al., 2016; Traynor et al., 2011).

The nurses who participated in the study considered that dementia-specific nursing skills needed to include the ability to assess a patient to determine if they were experiencing pain. As previously discussed, pain in the patient with dementia is often difficult to detect because of their loss of cognition and associated inability to recognise and communicate to nurses that they are experiencing pain (Brooker, 2003; Husebo et al., 2016; Karki, 2018; Malara et al., 2016; McGreevy, 2015; Tang et al., 2016). Subsequently, the nurses involved in this study identified that the skilled dementia nurse must be able to closely observe any changes in a patient’s behaviour and recognise that these changes may indicate the presence of pain (Demange, Pino, Kerhervé, Rigaud, & Cantegreil-Kallen, 2019; van Kooten, Delwel, et al., 2015). Laura spoke about how she had assessed a palliative patient for pain and was unable to convince the patient’s General Practitioner that they needed analgesia:

> *She was palliative, obviously in pain....moaning, grimacing... and the GP…he wouldn’t even order her morphine.*

Changes in behaviour can include increased aggression, restlessness or agitation, holding a body part, grimacing, moaning or decreased movement when they are usually active (Herr, Zwakhalen, & Swafford, 2017; Husebo et al., 2016; Malara et al., 2016). The skilled nurse who has detected changed behaviour and the possible presence of pain can institute measures such as hot or cold packs, massage, or the administration of analgesia to alleviate the pain, then assess the effectiveness of these strategies (Bullock et al., 2019; Farrell & Cole, 2016; Karki, 2018).

The nurses who participated in the study confirmed that many patients in the Dementia Specific Care Unit were routinely administered psychotropic medications to manage depression, anxiety and adverse behaviours without considering the needs of the patient or alternative strategies. The widespread use of multiple antipsychotics and psychotropics in Dementia Specific Care Units has been discussed in the literature, with concerns raised regarding the long-term efficacy and potential side effects of these medications (Clague, Mercer, McLean, Reynish, & Guthrie, 2016; Maust et al., 2015; Mueller et al., 2018; Mulders, Zuidema, et al., 2019; Nørgaard, Jensen-Dahm, Gasse, Hansen, & Waldemar, 2017; Parsons, 2017; van der Spek et al., 2018). The nurses involved in this study confirmed that the skilled nurse must maintain their knowledge regarding the administration of these medications and be able to evaluate the patient frequently for efficacy, possible medication interactions and unwanted side effects, and adjust the doses when required (Maust et al., 2015; Mulders et al., 2019; van der Spek et al., 2018).

The research literature confirms that patients in Dementia Specific Care Units who suffer injuries or episodes of illness often experience frequent transitions across the continuum of care, including frequent hospital presentations and admissions (Backhouse, Camino, & Mioshi, 2018). The assessment and treatment of patients with dementia in acute-care environments has been shown to be complicated by a lack of dementia knowledge and skill as well as the difficulty many healthcare practitioners experience in recognising and treating pain, delirium or decline in dementia patients' physical function (Digby et al., 2017; Farlow et al., 2016; P. Griffiths et al., 2015; Handley, Bunn, & Goodman, 2019; Kolonowski et al., 2015). As a result, the nurses who participated in this study confirmed that many patients with late-stage dementia were transferred back to the Dementia Specific Care Unit from the acute-care setting as soon as possible (Aminzadeh et al., 2012; Austrom et al., 2018; Briggs et al., 2015; Callabero et al., 2018; Cen et al., 2018; Clevenger et al., 2012). They also stated that they were often then required to care for acutely unwell dementia patients as a result, which required utilising a range of clinical skills and expertise to meet the needs of each patient (Clissett, Porock, Harwood, & Gladman, 2013; Deeks et al., 2016; Garcez et al., 2019). The requisite skills they identified included the ability to assess wounds and wound healing, complete complex wound dressings, administer nasogastric tube feedings, manage symptoms of serious illnesses, and detect rapid changes in a patient's health status (A. Jensen et al., 2019; Osborn et al., 2015). The nurses involved in this study compared this situation to working in "mini hospitals" because of the acuity and multitude of patient needs, the high demand and complexity of patient care, and the increased vulnerability of patients in the Dementia Specific Care Unit (Callabero et al., 2018; Digby et al., 2017; Kolonowski et al., 2015).

The fourth key element identified in the theory explaining nurses' perceptions of quality nursing care in the Dementia Specific Care Unit was the presence of support, which is discussed in the next section.

Supported.

The nurses who participated in this study perceived that supportive management decisions and actions and a positive organisational culture were crucial to the delivery of quality nursing care in the Dementia Specific Care Unit. This observation is supported by the research literature (Digby et al., 2017; Holahan et al., 2019; Scerri, Innes, & Scerri, 2015; Sjögren et al., 2017). Nurse autonomy, good leadership, and a philosophy of individualised patient care have also been identified by researchers as essential components of quality nursing care (Digby et al., 2017; Holahan et al., 2019; Scerri et al., 2015; Simmons et al., 2018; Sjögren et al., 2017; Slatyer et al., 2016; Stokes, 2017; Surr et al., 2016).

The nurses involved in this study identified that poor managerial support was common in the Dementia Specific Care Unit and was characterised by a perpetual shortage of resources, lack of dementia-specific training, high workloads, and a culture of fear and distrust. This perception is illustrated in Jane's comment:

> *Called me in, told me to focus on my job, not try to change the unit…"don't rock the boat"...said, "It's not as if they know, so just manage with what you have got."*

The research literature confirms that the lack of managerial support, stress and feelings of helplessness are common in Dementia Specific Care Units and often results in nurses becoming physically and emotionally overloaded and feeling that they are unable to provide quality nursing care (Poikkeus, Suhonen, Katajisto, & Leino-Kilpi, 2020; Romeo et al., 2018; Schatt & Frone, 2011; Schmidt & Diestal, 2013; P. Scott et al., 2018; Schaller et al., 2015; Woodhead et al., 2016). The nurses who participated in this study considered that this was particularly important in the Dementia Specific Care Unit where skilled, dementia-trained nurses were essential for the delivery of quality nursing care.

In contrast, the literature confirms that an organisation that offers staff support, acknowledgement, inclusion and best-practice models of care is providing a high level of support to nurses that empowers them to deliver quality nursing care (Frankel, 2008). Nurses who perceive that they are supported by their organisation have been shown to engage more in education and skill development activities and exhibit increased feelings of self-worth and competence (C. S. Chang, 2015; H. Chang et al., 2015; M. Chen et al., 2016; Gupta, Agarwal, & Khatri, 2016; X. Wang, Liu, Zou, Hao, & Wu, 2017). Perceived organisational support is acknowledged by the employees' perception that their work, efforts and actions are valued by the organisation, which results in them having a positive attitude and an increased commitment to their job and professional development (Blackstock, Harlos, Macleod, & Hardy, 2015; Johansen & Cadmus, 2016; Mathambu & Dodd, 2013; Pinkert et al., 2018; Vassbø et al., 2019).

As identified by the nurses involved in this study, the issue of high workloads, scheduled task-based care and competing priorities, such as answering telephones and excessive documentation requirements within designated timeframes, also compromised the delivery of quality nursing care in the Dementia Specific Care Unit. This observation is supported by the research literature (Sun et al., 2018; Tarzia, Fetherstonhaugh, Bauer, Beattie, & Nav, 2015; Tesad et al., 2014). As a result of these issues, nurses may experience reduced job autonomy and satisfaction and increased stress and burnout, which then further reduces their ability to provide what they perceive to be quality nursing care (Barbosa, Nolan, Sousa, & Figueiredo, 2017; Cadigan et al., 2012; Chenoweth, Stein-Parbury, Lapkin, & Wang, 2015; Cooke, 2018; Cooper, Barber, et al., 2016; Gilbert et al., 2019; Hoan & Ngo, 2019; Lourida et al., 2016; Romeo et al., 2018; A. Spector, Revolta, & Orrell, 2016; Szebehely, 2017; Tesad et al., 2014; Van Alphen et al., 2016; Zúñiga et al., 2015).

Grealish and Henderson (2016) and Gibb, Freeman, Ballantyne, and Corlis (2016) explored patient care models used by residential aged-care organisations and recommend that organisations should utilise flexible approaches to patient care and decision-making that is based on the knowledge and skills of nurses. Other findings indicate that in order to feel valued, nurses need to be treated with consideration and be supported by their organisation to think creatively when resolving issues in the Dementia Specific Care Unit (Gibb et al., 2016; Grealish & Henderson, 2016). Strategies to foster these feelings of belonging, value and support can include dementia-specific training as well as opportunities for staff development and involvement in decision-making based on the nurses' knowledge of patients and their needs (Chisengantambu, Robinson, & Evans, 2018; V. Cope, Jones, & Hendricks, 2016; Hogden et al., 2017; Marriott-Statham, Mackay, Brennan, & Mackay, 2018; Rasmussen, Henderson, Andrew, & Conroy, 2018). Recent research indicates that caring and supportive organisational cultures and improved quality of care for dementia patients can be provided through appropriate staff training, improved support and supervision of nurses and the development of visionary leaders (Hsu, Chiang, Chang, Huang, & Chen, 2015; Karantzas et al., 2016; Smythe et al., 2017). The assumption can therefore be made that a strong organisational culture that is characterised by respect and trust for nurses can result in the provision of person-centred care, positive patient outcomes and feelings of self-worth and empowerment in nurses (Hsu et al., 2015; Manojlovich & Ketefian, 2016).

The fifth and final key element in the theory is the reward nurses experience when caring for their patients in the Dementia Specific Care Unit, which is discussed in the next section.

Rewarding.

The nurses who participated in this study perceived that patients in the Dementia Specific Care Unit could still enjoy feelings of pleasure and joy when they were interacting with nurses and others despite the progression of their dementia and associated cognitive decline (Person & Hanssen, 2015). In the absence of a cure for dementia, there is an increased need to recognise the value of the caring and rewarding relationship between the nurse and patient in the Dementia Specific Care Unit. This relationship, characterised by moments of engagement and recognition, has been shown to assist in reducing feelings of social isolation and depression and can significantly improve the quality of life for patients in the Dementia Specific Care Unit (Evripidou et al., 2019).

The nurses identified that they experienced a sense of reward and fulfillment when they felt they were providing quality nursing care in the Dementia Specific Care Unit. They considered that the relationship with the patients in the Dementia Specific Care Unit should be based in love and compassion and confirmed that this was an essential part of quality nursing care. This is evident in the following comment from Jane:

> *Smiles, if you see the smiles on the faces of those patients and they do react to your face, that's one positive because you know if you get their trust, and even though they do have dementia, there is that trust there if they know, and they do…you walk in and get that beaming smile.*

Current research supports the importance of caring and loving relationships between nurses and patients that is based in the provision of empathy, love and compassion (Chambers & Ryder, 2018; Ersser, 2019; Monroe et al., 2015; Morgan, 2018; Morgan-Brown et al., 2019; M. O'Brien, 2018; Ray, 2016; Rokstad, Røsvik, et al., 2013; Royston et al., 2017; Sherwood & Barnsteiner, 2017; J. Shin, 2013). Human love, where nurses exhibit cultural respect and an affirming presence, has been shown to be fundamental for effective communication and establishing trust in the caring nurse–patient relationship and validates the comments of the nurses who participated in this study (Cleary & O'Doody, 2017; Ersser, 2019; Hemberg & Vilander, 2017; Nilsson, Edvardsson, & Rushton, 2019; M. O'Brien, 2018; Thorkildsen, Eriksson, & Råholm, 2015; Zamanzadeh et al., 2018).

The nurses involved in the study indicated that caring for patients in the Dementia Specific Care Unit was what they enjoyed and they obtained great personal satisfaction from these interactions, despite the challenges they faced every day. They felt that these interactions contributed to their ability to provide quality nursing care because they knew their patients intimately, felt wanted and needed, and were able to make a difference to each patient. Jane talked about how she felt when she interacted with her patients in the Dementia Specific Care Unit:

> *When the patient is happy, they are smiling…. I love it, I feel happy and satisfied with my care…..*

The importance and reward nurses experience from knowing their patients' life history, habits and preferences has been supported by the research undertaken in this area (Dunn et al., 2013; Ersser, 2019; Monroe et al., 2015; Morgan, 2018; Morgan-Brown et al., 2019; M. O'Brien, 2018; Scerri et al., 2015). The nurses who participated in the study talked of the joy and delight they experienced interacting with their patients when they did "the little things" that meant so much to the patients. This ability to connect with patients living with dementia is clearly based in the natural trust that exists between the nurse and the patient and has been recognised by research as an essential component of quality nursing care (Dunn et al., 2013; Ersser, 2019; M. O'Brien, 2018).

The nurses involved in this study also discussed how they used humour to connect with patients in the Dementia Specific Care Unit throughout their working day and how this was quality nursing care. They talked about the humorous stories they would share and the joy and happiness they felt when they laughed with their patients and could see them enjoying themselves. As Laura said:

> *I'll say to him…I can see you laughing at me…yes I can…and before you know it, he is laughing...that is quality care.... I love it.*

Humour is a form of communication that can be particularly effective in the Dementia Specific Care Unit to facilitate a connection between patients and nurses when there is an erosion of cognition (Person & Hanssen, 2015; Stevens, 2012; Tremayne, 2014). The use of humour is based in the acknowledgement of a comic or absurd situation, remark or action that generates feelings of closeness between the nurse and the patient (Low, Goodenough, et al., 2014; McCreaddie & Wiggins, 2008; Moos, 2011). Using humour in dementia nursing has been shown to facilitate the therapeutic nurse–patient relationship and enables patients to be treated as individuals, which results in increased feelings of involvement and wellbeing (Jeon et al., 2013; Clarke & Irwin, 2016; Kontos, Miller, Mitchell, & Stirling-Twist, 2017; Raviv, 2014).

Patients admitted to a Dementia Specific Care Unit do not automatically renounce their human rights on admission, but the nurses involved in this study said that many patients experienced difficulty in asserting these rights due to their cognitive decline and inability to communicate with others (F. Kelly & Innes, 2013; Splaine, 2008). The nurses discussed the feelings of accomplishment and satisfaction they had experienced when they were able to advocate for their patients and preserve their human rights. The research literature confirms that patient rights include the entitlement to receive adequate and appropriate medical treatment, the right to be involved in decision-making regarding their care, and the right to refuse care (Burton, 1997; Camp, 2017; Camp et al., 2018; Gamble & Dening, 2017; Hu, 2017; Parke, Hunter, Schulz, & Jouanne, 2019; Sinclair et al., 2019; Stokin, 2019; Swaffer, 2014, 2016). Wendy discussed what advocating for her patients meant to her:

> *It’s so much more than the basics; it is what they would want if they could speak for themselves…that’s quality nursing care.... I feel this is very important for them and for me...to preserve their rights at all times.*

Some of the nurses who participated in this study chose to advocate for their patients because of their personal experiences of poor-quality nursing care, while others just considered it to be part of their nursing duties to provide person-centred care. Current research supports the importance of advocacy not only for the patient in the Dementia Specific Care Unit but also for their family members (Cottrell et al., 2018; Sinclair et al., 2019; Stokin, 2019). The nurses acknowledged the importance of advocating for family members as they negotiated the healthcare system. They felt that this was important and part of quality nursing care. These concepts are supported by the research literature (Backhaus et al., 2018; Kelley, 2017; L. McCormack, Tillock, & Walmsley, 2017; Roselle, 2018; Verbeek, 2017).

Although providing quality nursing care in the Dementia Specific Care Unit is stressful and challenging, the literature confirms that nurses continue to work there because they love their patients and feel needed by them (Chenoweth, Merlyn, Jeon, Tait, & Duffield, 2014; Cleary & O'Doody, 2017; Cronfalk et al., 2018; Evripidou et al., 2019; Owens & Koch, 2015; Roberts & Bowers, 2015; Robertson et al., 2019). Despite facing a number of workplace issues, including feeling devalued and unsupported, the nurses involved in this study reported experiencing continued joy and satisfaction from caregiving. Some of them identified that they achieved satisfaction and enjoyment through altruism, while others just liked the job and the experience of working with patients in Dementia Specific Care Units. They experienced empathy for their patients and could look beyond the disease to see the person within and the value that that person with dementia still had to offer. Jane expressed her ability to feel empathy for her patients with the following comment:

> *I think, "what if that was me?" Everything is unfamiliar...this is not my home.... You are not my family.*

The research literature supports the importance of nurses continuing to view patients in the Dementia Specific Care Unit as individuals and as part of quality nursing care (Bird, 2014; Harmer et al., 2017; K. Marshall, 2013; Powell, 2018; Pulsford et al., 2016; Snyder, 2006; Wallin, Jakobsson, & Edberg, 2012). Some of the nurses involved in the study stated that they liked the feelings of joy and accomplishment they had when they interacted with patients throughout the day, provided comfort and emotional support through touch or just sharing a cup of tea, and when they felt they had provided the best possible nursing care. Others took pride in providing dignity, comfort, hope and love for their patients who live in, for them, a confusing and foreign world. These concepts are supported by the research in this field as being essential components of quality nursing care (Alonzo, 2017; Cooney & O'Shea, 2019; Heggestad & Slettebø, 2015).

Figure 7 illustrates the important concepts identified by nurses that together form the theory that *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding*.

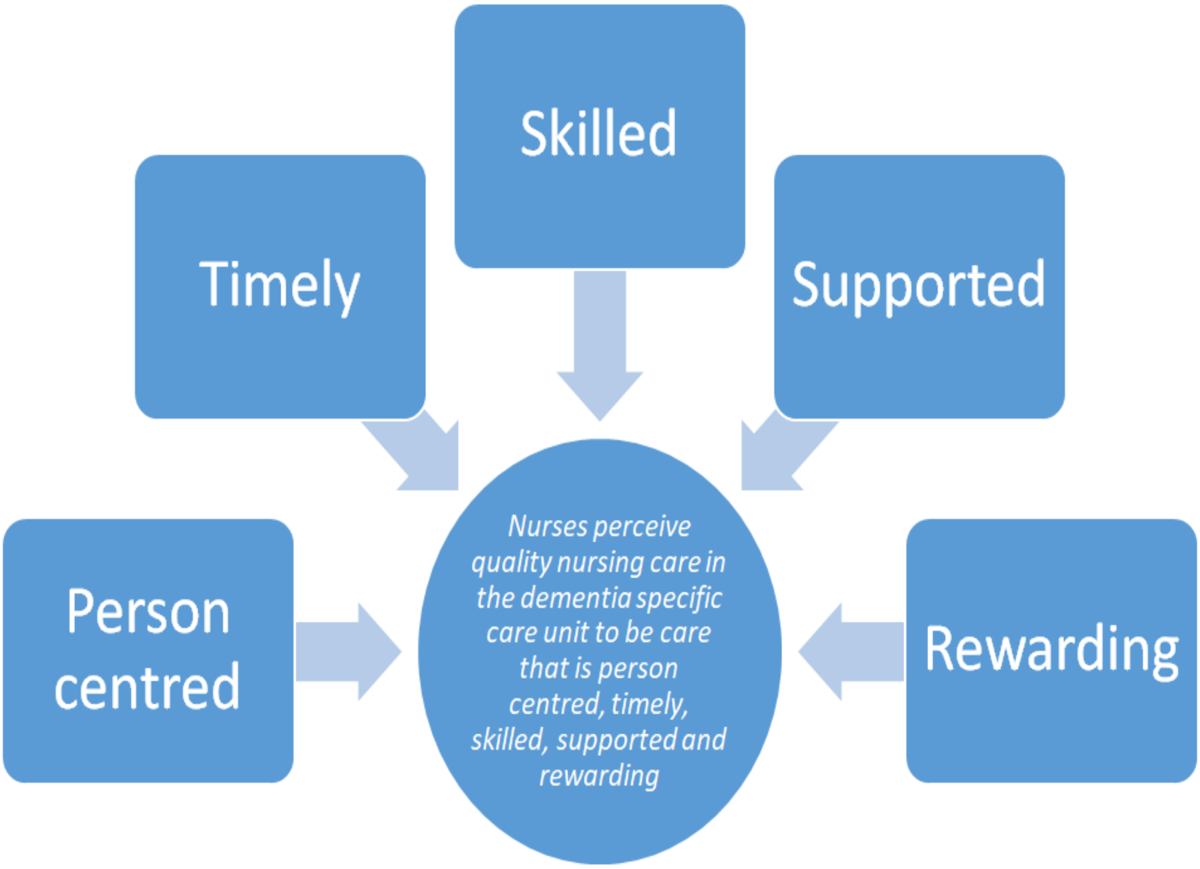


Figure 7. The concepts that form the theory.

The theory.

The theory – *Nurses perceive quality nursing care in the dementia specific care unit to be care that is person centred, timely, skilled, supported and rewarding* – has been evaluated against the predetermined set of criteria regarding the relevance of Grounded Theory research that has been identified by Charmaz (2014). Charmaz (2014) considers it vital that findings from Grounded Theory studies reflect precisely the data and the reliability of the data analysis process in addition to accurately reflecting what the participants believe is their reality. These criteria include credibility (logical and conceptual grounding), originality (significance of the study), resonance (offers meaning and scope to those for whom it may be relevant) and usefulness (knowledge development and practical application). Each of these criteria is evaluated in the following sections (Charmaz, 2014).

Credibility.

Credibility in Grounded Theory studies is based in the researcher's engagement with participants, the use of data gathered from various sources, examination of interview transcripts for accuracy, and ensuring that emerging categories, concepts and themes accurately reflect the reality identified by participants (Charmaz, 2014). Credibility in this study was based in my use of interviews and memos during data collection, which reflected the research processes and the meanings that are important to and constructed by the participants. I recorded the comments and stories of participants that reflected what they perceived quality nursing care in the Dementia Specific Care Unit to be.

Glaser (1992) recommends that the researcher ensure that each of the categories reaches saturation so as the theory is“ grounded” in the data and reflects what the participants valued. In my study, data collection and simultaneous analysis continued until all categories had been fully examined and saturated to ensure that the substantive theory was truly based in the views of participants. Charmaz (2014) recommends that the researcher move back and forward in the data during the data analysis process to ensure that the data is constantly compared as well as providing credibility to the process and the emerging theory. I used the participants' own words to provide guidance through the theory and how I reached my conclusions, which, again, adds credibility. The words evoked images of the care the nurses who participated in this study provided and identified what they considered to be important when delivering quality nursing care.

Finally, credibility was established in my study through the use of theoretical sampling and constant comparison of data. Codes were compared with codes, codes with categories, categories with categories, and categories with concepts. In addition, I recorded my theoretical and methodological decisions during this study in the form of memos, which will enable other researchers to replicate this study and adds further credibility to the findings from this study.

Originality.

As discussed in Chapter 2, the current literature has explored nursing care but does not define or explain nurses' perceptions of quality nursing care in the Dementia Specific Care Unit. This study provides information that broadens the understanding of quality nursing care in Dementia Specific Care Units and contributes to the establishment of new knowledge regarding this phenomenon. The data provided by the nurses who participated in this study clearly illustrates the elements of what they perceived to be quality nursing care, including seeing the person as an individual, the therapeutic relationship, maintaining personhood, and advocating for patients when necessary. This information is original as it pertains to the Dementia Specific Care Units studied and reflects current nursing care practice in the Dementia Specific Care Unit.

The theory – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding* – clearly demonstrates nurses' understanding of quality nursing care in relation to both theory and practice. As a result, this theory is original and makes a significant contribution to the existing body of knowledge regarding what constitutes quality nursing care.

Resonance.

The theory – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding* – reflects the reality, experiences and perceptions of the nurses who participated in this study and describes the phenomenon of quality nursing care in the Dementia Specific Care Unit. To establish resonance, I continuously revisited the words of participants by re-reading the transcripts, listening to the audio recordings of each interview, and ensuring the coding of the data accurately reflected the participants' comments. The data was analysed via the developed categories and concepts, which made sense of the data, and facilitated the development of the three themes and the resultant theory, which is "grounded in the data", thereby satisfying the criteria of resonance.

Usefulness.

An examination of the current empirical literature relating to nurses' perceptions of quality nursing care in Dementia Specific Care Units confirmed that there are no existing theories. As a result, the theory – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding* – not only makes a significant contribution to this existing body of knowledge but is also a practical theory that provides clarity regarding nurses' perceptions of quality nursing care in the Dementia Specific Care Unit. Participant information provided copious, rich, relevant and contemporary data relating to what they perceive constitutes current quality nursing care in the Dementia Specific Care Unit. The theory – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding* – provides valuable information regarding the relevance of models of nursing care identified earlier. The theory also highlights issues for clinical practice and provides recommendations for future research, thereby satisfying the criteria for usefulness. The issues of clinical practice and future research will be presented in the final chapter.

The analysed data has been presented in a form that is easy to understand as well as being meaningful and readable. The theory brings together the findings in a manner that can be used by the Australian Government and other decision-makers to appreciate the quality of nursing care that is required in the Dementia Specific Care Unit. The theory has also identified areas that provide the basis for further research into quality nursing care in the Dementia Specific Care Unit and has extended the knowledge of this topic. It is insightful regarding the current challenges and rewards of quality nursing care in the Dementia Specific Care Unit and provides recommendations to address the issues that have been identified by nurses, thereby demonstrating its usefulness.

This theory – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding* – represents how the nurses who participated in this study perceived quality nursing care in the Dementia Specific Care Unit. It highlights the rewards and constraints that can impact on nurses in this environment. This theory makes significant contributions to the discipline of dementia nursing and provides opportunities for further research into nurses' perceptions of quality nursing care in Dementia Specific Care Units and other clinical areas.

This chapter has discussed this theory and its contribution to quality nursing care research literature. Chapter 6 discusses the limitations and recommendations that have emerged from this study.

Chapter 6

Limitations, Recommendations and Conclusion

Limitations

The results of this study have contributed to the understanding of what is quality nursing care in the Dementia Specific Care Unit but there are some limitations. As in many qualitative studies, the sample size was small due to the limited uptake for participation. However, the participant number was sufficient to reach data saturation according to Grounded Theory criteria, as discussed in Chapter 3, and the findings are supported by the current literature.

Even though the number of participants was low, there were no identified issues relating to the conduct of the interviews, which yielded copious and rich information relating to what nurses perceive to be quality nursing care in Dementia Specific Care Units. The results may have provided wider resonance and transferability if the research had been expanded to include more Dementia Specific Care Units. If this research were to be repeated, attention would be given to recruiting additional participants from an increased number of Dementia Specific Care Units.

During this study, I utilised the constant comparison analysis process, where data was compared against data, codes against codes and categories against categories. Data saturation occurred when I reached the point where sampling more data did not reveal further information related to the research question and I was unable to identify new data to develop new properties of categories and that each category was clearly separate from others. At this point I saw similar instances and terms and examples repeated, which made me confident that each category was saturated with data, and the thick and rich descriptions of each category enabled the theory – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding* – to emerge.

As discussed in Chapter 2, the nurses who participated in this study represented a small, homogenous sample that reflected the current aged-care workforce within residential aged-care facilities in Australia (AIHW, 2019). The participant group consisted of eight females and one male, with six participants aged over 44 years, and all worked in Dementia Specific Care Units. These characteristics reflect the current aged and dementia care Australian nursing workforce, where nurses are more likely to be women, with over 56 per cent aged 44 years or older (AIHW, 2017). Participants provided copious and detailed information during their interviews regarding what they perceived quality nursing care in the Dementia Specific Care Unit to be. During the interview, I sought clarification from each participant on points and issues they raised and explored concepts exhaustively with each of them.

The value of the Grounded Theory identified from this study.

The value of a Grounded Theory approach for this study was validated by the development of the theory *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding,* which accurately reflects nurses perceptions of quality nursing care in Dementia Specific Care Units. As discussed earlier, validity in Grounded Theory research requires that the categories and themes that emerge from the data must accurately reflect what participants believe is their reality (Glaser, 1998). The criteria of rigour in Grounded Theory research was supported by my use of constant comparison throughout the data analysis process to allow codes, sub categories and categories to emerge from the data, validating the strength and suitability of the research design. Reflexivity and credibility in this Grounded Theory study occurred when I wrote and reviewed memos as categories emerged, again validating the strength of a Grounded Theory approach and frequently checked my interpretation of data with my supervisors.

The results of this study have a number of implications for nursing practice. First, findings from this study have highlighted the physical and emotional load nurses work under within the Dementia Specific Care Unit every day. This burden involves providing prescriptive, task-based nursing care within designated timeframes in the face of continuous challenging patient behaviours and ever-increasing workloads. Despite these pressures, nurses identify the strategies they use in order to meet both managerial expectations and their intrinsic need to provide quality nursing care.

A second implication centres on the lack of dementia-specific training and education available to nurses working in the Dementia Specific Care Unit. As described by the nurses involved in this study, the lack of educational opportunities within the aged-care sector, particularly within Dementia Specific Care Units, led to them acknowledging that there is a need for more education and support for nurses. Findings from this study also have implications for the continued development of nurses' dementia-specific knowledge. Further, the nurses stated that knowledge development is often unstructured and focused on the observation and copying of the actions of other staff members when delivering routine patient care. The provision of a structured education program for all nurses working in the Dementia Specific Care Unit may facilitate increased dementia knowledge and skill with a patient-centred focus of care.

Governments need to be sensitive to the factors impacting on nurses' ability to provide quality nursing care and take steps to overcome barriers within the Dementia Specific Care Unit. Additional government funding and support for residential aged-care facilities for increased staff education, support and resource provision would directly impact on the ability of nurses to provide quality nursing care within the Dementia Specific Care Unit. Understanding what quality nursing care is in Dementia Specific Care Units also provides a coherent picture of the relationships between nurses and patients and identifies variables that impact on the quality of life and outcomes for patients with late-stage dementia.

Recommendations

The following recommendations have been identified from the study's data and provide suggestions to improve the provision of quality nursing care to patients in Dementia Specific Care Units.

Recommendation 1: Person centred.

It is recommended that flexibility in nursing care delivery for patients in the Dementia Specific Care Unit should become normalised. There needs to be a recognised shift from prescriptive, task-based models of care to holistic person-centred patient care.

It is recommended that patient mealtimes and hygiene activities should be flexible and reflect the wishes and preferences of each patient and not those of the organisation.

Residential aged-care facility managers should implement and foster an organisational culture and philosophy of person-centred care at every level, where consideration is given to patient preferences, values and beliefs regarding their wellbeing. This culture should consistently seek to view the patient in the Dementia Specific Care Unit as an individual and appreciate the world they live in from their perspective.

Recommendation 2: Timely.

It is recommended that residential aged-care facility managers evaluate and address the physical and emotional load nurses work under in the Dementia Specific Care Unit. They need to review workloads, provide sufficient resources and have a clear understanding of what constitutes quality nursing care in the Dementia Specific Care Unit. The provision of appropriate workloads and resources will afford nurses the time and opportunity to accurately assess patients in the Dementia Specific Care Unit for pain, infections, dehydration or malnutrition; complete complex nursing care activities; and institute timely and appropriate patient care.

Recommendation 3: Skilled.

It is recommended that residential aged-care facility managers provide continuous, appropriate and structured dementia-specific training and education for nurses. The presence of a sufficient number of dementia-trained staff in the Dementia Specific Care Unit would mean that nurses could implement person-centred strategies to enhance the physical and psychological wellbeing of patients and provide quality nursing care.

It is also recommended that residential aged-care facility managers encourage, promote and financially support nurses to complete dementia-specific postgraduate qualifications in order to meet the complex needs and acuity of patients in the Dementia Specific Care Unit.

Recommendation 4: Supported.

Additional government funding and support should be provided for residential aged-care facilities that reflects the reality of resources required to provide quality nursing care in Dementia Specific Care Units.

Also, it is recommended that a cultural change within the nursing profession regarding working in aged and dementia care be implemented by the Australian Government. This cultural change, characterised by wage parity across all clinical areas, equal educational opportunities, clearly defined career progression and standardised working conditions, could alter healthcare practitioners’ perceptions of aged and dementia care and result in an increased number of Registered Nurses entering and remaining in the aged-care and dementia workforce long term.

Recommendation 5: Rewarding.

It is recommended that residential aged-care organisation managers provide a compassionate and caring organisation culture where nurses feel valued and supported and experience high levels of job satisfaction and reward.

Recommendation 6: Future research.

This study has provided important and contemporary information regarding what nurses perceive to be quality nursing care in the Dementia Specific Care Unit. As it has a small participant group, it could be recommended that further research be conducted into this topic to validate the identified Grounded Theory and add further to the existing body of knowledge relating to quality nursing care.

Information obtained from this study has highlighted the challenges nurses face every day when delivering quality nursing care in the Dementia Specific Care Unit. Further research could build on these findings and explore how nurses cope with these challenges and evaluate their effectiveness in meeting the needs of patients in the Dementia Specific Care Unit.

Summary and Conclusions

The significance of this study lies in its potential to improve the understanding of what constitutes quality nursing care in the Dementia Specific Care Unit from the perspective of nurses. Three themes were identified: Caring at the Coalface, Labour of Love, and The Business of Dementia Healthcare. These themes informed the development of the theory – *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding.*

The findings from this study indicate that nurses provide person-centred care and truly care for patients in the Dementia Specific Care Unit. The provision of person-centred care includes meeting the physical, spiritual and emotional needs of each patient, providing comfort for the patient, reaching the person within the disease, and making a difference to each patient every day. The importance of a caring environment, characterised by respect and dignity, was highlighted by the nurses who participated in this study as an essential part of quality nursing care.

This final chapter has provided an overview of the study and brings the thesis to a conclusion. As a result, this study has identified the substantive theory that *Nurses perceive quality nursing care in the Dementia Specific Care Unit to be care that is person centred, timely, skilled, supported and rewarding*. This theory has emerged from the three themes of Caring at the Coalface, Labour of Love, and The Business of Dementia Healthcare and identifies how nurses perceive quality nursing care in the Dementia Specific Care Unit.

References

Aasgaard, H. S., Landmark, B. T., & Öresland, S. (2017). Healthcare personnel's experiences of enhancing social community for people living in dementia special care units. *Nordic Journal of Nursing Research*, *37*(4), 186–193.

Abbott, K. M., Bettger, J. P., Hampton, K. N., & Kohler, H. P. (2015). The feasibility of measuring social networks among older adults in assisted living and dementia special care units. *Dementia*, *14*(2), 199–219.

Achterberg, W. P., Pieper, M. J., van Dalen-Kok, A. H., De Waal, M. W., Husebo, B. S., Lautenbacher, S., ... & Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interventions in Aging*, *8*, 1471–1482.

Adewuyi, M., Kimble, L. P., Dormire, S. L., & Sudia, T. (2018). Dementia care content in prelicensure nursing curricula: A pilot mixed-methods study. *Journal of Nursing Education*, *57*(2), 88–95.

Adlbrecht, L., Bartholomeyczik, S., & Mayer, H. (2018). Development of a program theory as a basis for the evaluation of a dementia special care unit. *Pflege*, *31*(3), 125–134.

Afshar, S., Roderick, P. J., Hill, A. G., Dimitrov, B. D., & Kowal, P. (2015). Global multimorbidity: A cross-sectional study of 28 countries using the World Health Surveys, 2003. *European Journal of Public Health*, *25*(suppl_3), ckv170-003.

Aiken, L. H., Clarke, S. P., Sloane, D. M., Lake, E. T., & Cheney, T. (2008). Effects of hospital care environment on patient mortality and nurse outcomes. *Journal of Nursing Administration*, *38*(5), 223–229.

Aiken, L. H., Sloane, D. M., Ball, J., Bruyneel, L., Rafferty, A. M., & Griffiths, P. (2018). Patient satisfaction with hospital care and nurses in England: An observational study. *BMJ Open*, *8*(1), e019189.

Aiken, L. H., Sloane, D., Griffiths, P., Rafferty, A. M., Bruyneel, L., McHugh, M., ... & Sermeus, W. (2017). Nursing skill mix in European hospitals: Cross-sectional study of the association with mortality, patient ratings, and quality of care. *BMJ Quality & Safety*, *26*(7), 559–568.

Åkerborg, Ö., Lang, A., Wimo, A., Sköldunger, A., Fratiglioni, L., Gaudig, M., & Rosenlund, M. (2016). Cost of dementia and its correlation with dependence. *Journal of Aging and Health*, *28*(8), 1448–1464.

Al Danaf, J., Chang, B. H., Shaear, M., Johnson, K. M., Miller, S., Nester, L., ... & Aboumatar, H. J. (2018). Surfacing and addressing hospitalized patients' needs: Proactive nurse rounding as a tool. *Journal of Nursing Management*, *26*(5), 540–547.

Alghamdi, M. G. (2016). Nursing workload: A concept analysis. *Journal of Nursing Management*, *24*(4), 449–457.

Algoso, M., Peters, K., Ramjan, L., & East, L. (2016). Exploring undergraduate nursing students' perceptions of working in aged care settings: A review of the literature. *Nurse Education Today*, *36*, 275–280.

Al-Hussami, M., Al-Momani, M., Hammad, S., Maharmeh, M., & Darawad, M. (2017). Patients' perception of the quality of nursing care and related hospital services. *Health and Primary Care*, *1*(2), 1–6.

Allen, D., Braithwaite, J., Sandall, J., & Waring, J. (2016). Towards a sociology of healthcare safety and quality. *Sociology of Health & Illness*, *38*(2), 181–197.

Allen, R. S., McDonough, I., Albright, A., Erickson, S., Brake, G., & Salekin, K. L. (2018). Assessment and restoration of competency to be executed: Issues related to dementia and cognitive disability. In S. S. Bush & A. L. Heck (Eds.), *Forensic geropsychology: Practice essentials* (pp. 135–166). Washington, DC: American Psychological Association.

Allers, K., Dörks, M., Schmiemann, G., & Hoffmann, F. (2017). Antipsychotic drug use in nursing home residents with and without dementia: Keep an eye on the pro re nata medication. *International Clinical Psychopharmacology*, *32*(4), 213–218.

Allison, T. A., Balbino, R. T., & Covinsky, K. E. (2019). Caring community and relationship centred care on an end-stage dementia special care unit. *Age and Ageing*, *48*(5), 727–734.

Alonzo, T. (2017). Hope for persons with dementia: Why comfort matters. *Generations*, *41*(1), 81–85.

Altintop, I., & Tatli, M. (2019). Physical abuse of the elderly: A 4-year retrospective evaluation in the emergency department. *Psychogeriatrics, 19*(1), 10–15.

Amador, S., Sampson, E. L., Goodman, C., & Robinson, L. (2019). A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. *Palliative Medicine*, *33*(4), 415–429.

Aminzadeh, F., Molnar, F. J., Dalziel, W. B., & Ayotte, D. (2012). A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. *Canadian Geriatrics Journal, 15*(3), 85–94.

Amiri, E., Ebrahimi, H., Vahidi, M., Asghari Jafarabadi, M., & Namdar Areshtanab, H. (2018). Relationship between nurses' moral sensitivity and the quality of care. *Nursing Ethics, 26*(4), 1265–1273.

Andersen, D., & Bengtsson, T. T. (2019). Timely care: Rhythms of bureaucracy and everyday life in cases involving youths with complex needs. *Time & Society, 28*(4), 1509–1531.

Anderson, K., Bird, M., MacPherson, S., & Blair, A. (2016). How do staff influence the quality of long-term dementia care and the lives of residents? A systematic review of the evidence. *International Psychogeriatrics*, *28*(8), 1263–1281.

Anderson, R. M. (1995). Patient empowerment and the traditional medical model: A case of irreconcilable differences?*Diabetes Care*, *18*(3), 412–415.

Andersson, E. K., Dellkvist, H., Bernow Johansson, U., & Skär, L. (2019). Relatives' experiences of sharing a written life story about a close family member with dementia who has moved to residential care: An interview study. *Nursing Open, 6*(2), 276–282.

Andersson, M., Paulsson, J., Malmqvist, I., & Lindahl, G. (2016). The use of common spaces in assisted living schemes for older persons: A comparison of somatic and dementia units. *Ageing & Society*, *36*(4), 837–859.

Andrews, J. (2017). "Wandering" and dementia. *British Journal of Community Nursing*, *22*(7), 322–323.

Annear, M. J. (2018). Knowledge of dementia among the Australian health workforce: A national online survey. *Journal of Applied Gerontology*, *39*(1), 62–73.

Annells, M. (1996). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research, 6*(3), 379–393.

Appelhof, B., Bakker, C., de Vugt, M. E., Zwijsen, S. A., Smalbrugge, M., Teerenstra, S., ... & Koopmans, R. T. (2019). Effects of a multidisciplinary intervention on the presence of neuropsychiatric symptoms and psychotropic drug use in nursing home residents withyoung-onset dementia: Behavior and Evolution of Young-Onset Dementia Part 2 (BEYOND-II) Study. *The American Journal of Geriatric Psychiatry*, *27*(6), 581–589.

Appleton, K., & Pereira, A. (2019). Behavioural changes in dementia and their impact on professional caregivers: A grounded theory approach. *Dementia*, *18*(4), 1479–1491.

Aragona, E., Ponce-Rios, J., Garg, P., Aquino, J., Winer, J. C., & Schainker, E. (2016). A quality improvement project to increase nurse attendance on pediatric family centered rounds. *Journal of Pediatric Nursing*, *31*(1), e3-e9.

Arens, O. B., Fierz, K., & Zúñiga, F. (2017). Elder abuse in nursing homes: Do special care units make a difference? A secondary data analysis of the Swiss Nursing Homes Human Resources Project. *Gerontology*, *63*(2), 169–179.

Armstrong, N. M., Gitlin, L. N., Parisi, J. M., Roth, D. L., & Gross, A. L. (2019). Association of physical functioning of persons with dementia with caregiver burden and depression in dementia caregivers: An integrative data analysis. *Aging & Mental Health*, *23*(5), 587–594.

Ashley, C., Brown, A., Halcomb, E., & Peters, K. (2018). Registered nurses transitioning from acute care to primary healthcare employment: A qualitative insight into nurses’ experiences. *Journal of Clinical Nursing*, *27*(3–4), 661–668.

Atwood, J. R., & Hinshaw, A. S. (1977). Multiple indicators of nurse and patient outcomes as a method for evaluating a change in staffing patterns. *Communicating Nursing Research, 10*, 235–255.

Australian Bureau of Statistics. (2015). *Causes of death, Australia, 2015* (No. 3303.0)Canberra, ACT: Author.

Australian Institute of Health and Welfare. (2019). *Government spending on aged care*. Retrieved from https://www.aihw.gov.au/reports/aged-care/gen-aged-care-data-government-spending-aged-care/contents/summary

Austrom, M. G., Boustani, M., & LaMantia, M. A. (2018). Ongoing medical management to maximize health and well-being for persons living with dementia. *The Gerontologist*, *58*(suppl_1), S48–S57.

Azermai, M., Petrovic, M., Elseviers, M. M., Bourgeois, J., Van Bortel, L. M., & Vander Stichele, R. H. (2012). Systematic appraisal of dementia guidelines for the management of behavioural and psychological symptoms. *Ageing Research Reviews*, *11*(1), 78–86.

Babchuck, W. A. (1997, October). *Glaser or Strauss? Grounded theory and adult education*. Paper presented at the Midwest Research-to-Practice Conference in Adult, Continuing and Community Education, East Lansing, Michigan.

Bach, S., & Ellis, P. (2018). *Leadership, management and team working in nursing*. Exeter, UK: Learning Matters.

Backhaus, R., Hoek, L., Van Haastregt, J., Verbeek, H., De Vries, E., & Hamers, J. (2018). Increasing family inclusion in nursing homes for people with dementia: A literature review. *Innovation in Aging*, *2*(suppl_1), 537.

Backhaus, R., van Rossum, E., Verbeek, H., Halfens, R. J., Tan, F. E., Capezuti, E., & Hamers, J. P. (2017). Work environment characteristics associated with quality of care in Dutch nursing homes: A cross-sectional study. *International Journal of Nursing Studies*, *66*, 15–22.

Backhaus, R., Verbeek, H., van Rossum, E., Capezuti, E., & Hamers, J. P. (2014). Nurse staffing impact on quality of care in nursing homes: A systematic review of longitudinal studies. *Journal of American Director's Association. 15*(6), 383–393.

Backhouse, T. (2014). *A mixed methods exploration into the management of behavioural and psychological symptoms of dementia in care homes: Care approaches, strategies and psychotropic medications.* (Doctoral dissertation). University of East Anglia, Norwich, UK.

Backhouse, T., Camino, J., & Mioshi, E. (2018). What do we know about behavioral crises in dementia? A systematic review. *Journal of Alzheimer's disease*, *62*(1), 99–113.

Backhouse, T., Killett, A., Penhale, B., Burns, D., & Gray, R. (2014). Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey. *Aging & Mental Health*, *18*(2), 187–193.

Backhouse, T., Killett, A., Penhale, B., & Gray, R. (2016). The use of non-pharmacological interventions for dementia behaviours in care homes: findings from four in-depth, ethnographic case studies. *Age and Ageing*, *45*(6), 856–863.

Backhouse, T., Penhale, B., Gray, R., & Killett, A. (2018). Questionable practices despite good intentions: coping with risk and impact from dementia-related behaviours in care homes. *Ageing & Society*, *38*(9), 1933–1958.

Backman, A., Sjögren, K., Lindkvist, M., Lövheim, H., & Edvardsson, D. (2016). Towards person-centredness in aged care: Exploring the impact of leadership. *Journal of Nursing Management*, *24*(6), 766–774.

Backman, A., Sjögren, K., Lindkvist, M., Lövheim, H., & Edvardsson, D. (2017). Characteristics of highly rated leadership in nursing homes using item response theory. *Journal of Advanced Nursing*, *73*(12), 2903–2913.

Backman, A., Sjögren, K., Lövheim, H., & Edvardsson, D. (2018). Job strain in nursing homes – Exploring the impact of leadership. *Journal of Clinical Nursing*, *27*(7–8), 1552–1560.

Bail, K., & Grealish, L. (2016). "Failure to Maintain": A theoretical proposition for a new quality indicator of nurse care rationing for complex older people in hospital. *International Journal of Nursing Studies*, *63*, 146–161.

Bail, K., Goss, J., Draper, B., Berry, H., Karmel, R., & Gibson, D. (2015). The cost of hospital-acquired complications for older people with and without dementia: A retrospective cohort study. *BMC Health Services Research*, *15*(91), 1–9.

Baillon, S. F., Narayana, U., Luxenberg, J. S., & Clifton, A. V. (2018). Valproate preparations for agitation in dementia. *Cochrane Database of Systematic Reviews*, (10), Article number: CD003945.

Bains, D., Singh, G., Kaur, N., & Singh, N. (2018). Development of biological self-cleaning wound-dressing gauze for the treatment of bacterial infection. *ACS Sustainable Chemistry & Engineering*, *7*(1), 969–978.

Ball, J. E., Murrells, T., Rafferty, A. M., Morrow, E., & Griffiths P. (2014). “Care left undone” during nursing shifts: Associations with workload and perceived quality of care. *BMJ Quality and Safety, 23,* 116–125.

Ballard, C., & Corbett, A. (2013). Agitation and aggression in people with Alzheimer’s disease. *Current Opinion in Psychiatry, 26*(3), 252–259.

Ballard, C., Corbett, A., Orrell, M., Williams, G., Moniz-Cook, E., Romeo, R., ... & Fossey, J. (2018). Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial. *PLoS Medicine*, *15*(2), 1–18.

Ballard, C., Khan, Z., Clack, H., & Corbett, A. (2011). Nonpharmacological treatment of Alzheimer disease. *The Canadian Journal of Psychiatry, 56*(10), 589–595

Ballard, C., Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., ... & Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet*, *390*(10113), 2673–2734.

Balzer, K., Schröder, R., Junghans, A., Stahl, U., Träder, J. M., & Köpke, S. (2016). Dementia care training in undergraduate nursing education: Lessons learned from a pilot study on a novel inter-professional training course. *BMC Nursing*, *15*, 1–3.

Bang, J., Spina, S., & Miller, B. L. (2015). Frontotemporal dementia. *The Lancet*, *386*(10004), 1672–1682.

Bangash, A., Stubbs, R., Khan, F., Samnani, S., Aziz, H., & Mitra, M. (2017). Association between antipsychotics and adverse outcomes in dementia. *Progress in Neurology and Psychiatry*, *21*(4), 20–26.

Barbosa, A., Nolan, M., Sousa, L., & Figueiredo, D. (2017). Implementing a psycho-educational intervention for care assistants working with people with dementia in aged-care facilities: Facilitators and barriers. *Scandinavian Journal of Caring Sciences*, *31*(2), 222–231.

Barnicoat, G., & Danson, M. (2015). The ageing population and smart metering: A field study of householders' attitudes and behaviours towards energy use in Scotland. *Energy Research & Social Science*, *9*, 107–115.

Barry, D. W., Melhado, T. V., Chacko, K. M., Lee, R. S. M., Steiner, J. F., & Kutner, J. S. (2006). Patient and physician perceptions of timely access to care. *Journal of General Internal Medicine*, *21*(2), 130–133.

Bartfay, E., Bartfay, W. J., & Gorey, K. M. (2016). Dementia care in Ontario, Canada: Evidence of more timely diagnosis among persons with dementia receiving care at home compared with residential facilities. *Public Health*, *130*, 6–12.

Barton, A. J. (2017). Role of the RN in primary care: Implications for nursing education. *Journal of Nursing Education*, *56*(3), 127–128.

Bassal, C., Czellar, J., Kaiser, S., & Dan-Glauser, E. S. (2016). Relationship between emotions, emotion regulation, and well-being of professional caregivers of people with dementia. *Research on Aging*, *38*(4), 477–503.

Bauer, J. M., & Sousa-Poza, A. (2015). Impacts of informal caregiving on caregiver employment, health, and family. *Journal of Population Ageing*, *8*(3), 113–145.

Bauer, M., Fetherstonhaugh, D., Blackberry, I., Farmer, J., & Wilding, C. (2019). Identifying support needs to improve rural dementia services for people with dementia and their carers: A consultation study in Victoria, Australia. *Australian Journal of Rural Health*, *27*(1), 22–27.

Bauer, M., Fetherstonhaugh, D., Haesler, E., Beattie, E., Hill, K. D., & Poulos, C. J. (2018). The impact of nurse and care staff education on the functional ability and quality of life of people living with dementia in aged care: A systematic review. *Nurse Education Today*, *67*, 27–45.

Baumbusch, J., Puurveen, G., Phinney, A., Beaton, M. D., & Leblanc, M. E. (2018). Family members' experiences and management of resident-to-resident abuse in long-term residential care. *Journal of Elder Abuse & Neglect*, *30*(5), 385–401.

Baumgart, M., Snyder, H. M., Carrillo, M. C., Fazio, S., Kim, H., & Johns, H. (2015). Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimer's & Dementia*, *11*(6), 718–726.

Baxter, R., Taylor, N., Kellar, I., & Lawton, R. (2016). What methods are used to apply positive deviance within healthcare organisations? A systematic review. *BMJ Quality & Safety*, *25*(3), 190–201.

Beard, H. P. J. R., & Bloom, D. E. (2015). Towards a comprehensive public health response to population ageing. *Lancet, 385*(9968), 658–661.

Beavis, A. L., Wethington, S., Vitale, M. R., Levinson, K., Viswanathan, A., Fader, A. N., & Stone, R. L. (2018). A quality improvement initiative to determine and address psychosocial and basic resource needs of patients in the gynecologic oncology clinic. *Gynecologic Oncology*, *149*, 124.

Beck, C., Ortigara, A., Mercer, S., & Shue, V. (1999). Enabling and empowering certified nursing assistants for quality dementia care. *International Journal of Geriatric Psychiatry*, *14*(3), 197–211.

Beck, E. R., McIlfatrick, S., Hasson, F., & Leavey, G. (2017). Nursing home manager's knowledge, attitudes and beliefs about advance care planning for people with dementia in long-term care settings: A cross-sectional survey. *Journal of Clinical Nursing*, *26*(17–18), 2633–2645.

Becker, S. (2016). *An interpretive description of the recruitment and retention of locum nurses working in rural and remote Australia*. (Doctoral dissertation). Retrieved from https://find.library.unisa.edu.au/primo-explore/fulldisplay?id=9916106906301831&vid=ROR&sortby=rank&lang=en_US

Beerens, H. C., de Boer, B., Zwakhalen, S. M., Tan, F. E., Ruwaard, D., Hamers, J. P., & Verbeek, H. (2016). The association between aspects of daily life and quality of life of people with dementia living in long-term care facilities: A momentary assessment study. *International Psychogeriatrics*, *28*(8), 1323–1331.

Beerens, H. C., Sutcliffe, C., Renom-Guiteras, A., Soto, M. E., Suhonen, R., Zabalegui, A., ... & RightTimePlaceCare Consortium. (2014). Quality of life and quality of care for people with dementia receiving long term institutional care or professional home care: The European RightTimePlaceCare study. *Journal of the American Medical Directors Association*, *15*(1), 54–61.

Beerens, H. C., Zwakhalen, S. M., Verbeek, H., E. S. Tan, F., Jolani, S., Downs, M., ... & Hamers, J. P. (2018). The relation between mood, activity, and interaction in long-term dementia care. *Aging & Mental Health*, *22*(1), 26–32.

Beerens, H. C., Zwakhalen, S. M., Verbeek, H., Ruwaard, D., Ambergen, A. W., Leino-Kilpi, H., ... & Bökberg, C. (2015). Change in quality of life of people with dementia recently admitted to long-term care facilities. *Journal of Advanced Nursing*, *71*(6), 1435–1447.

Beerens, H. C., Zwakhalen, S. M., Verbeek, H., Ruwaard, D., & Hamers, J. P. (2013). Factors associated with quality of life of people with dementia in long-term care facilities: A systematic review. *International Journal of Nursing Studies*, *50*(9), 1259-1270.

Benadé, P., Du Plessis, E., & Koen, M. P. (2017). Exploring resilience in nurses caring for older persons. *Health SA Gesondheid*, *22*(1), 138–149.

Bennett, H. Q., Norton, S., Bunn, F., Robinson, L., Rait, G., Goodman, C., ...& Matthews, F. E. (2018). The impact of dementia on service use by individuals with a comorbid health condition: A comparison of two cross-sectional analyses conducted approximately 10 years apart. *BMC Medicine*, *16*(1), 114.

Benson, D. M., Cameron, D., Humbach, E., Servino, L., & Gambert, S. R. (1987). Establishment and impact of a dementia unit within the nursing home. *Journal of the American Geriatrics Society*, *35*(4), 319–323.

Berg, L., Buckwalter, K. C., Chafetz, P. K., Gwyther, L. P., Holmes, D., Koepke, K. M., ... & Maslow, K. (1991). Special care units for persons with dementia. *Journal of the American Geriatrics Society*, *39*(12), 1229–1236.

Berger, A. A. (2018). *Media and communication research methods: An introduction to qualitative and quantitative approaches*. Thousand Oaks, CA: Sage Publications, Inc.

Berkowitz, B. (2016). The patient experience and patient satisfaction: Measurement of a complex dynamic. *Online Journal of Issues in Nursing*, *21*(1), Manuscript 1.

Berman, L., Raval, M. V., & Goldin, A. (2018). Process improvement strategies: Designing and implementing quality improvement research. S*eminars in Pediatric Surgery*, *27*(6), 379–385.

Bethell, J., Pringle, D., Chambers, L. W., Cohen, C., Commisso, E., Cowan, K., ... & McGilton, K. S. (2018). Patient and public involvement in identifying dementia research priorities. *Journal of the American Geriatrics Society*, *66*(8), 1608–1612.

Bianchetti, A., Benvenuti, P., Ghisla, K. M., Frisoni, G. B., & Trabucchi, M. (1997). An Italian model of dementia special care unit: Results of a pilot study. *Alzheimer's Disease and Associated Disorders, 11*(1), 53–56.

Bickford, B., Daley, S., Sleater, G., Hebditch, M., & Banerjee, S. (2019). Understanding compassion for people with dementia in medical and nursing students. *BMC Medical Education*, *19*(35), 1–8.

Bird, M. (2014). Dementia and suffering in nursing homes. In E. MacKinlay (Ed.), *Mental health and spirituality in later life* (pp. 63–82). New York, NY: Routledge.

Bjoerke-Bertheussen, J., Ehrt, U., Rongve, A., Ballard, C., & Aarsland, D. (2012). Neuropsychiatric symptoms in mild dementia with Lewy bodies and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, *34*(1), 1–6.

Blackstock, S., Harlos, K., Macleod, M. L., & Hardy, C. L. (2015). The impact of organisational factors on horizontal bullying and turnover intentions in the nursing workplace. *Journal of Nursing Management*, *23*(8), 1106–1114.

Bloom, D. E., Chatterji, S., Kowal, P., Lloyd-Sherlock, P., McKee, M., Rechel, B., ... & Smith, J. P. (2015). Macroeconomic implications of population ageing and selected policy responses. *The Lancet*, *385*(9968), 649–657.

Bloomer, M., Digby, R., Tan, H., Crawford, K., & Williams, A. (2016). The experience of family carers of people with dementia who are hospitalised. *Dementia*, *15*(5), 1234–1245.

Bluff, R. (1997). Evaluating qualitative research. *British Journal of Midwifery*, *5*(4), 232–235.

Bogossian, F., Winters-Chang, P., & Tuckett, A. (2014). "The pure hard slog that nursing is...": A qualitative analysis of nursing work. *Journal of Nursing Scholarship, 46*(5), 377–388.

Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). They know! – Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. *Palliative Medicine*, *30*(5), 456–470.

Bonnici-Mallia, A. M., Barbara, C., & Rao, R. (2018). Vascular cognitive impairment and vascular dementia. *InnovAiT*, *11*(5), 249–255.

Borraccino, A., Pera, R., & Lemma, P. (2019). "What being healthy means to me": A qualitative analysis uncovering the core categories of adolescents' perception of health. *PloS One*, *14*(6), e0218727.

Bouma, G. D., & Mason, M. (2018). Baby boomers downunder: The case of Australia. In W. C. Roof, J. W. Carroll, & D. A. Roozen (Eds.), *The post-war generation and the establishment of religion* (pp. 27–58). New York, NY: Routledge.

Bowes, A., & Dawson, A. (Eds.). (2019). *Designing environments for people with dementia.* Bingley, UK: Emerald Publishing Limited.

Bowman, G. S., Thompson, D. R., & Sutton, T. W. (1983). Nurses' attitudes towards the nursing process. *Journal of Advanced Nursing*, *8*(2), 125–129.

Brannelly, T., Gilmour, J. A., O'Reilly, H., Leighton, M., & Woodford, A. (2019). An ordinary life: People with dementia living in a residential setting. *Dementia*, *18*(2), 757–768.

Brasure, M., Desai, P., Davila, H., Nelson, V. A., Calvert, C., Jutkowitz, E., ... & Kane, R. L. (2018). Physical activity interventions in preventing cognitive decline and Alzheimer-type dementia: A systematic review. *Annals of Internal Medicine*, *168*(1), 30–38.

Bray, J., Evans, S., Bruce, M., Carter, C., Brooker, D., Milosevic, S., ...& Woods, C. (2015). Enabling hospital staff to care for people with dementia. *Nursing Older People, 27*(10), 29–32.

Brayne, C. E., & Chertkow, H. (2018). An action plan to face the challenge of dementia: International statement on dementia from IAP for health. *Journal of Prevention of Alzheimer's Disease*, *5*(3), 207–212.

Breitve, M. H., Brønnick, K., Chwiszczuk, L. J., Hynninen, M. J., Aarsland, D., & Rongve, A. (2018). Apathy is associated with faster global cognitive decline and early nursing home admission in dementia with Lewy bodies. *Alzheimer's Research & Therapy*, *10*(1), Article number: 83.

Briggs, A. M., Cross, M. J., Hoy, D. G., Sanchez-Riera, L., Blyth, F. M., Woolf, A. D., & March, L. (2016). Musculoskeletal health conditions represent a global threat to healthy aging: A report for the 2015 World Health Organization world report on ageing and health. *The Gerontologist*, *56*(suppl_2), S243–S255.

Briggs, R., Coary, R., Collins, R., Coughlan, T., O'Neill, D., & Kennelly, S. P. (2015). Acute hospital care: How much activity is attributable to caring for patients with dementia?*QJM: An International Journal of Medicine*, *109*(1), 41–44.

Broadstock, M., Ballard, C., & Corbett, A. (2014). Latest treatment options for Alzheimer's disease, Parkinson's disease dementia and dementia with Lewy bodies. *Expert Opinion on Pharmacotherapy*, *15*(13), 1797–1810.

Bronkhorst, B. (2015). Behaving safely under pressure: The effects of job demands, resources, and safety climate on employee physical and psychosocial safety behavior. *JournalofSafety Research*, *55*, 63–72.

Brooke, J., & Ojo, O. (2018). Elements of a sustainable, competent, and empathetic workforce to support patients with dementia during an acute hospital stay: A comprehensive literature review. *The International Journal of Health Planning and Management*, *33*(1), e10–e25.

Brooker, D. (2003). What is person-centred care in dementia?*Reviews in Clinical Gerontology*, *13*(3), 215–222.

Brooker, D. (2008). Person centred care. In R. Jacoby, T. Dening, & A. Thomas (Eds.), *Psychiatry in the elderly* (4th ed., pp. 476–491). Oxford, UK: Oxford University Press.

Brooker, D. (2012). Understanding dementia and the person behind the diagnostic label. *International Journal of Person Centered Medicine*, *2*(1), 11–17.

Brooker, D. J., & Woolley, R. J. (2007). Enriching opportunities for people living with dementia: The development of a blueprint for a sustainable activity-based model. *Aging and Mental Health*, *11*(4), 371–383.

Brooker, D., & Latham, I. (2015). *Person-centred dementia care: Making services better with the VIPS framework*. London, UK: Jessica Kingsley Publishers.

Brookmeyer, R., Kawas, C. H., Abdallah, N., Paganini-Hill, A., Kim, R. C., & Corrada, M. M. (2016). Impact of interventions to reduce Alzheimer's disease pathology on the prevalence of dementia in the oldest-old. *Alzheimer's & Dementia*, *12*(3), 225–232.

Brown, E. L., Agronin, M. E., & Stein, J. R. (2019). Interventions to enhance empathy and person-centered care for individuals with dementia: A systematic review. *Research in Gerontological Nursing*, *6,* 1–11.

Browne, K., Roseman, D., Shaller, D., & Edgman-Levitan, S. (2010). Measuring patient experience as a strategy for improving primary care. *Health Affairs*, *29*(5), 921–925.

Bryant, A., & Charmaz, K. (Eds.). (2019). *The SAGE handbook of current developments in grounded theory*. Thousand Oaks, CA: Sage Publications, Inc.

Buchan, J., & Seccombe, I. (2018). *Nurses work: An analysis of the UK nursing labour market*. London, UK: Routledge.

Buchan, J., Twigg, D., Dussault, G., Duffield, C., & Stone, P. W. (2015). Policies to sustain the nursing workforce: an international perspective. *International Nursing Review*, *62*(2), 162–170.

Buchanan, J., Collard, L., & Palmer, D. (2019). Koorliny birniny, ni, quoppa katatjin1: Respect and ethics in working with Indigenous Australian communities. In S. Banks & P. Westoby (Eds.), *Ethics, equity and community development* (pp. 123–142). Bristol, UK: Policy Press.

Buetow, S. (2019). Apophenia, unconscious bias and reflexivity in nursing qualitative research. *International Journal of Nursing Studies*, *89,* 8–13.

Bullock, L., Bedson, J., Jordan, J. L., Bartlam, B., Chew-Graham, C. A., & Campbell, P. (2019). Pain assessment and pain treatment for community-dwelling people with dementia: A systematic review and narrative synthesis. *International Journal of Geriatric Psychiatry*, *34*(6), 807–821.

Bunn, D. K., Abdelhamid, A., Copley, M., Cowap, V., Dickinson, A., Howe, A., ...& Smithard, D. (2016). Effectiveness of interventions to indirectly support food and drink intake in people with dementia: Eating and drinking well in dementia, a systematic review. *BMC Geriatrics, 16*(26), 1–18.

Burgio, L., Allen-Burge, R., Stevens, A., Davis, L., & Marson, D. (2018). Caring for Alzheimer’s disease patients: Issues of verbal communication and social interaction. In J. M. Clair & R. M. Allman (Eds.), *The gerontological prism: Developing interdisciplinary bridges* (pp. 231–258). Boca Raton, FL: CRC Press.

Burhans, L. M., & Alligood, M. R. (2010). Quality nursing care in the words of nurses. *Journal of Advanced Nursing, 66*(8), 1689–1697.

Burke, R. E., & Werner, R. M. (2019). Quality measurement and nursing homes: Measuring what matters. *BMJ Quality & Safety, 28*(7), 520–523.

Burnes, D., & Syed, M. (2018). Understanding how resident-to-resident aggression in long-term care dementia units unfolds. *Innovation in Aging, 2*(Suppl 1), 727.

Burnes, D., Pillemer, K., Caccamise, P. L., Mason, A., Henderson, C. R. Jr., Berman, J., ...& Salamone, A. (2015). Prevalence of and risk factors for elder abuse and neglect in the community: A population-based study. *Journal of the American Geriatrics Society, 63*(9), 1906–1912.

Burns, M., & McIlfatrick, S. (2015). Palliative care in dementia: Literature review of nurses’ knowledge and attitudes towards pain assessment. *International Journal of Palliative Nursing, 21*(8), 400–407.

Burrell, J. R., Halliday, G. M., Kril, J. J., Ittner, L. M., Götz, J., Kiernan, M. C., & Hodges, J. R. (2016). The frontotemporal dementia-motor neuron disease continuum. *The Lancet, 388* (10047), 919–931.

Burton, A. (1997). Dementia: A case for advocacy? In S. Hunter (Ed.), *Dementia: Challenges and new directions* (pp. 194–211). London, UK: Jessica Kingsley Publishers.

Byrne, G. J. (2005). Pharmacological treatment of behavioural problems in dementia. *Australian Prescriber, 28*(3), 67–70.

Caballero, R. G., Herreros, B., de Asúa, D. R., Gámez, S., Vega, G., & Olmos, L. G. (2018). Limitation of therapeutic effort in patients hospitalized in departments of internal medicine. *Revista Clínica Española (English Edition)*, *218*(1), 1–6.

Cadigan, R. O., Grabowski, D. C., Givens, J. L., & Mitchell, S. L. (2012). The quality of advanced dementia care in the nursing home: The role of special care units. *Medical Care*, *50*(10), 856–862.

Calia, C., Johnson, H., & Cristea, M. (2019). Cross-cultural representations of dementia: An exploratory study. *Journal of Global Health*, *9*(1), 1–11.

Calkins, M. P. (2018). Memory care and Alzheimer's units. In A. Sloan Devlin (Ed.), *Environmental psychology and human well-being: Effects of built and natural settings* (pp. 365–386). London, UK: Academic Press.

Callander, E. J., Corscadden, L., & Levesque, J. F. (2017). Out-of-pocket healthcare expenditure and chronic disease: Do Australians forego care because of the cost? *Australian Journal of Primary Health*, *23*(1), 15–22.

Cameron, F., & Brownie, S. (2010). Enhancing resilience in registered aged care nurses. *Australasian Journal on Ageing*, *29*(2), 66–71.

Camicioli, R., & Licis, L. (2004). Motor impairment predicts falls in specialized Alzheimer care units. *Alzheimer Disease & Associated Disorders*, *18*(4), 214–218.

Camp, C. J. (2017). Flexibility in persons with dementia. In J. D. Sinnott (Ed.), *Identity flexibility during adulthood: Perspectives in adult development* (pp. 99–114). Cham, Switzerland: SpringerIntern ational Publishing.

Camp, C. J., Bourgeois, M. S., & Erkes, J. (2018). Person-centered care as treatment for dementia. In G. E. Smith & S. T. Farias (Eds.), *APA handbook of dementia* (pp. 615–629). Washinton, DC: American Psychological Association.

Camp, C. J., & Camp, L. (2018). *Teaching empathy and conflict resolution to people with dementia: A guide for person-centered practice*. London, UK: Jessica Kingsley Publishers.

Campo, M., & Chaudhury, H. (2012). Informal social interaction among residents with dementia in special care units: Exploring the role of the physical and social environments. *Dementia, 11*(3), 401–423.

Carr, P. (2017). Types of dementia: An introduction. *British Journal of Healthcare Assistants*, *11*(3), 132–135.

Carter, C., Bray, J., Read, K., Harrison-Dening, K., Thompson, R., & Brooker, D. (2018). Articulating the unique competencies of admiral nurse practice. *Working with Older People*, *22*(3), 139–147.

Carter, G., McLaughlin, D., Kernohan, W. G., Hudson, P., Clarke, M., Froggatt, K., ...& Brazil, K. (2018). The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *Journal of Advanced Nursing*, *74*(7), 1595–1604.

Carter, M., Quail, Z., Bourke, A., & Young, C. (2019). A structured cognitive intervention pathway as a decision-support tool for non-pharmacological interventions within a dementia care service (Innovative practice). *Dementia*, 1471301219886243.

Castellan, C., Sluga, S., Spina, E., & Sanson, G. (2016). Nursing diagnoses, outcomes and interventions as measures of patient complexity and nursing care requirement in intensive care unit. *Journal of Advanced Nursing*, *72*(6), 1273–1286.

Cen, X., Li, Y., Hasselberg, M., Caprio, T., Conwell, Y., & Temkin-Greener, H. (2018). Aggressive behaviors among nursing home residents: Association with dementia and behavioral health disorders. *Journal of the American Medical Directors Association*, *19*(12), 1104–1109.

Chaio, P. C., Chien, W. C., Chung, C. H., Chu, C. W., Yeh, C. B., Huang, S. Y., ... & Tzeng, N. S. (2015). Cognitive enhancers associated with decreased risk of injury in patients with dementia: A nationwide cohort study in Taiwan. *Journal of Investigative Medicine*, *66*(3), 684–692.

Chambers, C., & Ryder, E. (2018). *Compassion and caring in nursing*. Abingdon, UK: Radcliffe Publishing.

Chandra, M., Duri, A., & Smith, M. (2019). Prevalence of chronic disease risk factors in 35-to 44-year-old humanitarian arrivals to New South Wales (NSW), Australia. *Australian Journal of Primary Health*, *25*(1), 19–23.

Chang, C. C., & Lin, L. C. (2005). Effects of a feeding skills training programme on nursing assistants and dementia patients. *Journal of Clinical Nursing*, *14*(10), 1185–1192.

Chang, C. S. (2015). Moderating effects of nurses' organizational support on the relationship between job satisfaction and organizational commitment. *Western Journal of Nursing Research*, *37*(6), 724–745.

Chang, E., Johnson, A., & Hancock, K. (2018). Principles for nursing practice: Advanced dementia. In E. Chang & A. Johnson (Eds.), *Living with chronic illness and disability: Principles for nursing practice* (3rd ed., pp. 267–286). Sydney, NSW: Elsevier.

Chang, H. Y., Shyu, Y. I. L., Wong, M. K., Friesner, D., Chu, T. L., & Teng, C. I. (2015). Which aspects of professional commitment can effectively retain nurses in the nursing profession? *Journal of Nursing Scholarship*, *47*(5), 468–476.

Charalambous, A., Radwin, L., Berg, A., Sjovall, K., Patiraki, E., Lemonidou, C., ...& Suhonen, R. (2016). An international study of hospitalized cancer patients' health status, nursing care quality, perceived individuality in care and trust in nurses: A path analysis. *International Journal of Nursing Studies*, *61*, 176–186.

Chari, A. V., Engberg, J., Ray, K. N., & Mehrotra, A. (2015). The opportunity costs of informal elder-care in the United States: New estimates from the American time use survey. *Health Services Research*, *50*(3), 871–882.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, UK: Sage Publications Ltd.

Charmaz, K. (2008). Constructionism and the grounded theory method. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 397–412). New York, NY: The Guildford Press.

Charmaz, K. (2014). *Constructing grounded theory*. (2nd ed.). London, UK: Sage Publications Ltd.

Charmaz, K. (2017). The power of constructivist grounded theory for critical inquiry. *Qualitative Inquiry*, *23*(1), 34–45.

Charmaz, K., & Belgrave, L. L. (2007). Grounded theory. In G. Ritzer (Ed.), *The Blackwell encyclopedia of sociology* (pp. 121–128). Hoboken, NJ: Wiley-Blackwell. doi:10.1002/9781405165518.wbeosg070

Charmaz, K., & Belgrave, L. L. (2012). Qualitative interviewing and grounded theory analysis. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft* (2nd ed., pp. 347–365). Thousand Oaks, CA: Sage Publications, Inc.

Charras, K., Eynard, C., & Viatour, G. (2016). Use of space and human rights: Planning dementia friendly settings. *Journal of Gerontological Social Work*, *59*(3), 181–204.

Chaudhury, H. (2008). *Remembering home: Rediscovering the self in dementia*. Baltimore, MD: The John Hopkins Unoversity Press.

Chaudhury, H., & Cooke, H. (2014). Design matters in dementia care: The role of the physical environment in dementia care settings. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care* (2nd ed., pp. 144–158). London. UK: Open University Press.

Chaudhury, H., Cooke, H. A., Cowie, H., & Razaghi, L. (2018). The influence of the physical environment on residents with dementia in long-term care settings: A review of the empirical literature. *The Gerontologist*, *58*(5), e325–e337.

Chaudhury, H., Hung, L., & Badger, M. (2013). The role of physical environment in supporting person-centered dining in long-term care: A review of the literature. *American Journal of Alzheimer's Disease & Other Dementias*, *28*(5), 491–500.

Chaudhury, H., Hung, L., Rust, T., & Wu, S. (2017). Do physical environmental changes make a difference? Supporting person-centered care at mealtimes in nursing homes. *Dementia*, *16*(7), 878–896.

Chen, M. F., Ho, C. H., Lin, C. F., Chung, M. H., Chao, W. C., Chou, H. L., & Li, C. K. (2016). Organisation-based self-esteem mediates the effects of social support and job satisfaction on intention to stay in nurses. *Journal of Nursing Management*, *24*(1), 88–96.

Chen, Y., Glass, K., Liu, B., Korda, R. J., Riley, T. V., & Kirk, M. D. (2017). Burden of Clostridium difficile infection: Associated hospitalization in a cohort of middle-aged and older adults. *American Journal of Infection Control*, *45*(5), 508–511.

Chen, Y., Kumfor, F., Landin-Romero, R., Irish, M., Hodges, J. R., & Piguet, O. (2018). Cerebellar atrophy and its contribution to cognition in frontotemporal dementias. *Annals of Neurology, 84*(1), 98–109.

Cheng, C., Bartram, T., Karimi, L., & Leggat, S. (2016). Transformational leadership and social identity as predictors of team climate, perceived quality of care, burnout and turnover intention among nurses. *Personnel Review*, *45*(6), 1200–1216.

Cheng, S. T. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Reports*, *19*(9), Article number: 64.

Chenitz, W., & Swanson, J. (1986). *From practice to grounded theory: Qualitative research in nursing.* Menlo Park, CA: Addison-Wesley Publishing.

Chenoweth, L., Merlyn, T., Jeon, Y. H., Tait, F., & Duffield, C. (2014). Attracting and retaining qualified nurses in aged and dementia care: Outcomes from an Australian study. *Journal of Nursing Management*, *22*(2), 234–247.

Chenoweth, L., Stein-Parbury, J., Lapkin, S., Wang, A., Liu, Z., & Williams, A. (2019). Effects of person-centered care at the organisational-level for people with dementia. A systematic review. *PloS One*, *14*(2), e0212686.

Chenoweth, L., Stein-Parbury, J., Lapkin, S., & Wang, Y. A. (2015). Organisational interventions for promoting person-centred care for people with dementia. *Cochrane Database of Systematic Reviews*, (11), 1–11.

Cherry, B., & Jacob, S. R. (2016). *Contemporary nursing: Issues, trends, & management*. St Louis, MO: Elsevier Health Sciences.

Chertkow, H. (2018). An action plan to face the challenge of dementia: International statement on dementia from IAP for health. *The Journal of Prevention of Alzheimer's Disease*, *5*(3), 207–212.

Chester, H., Clarkson, P., Davies, L., Hughes, J., Islam, M. S., Kapur, N., ... & Challis, D. (2018). Cognitive aids for people with early stage dementia versus treatment as usual (Dementia Early Stage Cognitive Aids New Trial (DESCANT)): Study protocol for a randomised controlled trial. *Trials*, *19*(1), Article number: 546.

Chisengantambu, C., Robinson, G. M., & Evans, N. (2018). Nurse managers and the sandwich support model. *Journal of Nursing Management*, *26*(2), 192–199.

Cho, E., Lee, N. J., Kim, E. Y., Kim, S., Lee, K., Park, K. O., & Sung, Y. H. (2016). Nurse staffing level and overtime associated with patient safety, quality of care, and care left undone in hospitals: A cross-sectional study. *International Journal of Nursing Studies*, *60*, 263–271.

Choi, Y. J., & Choi, H. B. (2019). Nurses'positive experiences in caring for older adults with dementia: A qualitative analysis. *Journal of Gerontological Nursing*, *45*(1), 31–37.

Cholerton, B., Johnson, C. O., Fish, B., Quinn, J. F., Chung, K. A., Peterson-Hiller, A. L., ... & Edwards, K. L. (2018). Sex differences in progression to mild cognitive impairment and dementia in Parkinson's disease. *Parkinsonism & Related Disorders*, *50*, 29–36.

Christopher, S. A., Chiarella, E. M., & Waters, D. (2015). Can Generation Y nurses supply areas of shortage? New graduate challenges in today's job market. *Australian Journal of Advanced Nursing, 33*(2), 35–44.

Cioffi, J., & Ferguson Am, L. (2009). Team nursing in acute care settings: Nurses' experiences. *Contemporary Nurse*, *33*(1), 2–12.

Cipriani, G., Nuti, A., & Di Fiorino, M. (2018). Pain and dementia. A brief review. *EC Neurology*, *10*, 643–652.

Ciudin, A., Espinosa, A., Simo-Servat, O., Ruiz, A., Alegret, M., Hernandez, C., ... & Simo, R. (2017). Type 2 diabetes is an independent risk factor for dementia conversion in patients with mild cognitive impairment. *Journal of Diabetes and Its Complications, 31*(8), 1272–1274.

Clague, F., Mercer, S. W., McLean, G., Reynish, E., & Guthrie, B. (2016). Comorbidity and polypharmacy in people with dementia: Insights from a large, population-based cross-sectional analysis of primary care data. *Age and Ageing*, *46*(1), 33–39.

Clarke, C., & Irwin, H. (2016). Humour and dementia. In C. Clarke & E. Wolverson (Eds.), *Positive psychology approaches to dementia* (pp. 110–132). London, UK: Jessica Kingsley Publishers.

Clarkson, P., Hughes, J., Roe, B., Giebel, C., Jolley, D., Poland, F., ... & Challis, D. (2018). Systematic review: Effective home support in dementia care, components and impacts – Stage 2, effectiveness of home support interventions. *Journal of Advanced Nursing*, *74*(3), 507–527.

Cleary, J., & Doody, O. (2017). Nurses' experience of caring for people with intellectual disability and dementia. *Journal of Clinical Nursing*, *26*(5–6), 620–631.

Clendon, J., & Walker, L. (2016). Juggling nursing and family care. *Kai Tiaki: Nursing New Zealand*, *22*(2), 26.

Clevenger, C. K., Chu, T. A., Yang, Z., & Hepburn, K. W. (2012). Clinical care of persons with dementia in the emergency department: A review of the literature and agenda for research. *Journal of the American Geriatrics Society*, *60*(9), 1742–1748.

Clifford, C., & Doody, O. (2018). Exploring nursing staff views of responsive behaviours of people with dementia in long-stay facilities. *Journal of Psychiatric and Mental Health Nursing*, *25*(1), 26–36.

Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R. (2013). The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families. *International Journal of Nursing Studies*, *50*(11), 1495–1503.

Cohen-Mansfield, J. (2018). The impact of group activities and their content on persons with dementia attending them. *Alzheimer's Research & Therapy*, *10*(1), Article number: 37.

Comans, T. A., Peel, N. M., Hubbard, R. E., Mulligan, A. D., Gray, L. C., & Scuffham, P. A. (2016). The increase in healthcare costs associated with frailty in older people discharged to a post-acute transition care program. *Age and Ageing*, *45*(2), 317–320.

Comino, E. J., Harris, M. F., Islam, M. F., Tran, D. T., Jalaludin, B., Jorm, L., ... & Haas, M. (2015). Impact of diabetes on hospital admission and length of stay among a general population aged 45 year or more: A record linkage study. *BMC Health Services Research*, *15*(1), Article number: 12.

Conn, D., Snowdon, J., & Purandare, N. (2017). Residential care for people with dementia. In D. Ames, J. T. O’Brien, & A. Burns (Eds.), *Dementia* (5th ed., pp. 312–323). Boca Raton, FL: CRC Press.

Connor, J. A., Mott, S., Green, A., Larson, C., & Hickey, P. (2016). Measurement of quality of nursing practice in congenital cardiac care. *American Journal of Critical Care*, *25*(2), 128–135.

Cooke, H. A. (2018). Staff personhood in dementia care settings:“Do they care about me?” *International Journal of Older People Nursing*, *13*(2), e12184.

Cooke, H., & Chaudhury, H. (2017). Actual vs. intended use of the physical environment in dementia care settings: Staff perspectives. *Innovation in Aging*, *1*(Suppl 1), 951.

Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher, 18*(4), 17–22.

Cooney, A., & O’Shea, E. (2019). The impact of life story work on person-centred care for people with dementia living in long-stay care settings in Ireland. *Dementia*, *18*(7–8), 2731–2746.

Cooper, C., Barber, J., Griffin, M., Rapaport, P., & Livingston, G. (2016). Effectiveness of START psychological intervention in reducing abuse by dementia family carers: Randomized controlled trial. *International Psychogeriatrics, 28*(6), 881–887.

Cooper, C., Marston, L., Barber, J., Livingston, D., Rapaport, P., Higgs, P., & Livingston, G. (2018). Do care homes deliver person-centred care? A cross-sectional survey of staff-reported abusive and positive behaviours towards residents from the MARQUE (Managing Agitation and Raising Quality of Life) English national care home survey. *PloS One, 13*(3), e0193399.

Cope, M. (2016). Transcripts: Coding and analysis. In D. Richardson (Ed.), *International encyclopedia of geography: People, the earth, environment and technology* (pp. 1–7). Hoboken, NJ: Wiley-Blackwell.

Cope, V. C., Jones, B., & Hendricks, J. (2016). Residential aged care nurses: Portraits of resilience. *Contemporary Nurse*, *52*(6), 736–752.

Cope, V. C., & Murray, M. (2017). Leadership styles in nursing. *Nursing Standard*, *31*(43), 61–70.

Corbett, A., Husebo, B., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D., & Ballard, C. (2012). Assessment and treatment of pain in people with dementia. *Nature Reviews Neurology*, *8*(5), 264–274.

Corbett, A., Pickett, J., Burns, A., Corcoran, J., Dunnett, S. B., Edison, P., ... & Kearns, I. (2012). Drug repositioning for Alzheimer’s disease. *Nature Reviews Drug Discovery, 11*(11), 833–846.

Corbett, A., Smith, J., & Ballard, C. (2012). New and emerging treatments for Alzheimer’s disease. *Expert Review of Neurotherapeutics, 12*(5), 535–543.

Corbett, A., Smith, J., Creese, B., & Ballard, C. (2012). Treatment of behavioral and psychological symptoms of Alzheimer’s disease. *Current Treatment Options in Neurology, 14*(2), 113–125.

Corbi, G., Grattagliano, I., Sabbà, C., Fiore, G., Spina, S., Ferrara, N., & Campobasso, C. P. (2019). Elder abuse: Perception and knowledge of the phenomenon by healthcare workers from two Italian hospitals. *Internal and Emergency Medicine, 14*(4), 549–555.

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, *13*(1), 3–21.

Cosgrave, C., Maple, M., & Hussain, R. (2018). An explanation of turnover intention among early-career nursing and allied health professionals working in rural and remote Australia – Findings from a grounded theory study. *Rural & Remote Health, 18*(3), 1–17.

Cottrell, L., Duggleby, W., Ploeg, J., McAiney, C., Peacock, S., Ghosh, S., ... & Swindle, J. (2018). Using focus groups to explore caregiver transitions and needs after placement of family members living with dementia in 24-hour care homes. *Aging & Mental Health*, *27,* 1–6.

Cousins, C., Burrows, R., Cousins, G., Dunlop, E., & Mitchell, G. (2016). An overview of the challenges facing care homes in the UK. *Nursing Older People*, *28*(9), 18–21.

Cox, T., Hoang, H., Goldberg, L. R., & Baldock, D. (2019). Aboriginal community understandings of dementia and responses to dementia care. *Public Health*, *172*, 15–21.

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; Merging or clear boundaries? *Journal of Advanced Nursing*, *26*(3), 623–630.

Crespo, M., Hornillos, C., & Gomez, M. M. (2013). Dementia special care units: A comparison with standard units regarding residents' profile and care features. *International Psychogeriatrics*, *25*(12), 2023–2031.

Crimmins, E. M., Saito, Y., Kim, J. K., Zhang, Y. S., Sasson, I., & Hayward, M. D. (2018). Educational differences in the prevalence of dementia and life expectancy with dementia: Changes from 2000 to 2010. *The Journals of Gerontology: Series B*, *73*(suppl_1), S20–S28.

Cronfalk, B. S., Norberg, A., & Ternestedt, B. M. (2018). They are still the same – Family members' stories about their relatives with dementia disorders as residents in a nursing home. *Scandinavian Journal of Caring Sciences*, *32*(1), 168–176.

Crossetti, M. D. G. O., Goes, M. G., & de Brum, C. N. (2016). Application of constructivist grounded theory in nursing research. *The Qualitative Report*, *21*(13), 48–53.

Cummings, J. L., Tong, G., & Ballard, C. (2019). Treatment combinations for Alzheimer's disease: Current and future pharmacotherapy options. *Journal of Alzheimer's Disease, 67*(3), 779–794.

Curryer, C., Gray, M., & Byles, J. E. (2018). Older women's expectations of care, reciprocity, and government support in Australia. "Am I Not Worthy?" *Ethics and Social Welfare*, *12*(3), 259–271.

Curtis, L. A., & Burns, A. (2015). *Unit costs of health and social care 2015*. Canterbury, UK: University of Kent.

Dai, M. H., Zheng, H., Zeng, L. D., & Zhang, Y. (2018). The genes associated with early-onset Alzheimer’s disease. *Oncotarget*, *9*(19), 15132–15143.

Dal Molin, A., Gatta, C., Boggio Gilot, C., Ferrua, R., Cena, T., Manthey, M., & Croso, A. (2018). The impact of primary nursing care pattern: Results from a before–after study. *Journal of Clinical Nursing*, *27*(5–6), 1094–1102.

Daley, S., Murray, J., Farina, N., Page, T. E., Brown, A., Basset, T., ...& Banerjee, S. (2019). Understanding the quality of life of family carers of people with dementia: Development of a new conceptual framework. *International Journal of Geriatric Psychiatry*, *34*(1), 79–86.

Davey, D. A. (2016). Alzheimer’s disease, cerebrovascular disease and dementia: Pathology, risk factors and prevention; a comprehensive approach. *Journal of. Neurology and Neuroscience*, *7*, 91–104.

Davidson, P., & Everett, B. (2015). Managing approaches to nursing care delivery. In E. Chang & J. Daly (Eds.), *Transitions in nursing: Preparing for professional practice* (4th ed., pp. 125–142). Sydney, NSW: Elsevier Health Sciences.

Davies, A., & James, A. (2016). *Geographies of ageing: Social processes and the spatial unevenness of population ageing*. Abingdon, UK: Routledge.

Davis, J., Morgans, A., Birks, M., & Browning, C. (2016). The rhetoric and reality of nursing in aged care: Views from the inside. *Contemporary Nurse*, *52*(2-3), 191–203.

Davison, T. E., McCabe, M. P., Bird, M., Mellor, D., MacPherson, S., Hallford, D., ...& O’Connor, D. W. (2016). Behavioral symptoms of dementia that present management difficulties in nursing homes: Staff perceptions and their concordance with informant scales. *Journal of Gerontological Nursing*, *43*(1), 34–43.

Davy, C., Bleasel, J., Liu, H., Tchan, M., Ponniah, S., & Brown, A. (2015). Effectiveness of chronic care models: Opportunities for improving healthcare practice and health outcomes: A systematic review. *BMC Health Services Research*, *15*(1), Article number: 194.

De Boer, B., Beerens, H., Katterbach, M., Viduka, M., Willemse, B., & Verbeek, H. (2018). The physical environment of nursing homes for people with dementia:

Traditional nursing homes, small-scale living facilities, and green care farms. *Healthcare, 6*(4), 137–148.

De Boer, B., Hamers, J. P., Zwakhalen, S. M., Tan, F. E., Beerens, H. C., & Verbeek, H. (2017). Green care farms as innovative nursing homes, promoting activities and social interaction for people with dementia. *Journal of the American Medical Directors Association*, *18*(1), 40–46.

Deeks, L. S., Cooper, G. M., Draper, B., Kurrle, S., & Gibson, D. M. (2016). Dementia, medication and transitions of care. *Research in Social and Administrative Pharmacy*, *12*(3), 450–460.

Deckers, K., van Boxtel, M. P., Schiepers, O. J., de Vugt, M., Munoz Sanchez, J. L., Anstey, K. J., ... & Köhler, S. (2015). Target risk factors for dementia prevention: A systematic review and Delphi consensus study on the evidence from observational studies. *International Journal of Geriatric Psychiatry*, *30*(3), 234–246.

De Kwaadsteniet, E. W., Kiyonari, T., Molenmaker, W. E., & van Dijk, E. (2019). Do people prefer leaders who enforce norms? Reputational effects of reward and punishment decisions in noisy social dilemmas. *Journal of Experimental Social Psychology*, *84*, 103800.

Delaney, L. J. (2018). Patient-centred care as an approach to improving health care in Australia. *Collegian*, *25*(1), 119–123.

Demange, M., Pino, M., Kerhervé, H., Rigaud, A. S., & Cantegreil-Kallen, I. (2019). Management of acute pain in dementia: A feasibility study of a robot-assisted intervention. *Journal of Pain Research*, *12*, 1833–1846.

Dening, K. H., Sampson, E. L., & De Vries, K. (2019). Advance care planning in dementia: Recommendations for healthcare professionals. *Palliative Care: Research and Treatment*, *12,* 1–10.

Dent, E., Hoon, E., Karnon, J., Newbury, J., Kitson, A., & Beilby, J. (2016). Frailty and health service use in rural South Australia. *Archives of Gerontology and Geriatrics*, *62*, 53–58.

Department of Health. (2016). *Medicare benefits schedule*. Retrieved from http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Home. Accessed June 26, 2017

Department of Health. (2017). *Ageing and aged care.* Retrieved from https://agedcare.health.gov.au/royal-commission-into-aged-care-quality-and-safety

Department of Prime Minister and Cabinet. (2018). *Announcement of Royal Commission into Aged Care Quality and Safety*. Retrieved from https://www.pm.gov.au/media/royal-commission-aged-care-quality-and-safety

Devanand, D. P. (2017). Prediction of response to antipsychotics in patients with dementia remains a conundrum. *The American Journal of Geriatric Psychiatry*, *25*(7), 717–718.

Dhakal, S., Nankervis, A., Connell, J., Fitzgerald, S., & Burgess, J. (2017). Attracting and retaining personal care assistants into the Western Australia (WA) residential aged care sector. *Labour & Industry: AJournal of the Social and Economic Relations of Work*, *27*(4), 333–349.

Digby, R., Lee, S., & Williams, A. (2017). The experience of people with dementia and nurses in hospital: An integrative review. *Journal of Clinical Nursing, 26*(9–10), 1152–1171.

Dixon, J., Laing, J., & Valentine, C. (2018). A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales. *Dementia*, 1471301218770478.

Dixon-Woods, M., & Martin, G. P. (2016). Does quality improvement improve quality?*Future Hospital Journal*, *3*(3), 191–194.

Doan, T., Brennan, S., & Osada, H. (2018, July). *Dementia care: Long-term care facilities' environmental design and quality-of-life of older adults*. Paper presented at the 29th International Nursing Research Congress: Innovative Global Nursing Practice and Education Through Research and Evidence-based Practice, Melbourne, Vic.

Dolja-Gore, X., Harris, M. L., Kendig, H., & Byles, J. E. (2017). Patterns of hospitalization risk for women surviving into very old age: Findings from the Australian longitudinal study on women's health. *Medical Care*, *55*(4), 352–361.

Donabedian A. (1966). Evaluating the quality of medical care. *The Milbank Quarterly*, *44*(3), 166–203.

Donabedian A. (2003). *An introduction to quality assurance in health care*. New York, NY: Oxford University Press.

D'Onofrio, G., Sancarlo, D., Ricciardi, F., Panza, F., Seripa, D., Cavallo, F., ... & Greco, A. (2017). Information and communication technologies for the activities of daily living in older patients with dementia: A systematic review. *Journal of Alzheimer's Disease*, *57*(3), 927–935.

Dong, H. S., Han, C., Jeon, S. W., Yoon, S., Jeong, H. G., Huh, Y. J., ... & Steffens, D. C. (2016). Characteristics of neurocognitive functions in mild cognitive impairment with depression. *International Psychogeriatrics*, *28*(7), 1181–1190.

Dossett, L. A., Hudson, J. N., Morris, A. M., Lee, M. C., Roetzheim, R. G., Fetters, M. D., & Quinn, G. P. (2017). The primary care provider (PCP)–cancer specialist relationship: A systematic review and mixed-methods meta-synthesis. *CA: ACancer Journal for Clinicians*, *67*(2), 156–169.

Dow, B., Vrantsidis, F., O'Brien, M., Joosten, M., & Gahan, L. (2020). Elder abuse in Australia. In M. A. Shankardass (Ed.), *International handbook of elder abuse and mistreatment* (pp. 559–574). Singapore, Singapore: Springer International Publishing.

Downs, M., & Collins, L. (2015). Person-centred communication in dementia care. *Nursing Standard*, *30*(11), 37–41.

Dreier, A., Thyrian, J. R., Eichler, T., & Hoffmann, W. (2016). Qualifications for nurses for the care of patients with dementia and support to their caregivers: A pilot evaluation of the dementia care management curriculum. *Nurse Education Today*, *36*, 310–317.

Dubois, B., Gauthier, S., & Cummings, J. (2013). The utility of the new research diagnostic criteria for Alzheimer's disease. *International Psychogeriatrics*, *25*(2), 175–177.

Dubois, C. A., D'Amour, D., Brault, I., Dallaire, C., Déry, J., Duhoux, A., ... & Zufferey, A. (2017). Which priority indicators to use to evaluate nursing care performance? A discussion paper. *Journal of Advanced Nursing*, *73*(12), 3154–3167.

Duckett, S. (2018). Expanding the breadth of Medicare: Learning from Australia. *Health Economics, Policy and Law*, *13*(3-4), 344–368.

Duffield, D., Diers, D., O'Brien-Pallas, L., Aisbett, C., Roche, M., King, M., & Aisbett, K. (2011). Nursing staffing, nursing workload, the work environment and patient outcomes. *Applied Nursing Research*, *24*(4), 244–255.

Duffield, C., Graham, E., Donoghue, J., Griffiths, R., Bichel-Findlay, J., & Dimitrelis, S. (2015). Workforce shortages and retention of older nurses. *Australian Nursing and Midwifery Journal*, *22*(7), 18–19.

Duffield, C., Roche, M., & Merrick, E. T. (2006). Methods of measuring nursing workload in Australia. *Collegian*, *13*(1), 16–22.

Duffy, E. I., Garry, J., Talbot, L., Pasternak, D., Flinn, A., Minardi, C., ... & Jawa, R. S. (2018). A pilot study assessing the spiritual, emotional, physical/environmental, and physiological needs of mechanically ventilated surgical intensive care unit patients via eye tracking devices, head nodding, and communication boards. *Trauma Surgery & Acute Care Open*, *3*(1), e000180.

Dunn, J., Balfour, M., Moyle, W., Cooke, M., Martin, K., Crystal, C., & Yen, A. (2013). Playfully engaging people living with dementia: Searching for Yum Cha moments. *International Journal of Play*, *2*(3), 174–186.

Dunphy, L. M., Winland-Brown, J., Porter, B., & Thomas, D. (2015). *Primary care: The art and science of advanced practice nursing* (4th ed.). Philadelphia, PA: F. A. Davis Company.

Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012). Moving beyond patient and client approaches: Mobilizing "authentic partnerships" in dementia care, support and services. *Dementia*, *11*(4), 427–452.

Dwolatzky, T., Brodsky, J., Azaiza, F., Clarfield, A. M., Jacobs, J. M., & Litwin, H. (2017). Coming of age: Health-care challenges of an ageing population in Israel. *The Lancet*, *389*(10088), 2542–2550.

Dworkin, S. L. (2012). Sample size policy for qualitative studies using in-depth interviews. *Archives of Sexual Behavior, 41*, 1319–1320.

Eckermann, S., Phillipson, L., & Fleming, R. (2019). Re-design of aged care environments is key to improved care quality and cost effective reform of aged and health system care. *Applied Health Economics and Health Policy*, *17*(2), 127–130.

Eckerström, C., Klasson, N., Olsson, E., Selnes, P., Rolstad, S., & Wallin, A. (2018). Similar pattern of atrophy in early- and late-onset Alzheimer’s disease. *Alzheimer’s & Dementia: Diagnosis, Assessment & Disease Monitoring*, *10*, 253–259.

Edney, L. C., Afzali, H. H. A., Cheng, T. C., & Karnon, J. (2018). Estimating the reference incremental cost-effectiveness ratio for the Australian health system. *PharmacoEconomics*, *36*(2), 239–252.

Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: Person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, *19*(17–18), 2611–2618.

Edvardsson, D., Petersson, L., Sjogren, K., Lindkvist, M., & Sandman, P. O. (2014). Everyday activities for people with dementia in residential aged care: Associations with person-centredness and quality of life. *International Journal of Older People Nursing*, *9*(4), 269–276.

Edvardsson, D., Sandman, P. O., & Rasmussen, B. (2012). Forecasting the ward climate: A study from a dementia care unit. *Journal of Clinical Nursing*, *21*(7-8), 1136–114.

Edvardsson, D., Sjögren, K., Lood, Q., Bergland, Å., Kirkevold, M., & Sandman, P. O. (2017). A person-centred and thriving-promoting intervention in nursing homes-study protocol for the U-Age nursing home multi-centre, non-equivalent controlled group before-after trial. *BMC Geriatrics*, *17*(1), Article number: 22.

Edvardsson, D., Watt, E., & Pearce, F. (2017). Patient experiences of caring and person-centredness are associated with perceived nursing care quality. *Journal of Advanced Nursing*, *73*(1), 217–227.

Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer’s disease: Current status and ways forward. *The Lancet Neurology*, *7*(4), 362–367.

Edward, K. L., Stephenson, J., Ousey, K., Lui, S., Warelow, P., & Giandinoto, J. A. (2016). A systematic review and meta-analysis of factors that relate to aggression perpetrated against nurses by patients/relatives or staff. *Journal of Clinical Nursing*, *25*(3–4), 289–299.

Ehrlich, K., Boström, A. M., Mazaheri, M., Heikkilä, K., & Emami, A. (2015). Family caregivers’ assessments of caring for a relative with dementia: A comparison of urban and rural areas. *International Journal of Older People Nursing*, *10*(1), 27–37.

Eliopoulos, C. (2015). *Fast facts for the long-term care nurse: What nursing home and assisted living nurses need to know in a nutshell*. New York, NY: Springer Publishing Company.

Elliott, K. E. J., Rodwell, J., & Martin, A. J. (2017). Aged care nurses’ job control influence satisfaction and mental health. *Journal of Nursing Management*, *25*(7), 558–568.

Ellis, P. (2019). *Evidence-based practice in nursing* (4th ed.). London, UK: Learning Matters.

El-Saifi, N., Moyle, W., Jones, C., & Tuffaha, H. (2018). Medication adherence in older patients with dementia: A systematic literature review. *Journal of Pharmacy Practice*, *31*(3), 322–334.

Eltaybani, S., Noguchi-Watanabe, M., Igarashi, A., Saito, Y., & Yamamoto-Mitani, N. (2018). Factors related to intention to stay in the current workplace among long-term care nurses: A nationwide survey. *International Journal of Nursing Studies*, *80*, 118–127.

Elvish, R., Burrow, S., Cawley, R., Harney, K., Pilling, M., Gregory, J., & Keady, J. (2018). “Getting to Know Me”: The second phase roll-out of a staff training programme for supporting people with dementia in general hospitals. *Dementia*, *17*(1), 96–109.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*(4286), 129–136.

Engward, H. (2013). Understanding grounded theory. *Nursing Standard*, *28*(7), 37–41.

Epp, T. D. (2003). Person-centred dementia care: A vision to be refined. *The Canadian Alzheimer Disease Review*, *5*(3), 14–19.

Eriksson, B., & Granerud, A. (2018). Psychiatric/mental health nursing care of the older adult: Mental health in old age. In J. C. Santos & J. R. Cutcliffe (Eds.), *European psychiatric/mental health nursing in the 21st century* (pp. 521–531). Cham, Switzerland: Springer International Publishing.

Ersser, S. J. (2019). *Nursing as a therapeutic activity: An ethnography*. Abingdon, UK: Routledge.

Estabrooks, C. A., Squires, J. E., Carleton, H. L., Cummings, G. G., & Norton, P. G. (2015). Who is looking after Mom and Dad? Unregulated workers in Canadian long-term care homes. *Canadian Journal on Aging*, *34*(1), 47–59.

Evans, R. J., & Donnelly, G. W. (2006). A model to describe the relationship between knowledge, skill, and judgment in nursing practice. *Nursing Forum*, *41*(4), 150–157.

Evripidou, M., Charalambous, A., Middleton, N., & Papastavrou, E. (2019). Nurses' knowledge and attitudes about dementia care: Systematic literature review. *Perspectives in Psychiatric Care*, *55*(1), 48–60.

Ezzati, A., Wang, C., Katz, M. J., Derby, C. A., Zammit, A. R., Zimmerman, M. E., ... & Lipton, R. B. (2019). The temporal relationship between pain intensity and pain interference and incident dementia. *Current Alzheimer Research*, *16*(2), 109–115.

Fairbrother, G. (2010). *Team-based versus patient allocation systems in nursing: A comparative evaluation and socio-cultural discussion.* (Doctoral dissertation). Retrieved from file:///C:/Users/PC/Downloads/whole%20(1).pdf

Fairbrother, G., Chiarella, M., & Braithwaite, J. (2015). Models of care choices in today's nursing workplace: Where does team nursing sit? *Australian Health Review*, *39*(5), 489–493.

Falk, A. C., & Wallin, E. M. (2016). Quality of patient care in the critical care unit in relation to nurse patient ratio: A descriptive study. *Intensive and Critical Care Nursing*, *35*, 74–79.

Fang, B., & Yan, E. (2018). Abuse of older persons with dementia: A review of the literature. *Trauma, Violence, & Abuse*, *19*(2), 127–147.

Farag, I., Howard, K., Hayes, A. J., Ferreira, M. L., Lord, S. R., Close, J. T., ... & Sherrington, C. (2015). Cost-effectiveness of a home-exercise program among older people after hospitalization. *Journal of the American Medical Directors Association*, *16*(6), 490–496.

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., ... & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, *13*(5), 572–581.

Farlow, M. R., Borson, S., Connor, S. R., Grossberg, G. T., & Mittelman, M. S. (2016). Quality improvement in skilled nursing facilities for residents with Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*, *31*(2), 156–162.

Farrell, M. J., & Cole, L. J. (2016). Central pathophysiology of dementia and pain. In S. Lautenbacher & S. J. Gibson (Eds.), *Pain in dementia* (pp. 55–70). Washington, DC: IASP Press.

Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist*, *58*(suppl_1), S10–S19.

Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Moniz-Cook, E. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. *The British Journal of Psychiatry*, *208*(5), 429–434.

Felton, G. (1975). Increasing the quality of nursing care by introducing the concept of primary nursing: A model project. *Nursing Research*, *24*(1), 27–32.

Feo, R., Kitson, A., & Conroy, T. (2018). How fundamental aspects of nursing care are defined in the literature: A scoping review. *Journal of Clinical Nursing*, *27*(11–12), 2189–2229. doi.org/10.1111/jocn.14313

Fernandes, M. J. V., & Mathai, M. A. (2019). Effectiveness of team nursing care model on satisfaction of nursing care among patients and nurses – A pre-experimental study. *Paripex-Indian Journal of Research*, *8*(4), 51–52.

Fernandez, R., Johnson, M., Tran, D. T., & Miranda, C. (2012). Models of care in nursing: A systematic review. *International Journal of Evidence-Based Healthcare, 10*(4), 324–337.

Holahan, C. J., Jacquart, J., & Moos, R. H. (2019). Health care work environments. In C. D. Llewellyn, S. Ayers, C. McManus, S. Newman, K. J. Petrie, T. A. Revenson, & J. Weinman (Eds.), *Cambridge handbook of psychology, health and medicine* (3rd ed., pp. 329–333). Cambridge, UK: Cambridge University Press.

Fetherstonhaugh, D., Haesler, E., & Bauer, M. (2019). Promoting mealtime function in people with dementia: A systematic review of studies undertaken in residential aged care. *International Journal of Nursing Studies, 96*, 99–118.

Fetherstonhaugh, D., Tarzia, L., Bauer, M., Nay, R., & Beattie, E. (2016). “The red dress or the blue?” How do staff perceive that they support decision making for people with dementia living in residential aged care facilities? *Journal of Applied Gerontology*, *35*(2), 209–226.

Field, S. (2015). Human rights and residential care for older persons– An Australian perspective. In H. Meenan, N. Rees, & I. Doron (Eds.), *Towards human rights in residential care for older persons* (pp. 46–65). Abingdon, UK: Routledge.

Fiorio, C. V., Gorli, M., & Verzillo, S. (2018). Evaluating organizational change in health care: The patient-centered hospital model. *BMC Health Services Research, 18*(1), 1–27.

Fischer, A., Landeira-Fernandez, J., Sollero de Campos, F., & Mograbi, D. C. (2019). Empathy in Alzheimer’s disease: Review of findings and proposed model. *Journal of Alzheimer’s Disease,* (Preprint), 1–13.

Fishman, G. A. (2018). Attending registered nurses: Evolving role perceptions in clinical care teams. *Nursing Economics*, *36*(1), 12–22.

Fitzpatrick, L. (2019). Practical strategies to help develop dementia-friendly hospital wards. *Nursing Older People*, *30*(2), 30–34.

Fleming, R., Goodenough, B., Low, L. F., Chenoweth, L., & Brodaty, H. (2016). The relationship between the quality of the built environment and the quality of life of people with dementia in residential care. *Dementia*, *15*(4), 663–680.

Flick, U. (2018). *An introduction to qualitative research* (6th ed.). London, UK: Sage Publications Ltd.

Flicker, B. (2018). *Managerial insight and optimal algorithms.* Working paper, McDermott Graduate Fellow and Doctoral Candidate in Operations Management, Jindal School of Management. Richardson, TX: University of Texas at Dallas.

Foley, G., & Timonen, V. (2015). Using grounded theory method to capture and analyze health care experiences. *Health Services Research*, *50*(4), 1195–1210.

Foster, P. D., Camacho, X., Vigod, S., Yao, Z., Juurlink, D. N., Paterson, J. M., ... & Gomes, T. (2016). Trends in the use and cost of antipsychotics among older adults from 2007 to 2013: A repeated cross-sectional study. *CMAJ Open*, *4*(2), E292–E297.

Fotaki, M. (2015). Why and how is compassion necessary to provide good quality healthcare? *International Journal of Health Policy and Management*, *4*(4), 199–201.

Fowler, J., Howarth, T., & Hardy, J. (2006). Trialing collaborative nursing models of care: The impact of change. *TheAustralian Journal of Advanced Nursing, 23*(4), 40–46.

Fox, M. T., Sidani, S., Butler, J. I., & Tregunno, D. (2017). Nurses’ perspectives on the geriatric nursing practice environment and the quality of older people’s care in Ontario acute care hospitals. *Canadian Journal of Nursing Research*, *49*(2), 94–100.

Franchi, B. (2016). Pharmacological management of behavioural and psychological symptoms of dementia. *Journal of Pharmacy Practice and Research*, *46*(3), 277–285.

Francis, K., Badger, A., McLeod, M., FitzGerald, M., Brown, A., & Staines, C. (2016). Strengthening nursing and midwifery capacity in rural New South Wales, Australia. *Collegian*, *23*(4), 363–366.

Frankel, A. (2008). What leadership styles should senior nurses develop? *Nursing Times*, *104*(35), 23–24.

Friedman, L. S., Avila, S., Rizvi, T., Partida, R., & Friedman, D. (2017). Physical abuse of elderly adults: Victim characteristics and determinants of revictimization. *Journal of the American Geriatrics Society*, *65*(7), 1420–1426.

Frisoni, G. B., Gozzetti, A., Bignamini, V., Vellas, B. J., Berger, A. K., Bianchetti, A., ... & Trabucchi, M. (1998). Special care units for dementia in nursing homes: A controlled study of effectiveness. *Archives of Gerontology and Geriatrics*, *26*(Supp 1), 215–224.

Gamble, K. J., & Dening, K. H. (2017). Role of the admiral nurse in supporting a person with dementia and their family carer. *Nursing Standard*, *32*(5), 44–51.

Gannon, B., Banks, J., Nazroo, J., & Munford, L. (2018). An econometric analysis of cognitive impairment and healthcare utilization in the ageing population. *Applied Economics*, *50*(50), 5454–5463.

Garbrah, W., Välimäki, T., Palovaara, M., & Kankkunen, P. (2017). Nursing curriculums may hinder a career in gerontological nursing: An integrative review. *International Journal of Older People Nursing*, *12*(3), e12152.

Garcez, F. B., Apolinario, D., Campora, F., Curiati, J. A. E., Jacob-Filho, W., & Avelino-Silva, T. J. (2019). Delirium and post-discharge dementia: Results from a cohort of older adults without baseline cognitive impairment. *Age and Ageing*, *48*(6), 845–851.

García-Goñi, M., Fouda, A., Calder, R. V., & Paolucci, F. (2018). A new funding model for a chronic-care focused healthcare system in Australia. *Health Policy and Technology*, *7*(3), 293–301.

Gardner, G., Gardner, A., & O'Connell, J. (2014). Using the Donabedian framework to examine the quality and safety of nursing service innovation. *Journal of Clinical Nursing*, *23*(1–2), 145–155.

Gauthier, S., Cummings, J., Ballard, C., Brodaty, H., Grossberg, G., Robert, P., & Lyketsos, C. (2010). Management of behavioral problems in Alzheimer's disease. *International Psychogeriatrics*, *22*(3), 346–372.

Gaw, A. (2016). Precision medicine and improving future health care to an ageing population. *Perspectives in Public Health*, *136*(2), 77–78.

Gelling, L. (2015). Qualitative research. *Nursing Standard*, *29*(30), 43–47.

Gerritsen, A. A., Bakker, C., Verhey, F. R., Bor, H., Pijnenburg, Y. A., de Vugt, M. E., & Koopmans, R. T. (2018). The progression of dementia and cognitive decline in a Dutch 2-year cohort study of people with young-onset dementia. *Journal of Alzheimer's Disease*, *63*(1), 343–351.

Gerritsen, D. L., van Beek, A. P. A., & Woods, R. T. (2018). Relationship of care staff attitudes with social well-being and challenging behavior of nursing home residents with dementia: A cross sectional study. *Aging & Mental Health*, *23*(11), 1517–1523.

Gibb, H., Freeman, M., Ballantyne, A., & Corlis, M. (2016). TeamCare: Development and evaluation of an evidence based model for supporting safer, quality care delivery to residents in aged care facilities. *Ageing International*, *41*(2), 117–138.

Gibbs, G. R. (2007). Thematic coding and categorizing. In G. R. Gibbs (Ed.), *Analyzing qualitative data* (pp. 38–55). London, UK: Sage Publications Ltd. doi.org/10.4135/9781849208574

Gibney, S., Ward, M., Sexton, E., & Shannon, S. (2017). Age-friendly environments and physical activity: A cross-sectional, observational study of the over 55s in Ireland. *Journal of Epidemiological Community Health*, *71*(Suppl 1), A30.

Gilbert, J., & Croxon, L. (2019). Dementia care. In L. Deravin & J. Anderson (Eds.), *Chronic care nursing: A framework for practice* (2nd ed., pp. 259–274). Melbourne, Vic: Cambridge University Press.

Gilbert, J., Ward, L., & Gwinner, K. (2019). Quality nursing care in dementia specific care units: A scoping review. *Dementia*, *18*(6), 2140–2157.

Gillis, K., Lahaye, H., Dom, S., Lips, D., Arnouts, H., & Van Bogaert, P. (2019). A person-centred team approach targeting agitated and aggressive behaviour amongst nursing home residents with dementia using the Senses Framework. *International Journal of Older People Nursing*, *14*(4), e12269.

Gilster, S. D., Boltz, M., & Dalessandro, J. L. (2018). Long-term care workforce issues: Practice principles for quality dementia care. *The Gerontologist*, *58*(suppl_1), S103–S113.

Gimm, G., Chowdhury, S., & Castle, N. (2018). Resident aggression and abuse in assisted living. *Journal of Applied Gerontology, 37*(8), 947–964.

Glaser, B. G. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1999). The future of grounded theory. *Qualitative Health Research, 9*(6), 836–845.

Glaser, B. G. (2002). Constructivist grounded theory? *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *3*(3), 1–14.

Glaser, B. G., & Holton, J. (2004). Remodeling grounded theory. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *5*(2), 1–22.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Piscataway, NJ: Transaction Publishers.

Glaser, B. G., & Strauss, A. L. (2017). *Discovery of grounded theory: Strategies for qualitative research* (eBook). New York, NY: Routledge.

Glaser, B. G., Strauss, A. L., & Strutzel, E. (1968). The discovery of grounded theory: Strategies for qualitative research. *Nursing Research, 17*(4), 364.

Gnanamanickam, E. S., Dyer, S. M., Milte, R., Harrison, S. L., Liu, E., Easton, T., ... & Crotty, M. (2018). Direct health and residential care costs of people living with dementia in Australian residential aged care. *International Journal of Geriatric Psychiatry, 33*(7), 859–866.

Godfrey, M., Young, J., Shannon, R., Skingley, A., Woolley, R., Arrojo, F., ... & Surr, C. A. (2018). The Person, Interactions and Environment programme to improve care of people with dementia in hospital: A multisite study. *Health Services and Delivery Research*, *6*(23).

Goel, A., & Ramavat, A. S. (2018). Absence of a formal long-term healthcare system for a rapidly ageing population is likely to create a crisis situation in the near future. *The National Medical Journal of India*, *31*(2), 103–104.

Gold, D. T., Sloane, P. D., Mathew, L. J., Bledsoe, M. M., & Konanc, D. A. (1991). Special care units: A typology of care settings for memory-impaired older adults. *The Gerontologist*, *31*(4), 467–475.

Goldberg, L. R., Price, A. D., Becker, S. E., & Bindoff, A. (2018). The critical importance of adopting a "personhood lens" in reframing support and care for those with dementia. In G. Macdonald & J. Mears (Eds.), *Dementia as social experience: Valuing life and care* (pp. 159–173). New York, NY: Routledge.

Gomperts, S. N. (2016). Lewy body dementias: Dementia with Lewy bodies and Parkinson disease dementia. *Continuum*, *22*(2 Dementia), 435–463.

Goodman, R. A., Lochner, K. A., Thambisetty, M., Wingo, T. S., Posner, S. F., & Ling, S. M. (2017). Prevalence of dementia subtypes in United States Medicare fee-for-service beneficiaries, 2011–2013. *Alzheimer's & Dementia, 13*(1), 28–37.

Gorman, L. L., & McDowell, J. R. (2018). Identifying the needs of critical and acute cardiac care nurses within the first two years of practice in Egypt using a nominal group technique. *Nurse Education in Practice, 28,* 127–134.

Gove, D., Downs, M., Vernooij-Dassen, M. J. F. J., & Small, N. (2016). Stigma and GPs' perceptions of dementia. *Aging & Mental Health*, *20*(4), 391–400.

Graham, G. (2018). How to make a particular case for person-centred patient care: A commentary on Alexandra Parvan. *Journal of Evaluation in Clinical Practice*, *24*(5), 1084–1086.

Granbo, R., Boulton, E., Saltvedt, I., Helbostad, J. L., & Taraldsen, K. (2019). My husband is not ill; he has memory loss-caregivers' perspectives on health care services for persons with dementia. *BMC Geriatrics*, *19*(1), Article number: 75.

Grandner, M. A., Li, J., Chang, Y. P., Jungquist, C., & Porock, D. (2017). Person-centered dementia care and sleep in assisted living residents with dementia: A pilot study. *Behavioral Sleep Medicine, 15*(2), 97–113.

Grant, L. A., Kane, R. A., Potthoff, S. J., & Ryden, M. (1996). Staff training and turnover in Alzheimer special care units: Comparisons with non-special care units. *Geriatric Nursing*, *17*(6), 278–282.

Grealish, L., & Henderson, A. (2016). Investing in organisational culture: Nursing students' experience of organisational learning culture in aged care settings following a program of cultural development. *Contemporary Nurse*, *52*(5), 569–575.

Greaves, J., Goodall, D., Berry, A., Shrestha, S., Richardson, A., & Pearson, P. (2018). Nursing workloads and activity in critical care: A review of the evidence. *Intensive and Critical Care Nursing*, *48*, 10–20.

Green, J., & Thorogood, N. (2018). *Qualitative methods for health research*. Thousand Oaks, CA: Sage Publications, Inc.

Gresham, M., Heffernan, M., & Brodaty, H. (2018). The Going to Stay at Home program: Combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, *30*(11), 1697–1706.

Griffiths, A. W., Kelley, R., Garrod, L., Perfect, D., Robinson, O., Shoesmith, E., ... & Surr, C. A. (2019). Barriers and facilitators to implementing dementia care mapping in care homes: Results from the DCM™ EPIC trial process evaluation. *BMC geriatrics*, *19*(1), Article number: 37.

Griffiths, P., Bridges, J., Sheldon, H., & Thompson, R. (2015). The role of the dementia specialist nurse in acute care: A scoping review. *Journal of Clinical Nursing*, *24*(9–10), 1394–1405.

Grimley, K. A. (2017). Never assume: The search for shared descriptions of quality nursing care. *Nurse Leader*, *15*(6), 413–418.

Groot, C., Hooghiemstra, A. M., Raijmakers, P. G. H. M., Van Berckel, B. N. M., Scheltens, P., Scherder, E. J. A., ... & Ossenkoppele, R. (2016). The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials. *Ageing Research Reviews*, *25*, 13–23.

Gruneir, A., Lapane, K. L., Miller, S. C., & Mor, V. (2008). Is dementia special care really special? A new look at an old question. *Journal of the American Geriatrics Society*, *56*(2), 199–205.

Gupta, V., Agarwal, U. A., & Khatri, N. (2016). The relationships between perceived organizational support, affective commitment, psychological contract breach, organizational citizenship behaviour and work engagement. *Journal of Advanced Nursing*, *72*(11), 2806–2817.

Gustafsson, M., Karlsson, S., & Lövheim, H. (2013). Inappropriate long-term use of antipsychotic drugs is common among people with dementia living in specialized care units. *BMC Pharmacology and Toxicology*, *14*(1), Article number: 10.

Haaksma, M. L., Leoutsakos, J. M. S., Bremer, J. A., Aalten, P., Ramakers, I. H., Verhey, F. R., ... & Melis, R. J. (2018). The clinical course and interrelations of dementia related symptoms. *International Psychogeriatrics*, *30*(6), 859–866.

Haas, L. E., Karakus, A., Holman, R., Cihangir, S., Reidinga, A. C., & de Keizer, N. F. (2015). Trends in hospital and intensive care admissions in the Netherlands attributable to the very elderly in an ageing population. *Critical Care*, *19*(1), Article number: 353.

Hadjistavropoulos, T., Voyer, P., Sharpe, D., Verreault, R., & Aubin, M. (2008). Assessing pain in dementia patients with comorbid delirium and/or depression. *Pain Management Nursing*, *9*(2), 48–54.

Haigh, C., & Miller, E. (2018). What really matters to patients? Digital storytelling as qualitative research. In P. Hardy & T. Sumner (Eds.), *Cultivating compassion: How digital storytelling is transforming healthcare* (pp. 257–266). Cham, Switzerland: Palgrave Macmillan.

Hajek, A., Brettschneider, C., Ernst, A., Posselt, T., Wiese, B., Prokein, J., ...& Stein, J. (2016). Longitudinal predictors of informal and formal caregiving time in community-dwelling dementia patients. *Social Psychiatry and Psychiatric Epidemiology*, *51*(4), 607–616.

Hajkowicz, S. A., Reeson, A., Rudd, L., Bratanova, A., Hodgers, L., Mason, C., & Boughen, N. (2016). *Tomorrow's digitally enabled workforce: Megatrends and scenarios for jobs and employment in Australia over the coming twenty years.* Brisbane, Qld: CSIRO.

Hall, L. M., & Doran, D. (2004). Nurse staffing, care delivery model, and patient care quality. *Journal of Nursing Care Quality*, *19*(1), 27–33.

Hallberg, L. R. (2006). The “core category” of grounded theory: Making constant comparisons. *International Journal of Qualitative Studies on Health and Well-Being, 1*(3), 141–148.

Hampshire, K., Porter, G., Mariwah, S., Munthali, A., Robson, E., Owusu, S. A., ... & Milner, J. (2016). Who bears the cost of “informal mhealth”? Health-workers’ mobile phone practices and associated political-moral economies of care in Ghana and Malawi. *Health Policy and Planning, 32*(1), 34–42.

Hampton, D., Tharp-Barrie, K., & Kay Rayens, M. (2019). Experience of nursing leaders with workplace bullying and how to best cope. *Journal of Nursing Management, 27*(3), 517–526.

Han, A., Kunik, M. E., & Richardson, A. (2019). Compassionate Touch® delivered by long-term care staff for residents with dementia: Preliminary results. *Journal of Social Service Research*. doi:10.1080/01488376.2019.1626320.

Han, S. D., Olsen, B. J., & Mosqueda, L. A. (2019). Elder abuse identification and intervention. In L. D. Ravdin & H. L Katzen (Eds.), *Handbook on the neuropsychology of aging and dementia* (2nd ed., pp. 197–203). Cham, Switzerland: Springer International Publishing.

Handley, M., Bunn, F., & Goodman, C. (2019). Supporting general hospital staff to provide dementia sensitive care: A realist evaluation. *International Journal of Nursing Studies*, *96*, 61–71.

Hands, C., Dankwa, S., Murray, M., Kenyon, P., Doherty, S., Goldberg, K., ...& Taylor, S. (2018). G259 Delivering nurse-led emergency paediatric care in Sierra Leonean hospitals: The effect on quality of care and mortality. *Archives of Disease in Childhood, 103*(Suppl_1), A106.

Hanson, L. C., Zimmerman, S., Song, M. K., Lin, F. C., Rosemond, C., Carey, T. S., & Mitchell, S. L. (2017). Effect of the goals of care intervention for advanced dementia: A randomized clinical trial. *JAMA Internal Medicine, 177*(1), 24–31.

Harmer, A. M., Peart, C., Owen, D., Harper, P., Smith, L., Heaney, D., & Rance, H. (2017). *Visiting the memory cafe and other dementia care activities: Evidence-based interventions for care homes*. London, UK: Jessica Kingsley Publishers.

Harris, T. (2015). Grounded theory. *Nursing Standard, 29*(35), 32–39.

Harrison, C., Henderson, J., Miller, G., & Britt, H. (2016). The prevalence of complex multimorbidity in Australia. *Australian and New Zealand Journal of Public Health*, *40*(3), 239–244.

Hazelhof, T. J. G. M., Schoonhoven, L., van Gaal, B. G. I., Koopmans, R. T. C. M., & Gerritsen, D. L. (2016). Nursing staff stress from challenging behaviour of residents with dementia: A concept analysis. *International Nursing Review*, *63*(3), 507–516.

Heggestad, A. K. T., & Slettebø, Å. (2015). How individuals with dementia in nursing homes maintain their dignity through life storytelling–A case study. *Journal of Clinical Nursing*, *24*(15–16), 2323–2330.

Helgesen, A. K., Larsson, M., & Athlin, E. (2014). Patient participation in special care units for persons with dementia: A losing principle?*Nursing Ethics*, *21*(1), 108–118.

Hemberg, J. A. V., & Vilander, S. (2017). Cultural and communicative competence in the caring relationship with patients from another culture. *Scandinavian Journal of Caring Sciences*, *31*(4), 822–829.

Hendry, A. J., Beard, F. H., Dey, A., Meijer, D., Campbell-Lloyd, S., Clark, K. K., ... & Sheppeard, V. (2018). Closing the vaccination coverage gap in New South Wales: The Aboriginal Immunisation Healthcare Worker program. *Medical Journal of Australia*, *209*(1), 24–28.

Hennings, J., & Froggatt, K. (2019). The experiences of family caregivers of people with advanced dementia living in nursing homes with a specific focus on spouses: A narrative literature review. *Dementia*, *18*(1), 303–322.

Henning-Smith, C. E., Gonzales, G., & Shippee, T. P. (2016). Barriers to timely medical care for older adults by disability status and household composition. *Journal of Disability Policy Studies*, *27*(2), 116–127.

Hernandorena, I., Duron, E., Vidal, J. S., & Hanon, O. (2017). Treatment options and considerations for hypertensive patients to prevent dementia. *Expert Opinion on Pharmacotherapy*, *18*(10), 989–1000.

Herr, K., Zwakhalen, S., & Swafford, K. (2017). Observation of pain in dementia. *Current Alzheimer Research*, *14*(5), 486–500.

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A systematic review of dementia-related stigma research: Can we move the stigma dial? *The American Journal of Geriatric Psychiatry*, *26*(3), 316–331.

Hessler, J. B., Schäufele, M., Hendlmeier, I., Junge, M. N., Leonhardt, S., Weber, J., & Bickel, H. (2018). Behavioural and psychological symptoms in general hospital patients with dementia, distress for nursing staff and complications in care: Results of the general hospital study. *Epidemiology and Psychiatric Sciences*, *27*(3), 278–287.

Hickman, L. D., Neville, S., Fischer, T., Davidson, P. M., & Phillips, J. L. (2016). Call to action: Greater investment in the registered nurse role is required to improve care outcomes for dementia patients living in residential aged care and their families. *Contemporary Nurse*, *52*(2–3), 137–139.

Hinkle, L. J., Bosslet, G. T., & Torke, A. M. (2015). Factors associated with family satisfaction with end-of-life care in the ICU. *Chest*, *147*(1), 82–93.

Hoan, H., & Ngo, T. M. K. (2019). *Nurses' perceptions towards delivering care for patients with dementia: A literature review.* Jyväskylä, Finland: Jyväskylä University of Applied Sciences.

Hobson, P. (2019). *Enabling people with dementia: Understanding and implementing person-centred care*. Cham, Switzerland: Springer Interantional Publishing.

Hodgkin, S., Warburton, J., Savy, P., & Moore, M. (2017). Workforce crisis in residential aged care: Insights from rural, older workers. *Australian Journal of Public Administration*, *76*(1), 93–105.

Hoffart, N., & Woods, C. Q. (1996). Elements of a nursing professional practice model. *Journal of Professional Nursing*, *12*(6), 354–364.

Hogden, A., Greenfield, D., Brandon, M., Debono, D., Mumford, V., Westbrook, J., & Braithwaite, J. (2017). How does accreditation influence staff perceptions of quality in residential aged care? *Quality in Ageing and Older Adults*, *18*(2), 131–144.

Høgsnes, L., Danielson, E., Norbergh, K. G., & Melin-Johansson, C. (2016). Healthcare professionals' documentation in nursing homes when caring for patients with dementia in end of life–a retrospective records review. *Journal of Clinical Nursing*, *25*(11–12), 1663–1673.

Hogston, R. (1995). Quality nursing care: A qualitative enquiry. *Journal of Advanced Nursing*, *21*(1), 116–124.

Holanda, F. L. D., Marra, C. C., & Cunha, I. C. K. O. (2015). Professional competency profile of nurses working in emergency services. *ActaPaulista de Enfermagem*, *28*(4), 308–314.

Holst, A., & Skär, L. (2017). Formal caregivers’ experiences of aggressive behaviour in older people living with dementia in nursing homes: A systematic review. *International Journal of Older People Nursing*, *12*(4), e12158.

Honda, M., Ito, M., Ishikawa, S., Takebayashi, Y., & Tierney, L. (2016). Reduction of behavioral psychological symptoms of dementia by multimodal comprehensive care for vulnerable geriatric patients in an acute care hospital: A case series. *Case Reports in Medicine*, *2016,* Article ID: 4813196.

Hopkins, W. (2017). *Evaluating nurses’ self-efficacy in caring for patients with dementia.* (Doctoral dissertation). Retrieved from https://scholarworks.waldenu.edu/cgi/viewcontent.cgi?article=4553&context=dissertations

Hopkinson, M. D., Reavell, J., Lane, D. A., & Mallikarjun, P. (2018). Cognitive behavioral therapy for depression, anxiety, and stress in caregivers of dementia patients: A systematic review and meta-analysis. *The Gerontologist*, *59*(4), e343-e362.

Houghton, C., Murphy, K., Brooker, D., & Casey, D. (2016). Healthcare staffs’ experiences and perceptions of caring for people with dementia in the acute setting: Qualitative evidence synthesis. *International Journal of Nursing Studies*, *61*, 104–116.

Howard, R. J., Juszczak, E., Ballard, C. G., Bentham, P., Brown, R. G., Bullock, R., ... & Knapp, M. (2007). Donepezil for the treatment of agitation in Alzheimer’s disease. *New England Journal of Medicine*, *357*(14), 1382–1392.

Howdon, D., & Rice, N. (2018). Healthcare expenditures, age, proximity to death and morbidity: Implications for an ageing population. *Journal of Health Economics*, *57*, 60–74.

Hsu, C. P., Chiang, C. Y., Chang, C. W., Huang, H. C., & Chen, C. C. (2015). Enhancing the commitment of nurses to the organisation by means of trust and monetary reward. *Journal of Nursing Management, 23*(5), 567–576.

Hu, W. T. (2017). No doubts about dementia advocacy. *The Lancet. Psychiatry*, *4*(11), 830–830.

Huber, E., Kleinknecht-Dolf, M., Müller, M., Kugler, C., & Spirig, R. (2017). Mixed-method research protocol: Defining and operationalizing patient-related complexity of nursing care in acute care hospitals. *Journal of Advanced Nursing*, *73*(6), 1491–1501.

Hulko, W., Wilson, D., & Balestrery, J. (Eds.). (2019). *Indigenous peoples and dementia: New understandings of memory loss and memory care*. Vancouver, Canada: UBC Press.

Hung, L., & Chaudhury, H. (2011). Exploring personhood in dining experiences of residents with dementia in long-term care facilities. *Journal of Aging Studies*, *25*(1), 1–12.

Hunter, A., Murphy, K., Grealish, A., Casey, D., & Keady, J. (2011). Navigating the grounded theory terrain. Part 2. *Nurse Researcher*, *19*(1), 6–11.

Hunter, K., & Cook, C. (2018). Role-modelling and the hidden curriculum: New graduate nurses' professional socialisation. *Journal of Clinical Nursing*, *27*(15-16), 3157–3170.

Hunter, P., Kaasalainen, S., Wickson-Griffiths, A., Sussman, T., Venturato, L., McCleary, L., & Thompson, G. N. (2018). Meaningful connections in dementia end of life care in long term care homes. *BMC Psychiatry, 18,* Article number: 307.

Hunter, P. V., Hadjistavropoulos, T., & Kaasalainen, S. (2016). A qualitative study of nursing assistants' awareness of person-centred approaches to dementia care. *Ageing & Society*, *36*(6), 1211–1237.

Hunter, S., & Levett-Jones, T. (2010). The practice of nurses working with older people in long-term care: An Australian perspective. *Journal of Clinical Nursing*, *19*(3–4), 527–536.

Husebo, B. S., Achterberg, W., & Flo, E. (2016). Identifying and managing pain in people with Alzheimer's disease and other types of dementia: A systematic review. *CNS Drugs*, *30*(6), 481–497.

Inkley, F., & Goldberg, S. (2016). Managing verbal agitation in people with dementia and delirium. *Nursing Older People*, *28*(2), 33–37.

Ismail, Z., Gatchel, J., Bateman, D. R., Barcelos-Ferreira, R., Cantillon, M., Jaeger, J., ... & Mortby, M. E. (2018). Affective and emotional dysregulation as pre-dementia risk markers: Exploring the mild behavioral impairment symptoms of depression, anxiety, irritability, and euphoria. *International Psychogeriatrics*, *30*(2), 185–196.

Jackson, C., Leadbetter, T., Martin, A., Wright, T., & Manley, K. (2015). Making the complexity of community nursing visible: The Cassandra Project. *British Journal of Community Nursing*, *20*(3), 126–133.

Jackson, T. A., Gladman, J. R., Harwood, R. H., MacLullich, A. M., Sampson, E. L., Sheehan, B., & Davis, D. H. (2017). Challenges and opportunities in understanding dementia and delirium in the acute hospital. *PLoS Medicine*, *14*(3), e1002247.

James, S. R., Nelson, K., & Ashwill, J. (2014). *Nursing care of children: Principles and practice*. St Louis, MO: Elsevier Health Sciences.

Jarrar, M. T., Minai, M. S., Al-Bsheish, M., Meri, A., & Jaber, M. (2018). Hospital nurse shift length, patient-centered care, and the perceived quality and patient safety. *The International Journal of Health Planning and Management*, *34*(1), e387–e396.

Javanparast, S., Maddern, J., Baum, F., Freeman, T., Lawless, A., Labonté, R., & Sanders, D. (2018). Change management in an environment of ongoing primary health care system reform: A case study of Australian primary health care services. *The International Journal of Health Planning and Management*, *33*(1), e76–e88.

Jenkins, B. (2016). “We are the international nurses”: An exploration of internationally qualified nurses’ experiences of transitioning to New Zealand and working in aged care. *Nursing Praxis in New Zealand*, *32*(2), 9–20.

Jennings, L. A., Laffan, A. M., Schlissel, A. C., Colligan, E., Tan, Z., Wenger, N. S., & Reuben, D. B. (2019). Health care utilization and cost outcomes of a comprehensive dementia care program for Medicare beneficiaries. *JAMA Internal Medicine*, *179*(2), 161–166.

Jennings, L. A., Palimaru, A., Corona, M. G., Cagigas, X. E., Ramirez, K. D., Zhao, T., ... & Reuben, D. B. (2017). Patient and caregiver goals for dementia care. *Quality of Life Research*, *26*(3), 685–693.

Jensen, A. M., Pedersen, B. D., Olsen, R. B., Wilson, R. L., & Hounsgaard, L. (2018). “If only they could understand me!” Acute hospital care experiences of patients with Alzheimer’s disease. *Dementia,* 1471301218820483.

Jensen, A. M., Pedersen, B. D., Wilson, R. L., Olsen, R. B., & Hounsgaard, L. (2019). Nurses’ experiences of delivering acute orthopaedic care to patients with dementia. *International Journal of Older People Nursing, 14*(4), e12271.

Jensen, P. M., Fraser, F., Shankardass, K., Epstein, R., & Khera, J. (2009). Are long-term care residents referred appropriately to hospital emergency departments? *Canadian Family Physician*, *55*(5), 500–505.

Jeon, Y. H., Govett, J., Low, L. F., Chenoweth, L., McNeill, G., Hoolahan, A., Brodaty, H., & O’Connor, D. (2013). Care planning practices for behavioural and psychological symptoms of dementia in residential aged care: A pilot of an education toolkit informed by the Aged Care Funding Instrument. *Contemporary Nurse, 44*(2), 156–169.

Jeon, Y. H., McKenzie, H., Krein, L., Flaherty, I., & Gillespie, J. (2017). Preferences, choices and decision-making: A qualitative study on the experiences of family carers and people with advanced dementia. *Alzheimer’s & Dementia, 13*(7), P1248–P1249.

Johansen, M. L., & Cadmus, E. (2016). Conflict management style, supportive work environments and the experience of work stress in emergency nurses. *Journal of Nursing Management, 24*(2), 211–218.

Johnson, C. (2019). Consent when prescribing to dementia patients. *Australian Medicine*, *31*(2), 18.

Johnson, J. K., & Sollecito, W. A. (2018). *McLaughlin & Kaluzny's continuous quality improvement in health care* (4th ed.). Burlington, MA: Jones & Bartlett Learning.

Johnson, S., Ostaszkiewicz, J., & O'Connell, B. (2009). Moving beyond resistance to restraint minimization: A case study of change management in aged care. *Worldviews on Evidence-Based Nursing*, *6*(4), 210–218.

Jokanovic, N., Ferrah, N., Lovell, J. J., Weller, C., Bugeja, L., Bell, J. S., & Ibrahim, J. E. (2019). A review of coronial investigations into medication-related deaths in residential aged care. *Research in Social and Administrative Pharmacy*, *15*(4), 410–416.

Jones, C., Moyle, W., & Stockwell-Smith, G. (2013). Caring for older people with dementia: An exploratory study of staff knowledge and perception of training in three Australian dementia care facilities. *Australasian Journal on Ageing*, *32*(1), 52–55.

Jones, C., Sung, B., & Moyle, W. (2015). Assessing engagement in people with dementia: A new approach to assessment using video analysis. *Archives of Psychiatric Nursing*, *29*(6), 377–382.

Jootun, D., & McGhee, G. (2011). Effective communication with people who have dementia. *Nursing Standard*, *25*(25), 40–46.

Jorm, A. F., & O'Brien, J. (2019). The epidemiology of vascular dementia: An overview and commentary. In J. O'Brien, D. Ames, L. Gustafson, M. Folstein, & E. Chiu, (Eds.), *Cerebrovascular disease and dementia*: *Pathology, neuropsychiatry and management* (2nd ed., pp. 93–98). London, UK: Taylor and Francis Group.

Joyce, N. R., McGuire, T. G., Bartels, S. J., Mitchell, S. L., & Grabowski, D. C. (2018). The impact of dementia special care units on quality of care: An instrumental variables analysis. *Health Services Research*, *53*(5), 3657–3679.

Jutkowitz, E., Brasure, M., Fuchs, E., Shippee, T., Kane, R. A., Fink, H. A., ... & Kane, R. L. (2016). Care-delivery interventions to manage agitation and aggression in dementia nursing home and assisted living residents: A systematic review and meta-analysis. *Journal of the American Geriatrics Society*, *64*(3), 477–488.

Jutkowitz, E., Kane, R. L., Gaugler, J. E., MacLehose, R. F., Dowd, B., & Kuntz, K. M. (2017). Societal and family lifetime cost of dementia: Implications for policy. *Journal of the American Geriatrics Society*, *65*(10), 2169–2175.

Kagan, S. H., & Melendez-Torres, G. J. (2015). Ageism in nursing. *Journal of Nursing Management*, *23*(5), 644–650.

Kalaria, R. N. (2018). The pathology and pathophysiology of vascular dementia. *Neuropharmacology*, *134*, 226–239.

Kalaria, R. N., & Ballard, C. (1999). Overlap between pathology of Alzheimer disease and vascular dementia. *Alzheimer Disease and Associated Disorders, 13,* S115–S123.

Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2015). Assessment and management of behavioral and psychological symptoms of dementia. *BMJ*, *350*, h369.

Kales, H. C., Lyketsos, C. G., Miller, E. M., & Ballard, C. (2019). Management of behavioral and psychological symptoms in people with Alzheimer's disease: An international Delphi consensus. *International Psychogeriatrics*, *31*(1), 83–90.

Kalogianis, M. J., Wimmer, B. C., Turner, J. P., Tan, E. C., Emery, T., Robson, L., ... & Bell, J. S. (2016). Are residents of aged care facilities willing to have their medications deprescribed?*Research in Social and Administrative Pharmacy*, *12*(5), 784–788.

Kaminski, M. F., Thomas-Gibson, S., Bugajski, M., Bretthauer, M., Rees, C. J., Dekker, E., ...& Anderson, J. (2017). Performance measures for lower gastrointestinal endoscopy: A European Society of Gastrointestinal Endoscopy (ESGE) quality improvement initiative. *Endoscopy*, *49*(4), 378–397.

Kane, J. P., Surendranathan, A., Bentley, A., Barker, S. A., Taylor, J. P., Thomas, A. J., ... & O'Brien, J. T. (2018). Clinical prevalence of Lewy body dementia. *Alzheimer's Research & Therapy*, *10*(1), Article number: 19.

Karantzas, G. C., McCabe, M. P., Mellor, D., Von Treuer, K., Davison, T. E., O'Connor, D., ... & Konis, A. (2016). Organizational climate and self-efficacy as predictors of staff strain in caring for dementia residents: A mediation model. *Archives of Gerontology and Geriatrics*, *66*, 89–94.

Karki, A. (2018). *Pain assessment in elderly residents with severe dementia–Nurses' point of view*. (Master's thesis). Helsinki Metropolia University of Applied Sciences, Helsinki, Finland.

Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M. S., Stephan, A., ... & RightTimeCarePlace Consortium. (2015). Dementia care in European countries from the perspective of people with dementia and their caregivers. *Journal of Advanced Nursing*, *71*(6), 1405–1416.

Karlsson, S., Hallberg, I. R., Midlöv, P., & Fagerström, C. (2017). Trends in treatment with antipsychotic medication in relation to national directives in people with dementia–a review of the Swedish context. *BMC Psychiatry*, *17*(1), Article number: 251.

Karlstedt, M., Wadensten, B., Fagerberg, I., & Pöder, U. (2015). Is the competence of Swedish registered nurses working in municipal care of older people merely a question of age and postgraduate education?*Scandinavian Journal of Caring Sciences*, *29*(2), 307–316.

Kay, K., Evans, A., & Glass, N. (2015). Moments of speaking and silencing: Nurses share their experiences of manual handling in healthcare. *Collegian*, *22*(1), 61–70.

Ke, Y. X., Hu, S. H., Takemura, N., & Lin, C. C. (2019). Perceived quality of palliative care in intensive care units among doctors and nurses in Taiwan. *International Journal for Quality in Health Care*, mzz003.

Kelley, R. S. (2017). *"Knowing the person"- The use of families' knowledge and expertise in delivering care and valued outcomes for people with dementia on acute wards.* (Doctoral dissertation). University of Leeds, Leeds, UK.

Kelly, F., & Innes, A. (2013). Human rights, citizenship and dementia care nursing. *International Journal of Older People Nursing*, *8*(1), 61–70.

Kelly, L. A., & Adams, J. M. (2018). Nurse leader burnout: How to find your joy. *Nurse Leader*, *16*(1), 24–28.

Kendall, J. (1999). Axial coding and the grounded theory controversy. *Western Journal of Nursing Research*, *21*(6), 743–757.

Kendig, H., McDonald, P., & Piggott, J. (Eds.). (2016). *Population ageing and Australia's future*. Canberra, ACT: ANU Press.

Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y. S., Shelburne, N., ... & Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, *122*(13), 1987–1995.

Khan, S. N. (2014). Qualitative research method: Grounded theory. *International Journal of Business and Management*, *9*(11), 224–233.

Khan, S. S., Ye, B., Taati, B., & Mihailidis, A. (2018). Detecting agitation and aggression in people with dementia using sensors: A systematic review. *Alzheimer's & Dementia*, *14*(6), 824–832.

Killett, A., Burns, D., Kelly, F., Brooker, D., Bowes, A., La Fontaine, J., ... & O'Neill, M. (2016). Digging deep: How organisational culture affects care home residents' experiences. *Ageing & Society*, *36*(1), 160–188.

Killin, L. O., Starr, J. M., Shiue, I. J., & Russ, T. C. (2016). Environmental risk factors for dementia: A systematic review. *BMC Geriatrics*, *16*(1), Article number: 175.

Kilroy, S., Flood, P. C., Bosak, J., & Chênevert, D. (2016). Perceptions of high-involvement work practices and burnout: The mediating role of job demands. *Human Resource Management Journal*, *26*(4), 408–424.

Kim, H. (2016). Behavioral and psychological symptoms of dementia. *Annals of Psychiatry and Mental Health*, *4*(7), 1086–1093.

Kim, H., Lee, S., Cheon, J., Hong, S., & Chang, M. (2018). A comparative study to identify factors of caregiver burden between baby boomers and post baby boomers: A secondary analysis of a US online caregiver survey. *BMC Public Health*, *18*(1), Article number: 579.

Kim, S. K., & Park, M. (2017). Effectiveness of person-centered care on people with dementia: A systematic review and meta-analysis. *Clinical Interventions in Aging*, *12*, 381–397.

King, D., Svensson, S., & Wei, Z. (2017). Not always a quick fix: The impact of employing temporary agency workers on retention in the Australian aged care workforce. *Journal of Industrial Relations*, *59*(1), 85–103.

Kingma, M. (2018). *Nurses on the move: Migration and the global health care economy*. London, UK: Cornell University Press.

Kinley, N., & Ben-Hur, S. (2015). *Changing employee behavior: A practical guide for managers*. Basingstoke, UK: Palgrave McMillan.

Kirkham, J., Sherman, C., Velkers, C., Maxwell, C., Gill, S., Rochon, P., & Seitz, D. (2017). Antipsychotic use in dementia: Is there a problem and are there solutions? *The Canadian Journal of Psychiatry, 62*(3), 170–181.

Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J., & Bond, J. (2011). The impact of organisational culture on the delivery of person-centred care in services providing respite care and short breaks for people with dementia. *Health & Social Care in the Community, 19*(4), 438–448.

Kirsebom, M., Hedström, M., Wadensten, B., & Pöder, U. (2014). The frequency of and reasons for acute hospital transfers of older nursing home residents. *Archives of Gerontology and Geriatrics*, *58*(1), 115–120.

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing, 69*(1), 4–15.

Kitwood, T. (1988). The technical, the personal, and the framing of dementia. *Social Behaviour, 3*(2), 161–179.

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, *1*(1), 13–22.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing & Society, 12*(3), 269–287.

Klaasen, K., Groenewegen, T., Mitchell, L. A., & Wilson, S. (2016). From primary nurse to collaborative nursing care team: Early feedback on a new model. *Healthcare Management Forum, 29*(3), 121–125.

Kogan, A. C., Wilber, K., & Mosqueda, L. (2016). Person-centered care for older adults with chronic conditions and functional impairment: A systematic literature review. *Journal of the American Geriatrics Society*, *64*(1), e1–e7.

Kok, J. S., van Heuvelen, M. J., Berg, I. J., & Scherder, E. J. (2016). Small scale homelike special care units and traditional special care units: Effects on cognition in dementia: A longitudinal controlled intervention study. *BMC Geriatrics*, *16*(1), Article number: 47.

Kolanowski, A., Fortinsky, R. H., Calkins, M., Devanand, D. P., Gould, E., Heller, T., ... & Zimmerman, S. (2018). Advancing research on care needs and supportive approaches for persons with dementia: recommendations and rationale. *Journal of the American Medical Directors Association*, *19*(12), 1047–1053.

Kontos, P. C., Miller, K. L., Mitchell, G. J., & Stirling-Twist, J. (2017). Presence redefined: The reciprocal nature of engagement between elder-clowns and persons with dementia. *Dementia*, *16*(1), 46–66.

Kontos, P. C., & Naglie, G. (2007). Bridging theory and practice: Imagination, the body, and person-centred dementia care. *Dementia*, *6*(4), 549–569.

Kovach, C. R., Logan, B. R., Simpson, M. R., & Reynolds, S. (2010). Factors associated with time to identify physical problems of nursing home residents with dementia. *American Journal of Alzheimer s Disease & Other Dementias*, *25*(4), 317–323.

Kovach, C. R., Weisman, G., Chaudhury, H., & Calkins, M. (1997). Impacts of a therapeutic environment for dementia care. *American Journal of Alzheimer's Disease*, *12*(3), 99–110.

Koy, V., Yunibhand, J., Angsuroch, Y., & Fisher, M. L. (2015). Relationship between nursing care quality, nurse staffing, nurse job satisfaction, nurse practice environment, and burnout: Literature review. *International Journal of Research in Medical Sciences*, *3*(8), 1825–1831.

Kras, K. R., Dmello, J. R., Meyer, K. S., Butterfield, A. E., & Rudes, D. S. (2019). Attitudes toward punishment, organizational commitment, and cynicism: A multilevel analysis of staff responses in a juvenile justice agency. *Criminal Justice and Behavior*, *46*(3), 475–491.

Kulig, J. C., Townshend, I., Kosteniuk, J., Karunanayake, C., Labrecque, M. E., & MacLeod, M. L. (2018). Perceptions of sense of community and community engagement among rural nurses: Results of a national survey. *International Journal of Nursing Studies*, *88*, 60–70.

Küller, R. (2015). 13. Familiar design helps dementia patients cope. In W. F. E. Preiser, J. C. Vischer, & E. T. White (Eds.), *Design intervention: Toward a more humane architecture* (pp. 255–267). Abingdon, UK: Routledge.

Kumfor, F., Baez, S., & Ibañez, A. (2016). Frontotemporal dementia and potential therapeutics. In M-K. Sun (Ed.), *Research progress in Alzheimer's disease and dementia: Volume 6* (pp. 129–167). Hauppauge, NY: Nova Science Publishers.

Kutney-Lee, A., Sloane, D. M., & Aitken, L. H. (2015). An increase in the number of nurses with baccalaureate degrees is linked to lower rates of postsurgery mortality. *Health Affairs, 32*(3), 579–586.

Kwok, C., Bates, K. A., & Ng, E. S. (2016). Managing and sustaining an ageing nursing workforce: Identifying opportunities and best practices within collective agreements in Canada. *Journal of Nursing Management*, *24*(4), 500–511.

Labrague, L. J., McEnroe Petitte, D. M., Leocadio, M. C., Van Bogaert, P., & Tsaras, K. (2018, July). Perceptions of organizational support and its impact on nurses' job outcomes. *Nursing Forum, 53*(3), 339–347.

Lachs, M. S., Teresi, J. A., Ramirez, M., Van Haitsma, K., Silver, S., Eimicke, J. P., ... & Pillemer, K. A. (2016). The prevalence of resident-to-resident elder mistreatment in nursing homes. *Annals of internal medicine*, *165*(4), 229–236.

Lai, C. K., Yeung, J. H., Mok, V., & Chi, I. (2009). Special care units for dementia individuals with behavioural problems. *Cochrane Database of Systematic Reviews, 4,* CD006470.

Lalic, S., Jamsen, K. M., Wimmer, B. C., Tan, E. C., Hilmer, S. N., Robson, L., ...& Bell, J. S. (2016). Polypharmacy and medication regimen complexity as factors associated with staff informant rated quality of life in residents of aged care facilities: A cross-sectional study. *European Journal of Clinical Pharmacology*, *72*(9), 1117–1124.

Lambert, M. (2019). Grounded theory. In M. Lambert (Ed.), *Practical research methods in education: An early researcher's critical guide* (pp. 132–141). Abingdon, UK: Routledge.

Landeiro, F., Wace, H., Ghinai, I., Nye, E., Mughal, S., Walsh, K., ... & Roadmap Group. (2018). Resource utilisation and costs in predementia and dementia: A systematic review protocol. *BMJ Open*, *8*(1), e019060.

Langhammer, B., Sagbakken, M., Kvaal, K., Ulstein, I., Nåden, D., & Rognstad, M. K. (2019). Music therapy and physical activity to ease anxiety, restlessness, irritability, and aggression in individuals with dementia with signs of frontotemporal lobe degeneration. *Journal of Psychosocial Nursing and Mental Health Services*, *57*(5), 29–37.

Lanza, M. (2016). Patient aggression in real time on geriatric inpatient units. *Issues in Mental Health Nursing*, *37*(1), 53–58.

Laschinger, H. K. S., & Fida, R. (2015). Linking nurses' perceptions of patient care quality to job satisfaction: the role of authentic leadership and empowering professional practice environments. *Journal of Nursing Administration*, *45*(5), 276–283.

Laschinger, H. K. S., Read, E., Wilk, P., & Finegan, J. (2014). The influence of nursing unit empowerment and social capital on unit effectiveness and nurse perceptions of patient care quality. *Journal of Nursing Administration*, *44*(6), 347–352.

Laske, R. A., & Stephens, B. A. (2018). Confusion states: Sorting out delirium, dementia, and depression. *Nursing Made Incredibly Easy*, *16*(6), 13–16.

Laver, K., Cumming, R., Dyer, S., Agar, M., Anstey, K., Beattie, E., ... & Yates, M. W. (2016). Clinical practice guidelines for dementia in Australia. *The Medical Journal of Australia, 204*(5), 191–193.

Lavrencic, L. M., Bennett, H., Daylight, G., Draper, B., Cumming, R., Mack, H., ... & Radford, K. (2019). Cognitive test norms and comparison between healthy ageing, mild cognitive impairment, and dementia: A population-based study of older Aboriginal Australians. *Australian Journal of Psychology, 71*(3), 249–260.

Lawrence, V., Fossey, J., Ballard, C., Ferreira, N., & Murray, J. (2016). Helping staff to implement psychosocial interventions in care homes: Augmenting existing practices and meeting needs for support. *International Journal of Geriatric Psychiatry*, *31*(3), 284–293.

Laybourne, A., Livingston, G., Cousins, S., Rapaport, P., Lambe, K., La Frenais, F., ... & Cooper, C. (2019). Carer coping and resident agitation as predictors of quality of life in care home residents living with dementia: Managing agitation and raising quality of life (MARQUE) – English national care home prospective cohort study. *International Journal of Geriatric Psychiatry*, *34*(1), 106–113.

Lea, E. J., Mason, R. L., Eccleston, C., & Robinson, A. L. (2016, September). *Aspects of WIL that improve student nurses' attitudes towards working in aged care*. Paper presented at the Australian Collaborative Education Network 2016 Conference, Sydney, NSW.

Lee, R. (2019). Mortality forecasts and linear life expectancy trends. In T. Bengsston & N. Keilman (Eds.), *Old and new perspectives on mortality forecasting* (pp. 167–183). Cham, Switzerland: Springer International Publishing.

Lee, S. Y., Chaudhury, H., & Hung, L. (2015). Effects of physical environment on health and behaviors of residents with dementia in long-term care facilities: A longitudinal study. *Research in Gerontological Nursing*, *9*(2), 81–91.

Lee, S. Y., Chaudhury, H., & Hung, L. (2016). Exploring staff perceptions on the role of physical environment in dementia care setting. *Dementia*, *15*(4), 743–755.

Leff, B., Carlson, C. M., Saliba, D., & Ritchie, C. (2015). The invisible homebound: Setting quality-of-care standards for home-based primary and palliative care. *Health Affairs*, *34*(1), 21–29.

Leggett, A., Connell, C., Dubin, L., Dunkle, R., Langa, K. M., Maust, D. T., ... & Kales, H. C. (2019). Dementia care across a tertiary care health system: What exists now and what needs to change. *Journal of the American Medical Directors Association*, *20*(10), 1307–1312.

Leider, J. P., Coronado, F., Beck, A. J., & Harper, E. (2018). Reconciling supply and demand for state and local public health staff in an era of retiring baby boomers. *American Journal of Preventive Medicine*, *54*(3), 334–340.

Lempert, L. B. (2007). Asking questions of the data: Memo writing in the grounded theory tradition. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 245–264). London, UK: Sage Publications Ltd.

Lenthall, S., Wakerman, J., Opie, T., Dunn, S., MacLeod, M., Dollard, M., ...& Knight, S. (2011). Nursing workforce in very remote Australia, characteristics and key issues. *Australian Journal of Rural Health*, *19*(1), 32–37.

Leon, J., & Ory, M. G. (1999). Effectiveness of special care unit (SCU) placements in reducing physically aggressive behaviors in recently admitted dementia nursing home residents. *American Journal of Alzheimer's Disease, 14*(5), 270–277.

Levy, D. L. (2016). Discovering grounded theories for social justice. In C. W. Johnson & D. C. Parry (Eds.), *Fostering social justice through qualitative inquiry: A methodological guide* (pp. 71–100). Abingdon, UK: Routledge.

Lewis, K. E., & Tamblyn, R. M. (1987). The problem-based learning approach in baccalaureate nursing education: How effective is it? *Canadian Journal of Nursing Research Archive*, *19*(2), 17–26.

Li, J., Grandner, M. A., Chang, Y. P., Jungquist, C., & Porock, D. (2017). Person-centered dementia care and sleep in assisted living residents with dementia: A pilot study. *Behavioral Sleep Medicine*, *15*(2), 97–113.

Liang, C. K., Chou, M. Y., Chen, L. Y., Wang, K. Y., Lin, S. Y., Chen, L. K., ... & Loh, C. H. (2017). Delaying cognitive and physical decline through multi-domain interventions for residents with mild-to-moderate dementia in dementia care units in Taiwan: A prospective cohort study. *Geriatrics & Gerontology International*, *17*(Suppl_1), 36–43.

Licqurish, S., & Seibold, C. (2011). Applying a contemporary grounded theory methodology. *Nurse Researcher*, *18*(4), 11–16.

Liljegren, M., Landqvist Waldö, M., & Englund, E. (2018). Physical aggression among patients with dementia, neuropathologically confirmed post-mortem. *International Journal of Geriatric Psychiatry, 33*(2), e242–e248.

Lillekroken, D., Hauge, S., & Slettebø, Å. (2017). The meaning of slow nursing in dementia care. *Dementia*, *16*(7), 930–947.

Lim, R. H., & Sharmeen, T. (2018). Medicines management issues in dementia and coping strategies used by people living with dementia and family carers: A systematic review. *International Journal of Geriatric Psychiatry*, *33*(12), 1562–1581.

Lin, W., Xie, Y. C., Cheng, P. Y., Dong, L. Y., Hung, G. U., & Chiu, P. Y. (2018). Association of visual hallucinations with very mild degenerative dementia due to dementia with Lewy bodies. *PloS One*, *13*(10), e0205909.

Lindquist, R., Tracy, M. F., & Snyder, M. (Eds.). (2018). *Complementary andalternative therapies in nursing*. New York, NY: Springer Publishing Company.

Lindy, C., & Schaefer, F. (2010). Negative workplace behaviours: An ethical dilemma for nurse managers. *Journal of Nursing Management*, *18*(3), 285–292.

Lingard, L., Albert, M., & Levinson, W. (2008). Grounded theory, mixed methods, and action research. *BMJ*, *337*, a567.

Liu, Y., Aungsuroch, Y., & Yunibhand, J. (2016). Job satisfaction in nursing: A concept analysis study. *International Nursing Review*, *63*(1), 84–91.

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., ... & Mukadam, N. (2017). Dementia prevention, intervention, and care. *TheLancet*, *390*(10113), 2673–2734.

Lo, R. Y. (2017). The borderland between normal aging and dementia. *Tzu-Chi Medical Journal*, *29*(2), 65–71.

Long, J. M., & Day, G. S. (2018). Autoimmune dementia. *Seminars in Neurology, 38*(3), 303–315.

Lood, Q., Björk, S., Sköldunger, A., Backman, A., Sjögren, K., & Edvardsson, D. (2017). The relative impact of symptoms, resident characteristics and features of nursing homes on residents’ participation in social occupations: Cross-sectional findings from U-Age Swenis. *Journal of Occupational Science*, *24*(3), 327–337.

Lopreite, M., & Mauro, M. (2017). The effects of population ageing on health care expenditure: A Bayesian VAR analysis using data from Italy. *Health Policy*, *121*(6), 663–674.

Louch, G., Mohammed, M. A., Hughes, L., & O’Hara, J. (2019). “Change is what can actually make the tough times better”: A patient-centred patient safety intervention delivered in collaboration with hospital volunteers. *Health Expectations*, *22*(1), 102–113.

Lourida, I., Abbott, R. A., Lang, I. A., Rogers, M., Kent, B., & Thompson-Coon, J. (2016). Dissemination and implementation in dementia care: A mixed-methods systematic review. *BMC Geriatrics, 17,* Article number: 147.

Louro, M., Matos, A., Vaio, T., Leitão, S., Santos, R., & Carvalho, A. (2018). Pain management in patients with advanced dementia: A Portuguese study. *International Journal of Innovative Studies in Medical Sciences, 2*(1), 4–7.

Low, L. F., Fletcher, J., Goodenough, B., Jeon, Y. H., Etherton-Beer, C., MacAndrew, M., & Beattie, E. (2015). A systematic review of interventions to change staff care practices in order to improve resident outcomes in nursing homes. *PloS One, 10*(11), e0140711.

Low, L. F., Goodenough, B., Fletcher, J., Xu, K., Casey, A. N., Chenoweth, L., ... & Brodaty, H. (2014). The effects of humor therapy on nursing home residents measured using observational methods: The SMILE cluster randomized trial. *Journal of the American Medical Directors Association, 15*(8), 564–569.

Low, L. F., Swaffer, K., McGrath, M., & Brodaty, H. (2018). Do people with early stage dementia experience Prescribed Disengagement? A systematic review of qualitative studies. *International Psychogeriatrics, 30*(6), 807–831.

Lowton, K., Hiley, C., & Higgs, P. (2017). Constructing embodied identity in a “new” ageing population: A qualitative study of the pioneer cohort of childhood liver transplant recipients in the UK. *Social Science & Medicine, 172*, 1–9.

Lu, H., Zhao, Y., & While, A. (2019). Job satisfaction among hospital nurses: A literature review. *International Journal of Nursing Studies, 94,* 21–31.

Ludden, G. D., van Rompay, T. J., Niedderer, K., & Tournier, I. (2019). Environmental design for dementia care towards more meaningful experiences through design. *Maturitas, 128*, 10–16.

Maatouk, I., Müller, A., Angerer, P., Schmook, R., Nikendei, C., Herbst, K., ...& Gündel, H. (2018). Healthy ageing at work – efficacy of group interventions on the mental health of nurses aged 45 and older: Results of a randomised, controlled trial. *PloS One, 13*(1), e0191000.

Macfarlane, S., & O’Connor, D. (2016). Managing behavioural and psychological symptoms in dementia. *Australian Prescriber, 39*(4), 123–125.

Machiels, M., Metzelthin, S. F., Hamers, J. P., & Zwakhalen, S. M. (2017). Interventions to improve communication between people with dementia and nursing staff during daily nursing care: A systematic review. *International Journal of Nursing Studies*, *66*, 37–46.

Maeland, M. J., Joa, I., & Testad, I. (2013). Agitation and function in care in persons with dementia, prevalence and correlations. *Sykepleien Forskning*, *8*, 232–241.

Maiese, K. (2018). Dampening the progression of dementia. *Current Neurovascular Research*, *15*(2), 93.

Malara, A., De Biase, G. A., Bettarini, F., Ceravolo, F., Di Cello, S., Garo, M., ... & Rispoli, V. (2016). Pain assessment in elderly with behavioral and psychological symptoms of dementia. *Journal of Alzheimer's Disease*, *50*(4), 1217–1225.

Manes, F. (2016). The huge burden of dementia in Latin America. *The Lancet Neurology*, *15*(1), 29.

Manojlovich, M., & Ketefian, S. (2016). The effects of organizational culture on nursing professionalism: Implications for health resource planning. *Canadian Journal of Nursing Research Archive*, *33*(4), 15–34.

Mar, J., Soto-Gordoa, M., Arrospide, A., Moreno-Izco, F., & Martínez-Lage, P. (2015). Fitting the epidemiology and neuropathology of the early stages of Alzheimer's disease to prevent dementia. *Alzheimer's Research & Therapy*, *7*(1), Article number: 2.

Mariani, E., Vernooij-Dassen, M. J. F. J., Koopmans, R., Engels, Y., & Chattat, R. (2017). Shared decision-making in dementia care planning: Barriers and facilitators in two European countries. *Aging & Mental Health*, *21*(1), 31–39.

Markey, R. (2018). Introduction: Global patterns of participation. In R. Markey, P. Gollan, A. Hodkinson, A. Chouraqui, & U. Veersma (Eds.), *Models of employee participation in a changing global environment*: *Diversity and interaction* (pp. 3–22). New York, NY: Routledge.

Marriott-Statham, K., Mackay, M., Brennan, N., & Mackay, J. (2018). Empowering aged care nurses to deliver person-centred care: Enabling nurses to shine. *Nurse Education in Practice*, *31*, 112–117.

Marshall, K. (2013). *Puppetry in dementia care: Connecting through creativity and joy*. London, UK: Jessica Kingsley Publishers.

Marshall, M. (1993). *Small scale, domestic style, longstay accommodation for people with dementia*. Stirling, UK: University of Stirling.

Martyr, A., & Clare, L. (2018). Awareness of functional ability in people with early-stage dementia. *International Journal of Geriatric Psychiatry, 33*(1), 31–38.

Maslow, K., & Ory, M. (2001). Dementia special care unit research. *Alzheimer's Care Quarterly*, *2*(3), 10–16.

Mathers, C. D., Stevens, G. A., Boerma, T., White, R. A., & Tobias, M. I. (2015). Causes of international increases in older age life expectancy. *The Lancet*, *385*(9967), 540–548.

Mathumbu, D., & Dodd, N. (2013). Perceived organisational support, work engagement and organisational citizenship behaviour of nurses at Victoria Hospital. *Journal of Psychology*, *4*(2), 87–93.

Maust, D. T., Kim, H. M., Seyfried, L. S., Chiang, C., Kavanagh, J., Schneider, L. S., & Kales, H. C. (2015). Antipsychotics, other psychotropics, and the risk of death in patients with dementia: Number needed to harm. *JAMA Psychiatry*, *72*(5), 438–445.

Mavromaras, K., Knight, G., Isherwood, L., Crettenden, A., Flavel, J., Karmel, T., ... & Wei, Z. (2017). *The aged care workforce, 2016.* A report prepared for the Department of Health. Canberra, ACT: Australian Government.

May, H., Edwards, P., & Brooker, D. (2009). *Enriched care planning for people with Dementia: A good practice guide to delivering person-centred care*. London, UK: Jessica Kingsley Publishers.

Mayrhofer, A., & Goodman, C. (2016). Workforce development in dementia care through education and training: An audit of two counties. *The Journal of Mental Health Training, Education and Practice, 11*(2), 112–121.

McCann, P. (2017). Urban futures, population ageing and demographic decline. *Cambridge Journal of Regions, Economy and Society*, *10*(3), 543–557.

McConnell, E. S., & Meyer, J. (2019). Assessing quality for people living with dementia in residential long-term care: Trends and challenges. *Gerontology & Geriatric Medicine*, *5*, 2333721419861198. doi:10.1177/2333721419861198

McCormack, B. (2004). Person-centredness in gerontological nursing: An overview of the literature. *Journal of Clinical Nursing*, *13*, 31–38.

McCormack, B., & McCance, T. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, *56*(5), 472–479.

McCormack, B., & McCance, T. (Eds.). (2016). *Person-centred practice in nursing and health care: theory and practice*. Chichester, UK: John Wiley & Sons.

McCormack, L., Tillock, K., & Walmsley, B. D. (2017). Holding on while letting go: Trauma and growth on the pathway of dementia care in families. *Aging & Mental Health*, *21*(6), 658–667.

McCreaddie, M., & Wiggins, S. (2008). The purpose and function of humour in health, health care and nursing: A narrative review. *Journal of Advanced Nursing*, *61*(6), 584–595.

McCulloch, S. J., & Miller, P. K. (2019, April). *Healthy ageing: The flower children's emotional responses to music in exercise.* Paper presented at BASES Student Conference 2019: Sport and Exercise Science – Transforming Lives, Dundee, UK.

McEwen, M., & Wills, E. M. (2017). *Theoretical basis for nursing.* Philadelphia, PA: Lippincott Williams & Wilkins.

McGhee, G., Marland, G. R., & Atkinson, J. (2007). Grounded theory research: Literature reviewing and reflexivity. *Journal of Advanced Nursing*, *60*(3), 334–342.

McGilton, K. S., Bowers, B. J., Heath, H., Shannon, K., Dellefield, M. E., Prentice, D., ... & Mueller, C. A. (2016). Recommendations from the international consortium on professional nursing practice in long-term care homes. *Journal of the American Medical Directors Association*, *17*(2), 99–103.

McGilton, K. S., Tourangeau, A., Kavcic, C., & Wodchis, W. P. (2013). Determinants of regulated nurses’ intention to stay in long-term care homes. *Journal of Nursing Management*, *21*(5), 771–781.

McGreevy, J. (2015). Dementia and the person-centred care approach. *Nursing Older People*, *27*(8), 27–31.

McGreevy, J. (2016). Implementing culture change in long-term dementia care settings. *Nursing Standard*, *30*(19), 44–50.

McKeith, I. G., Boeve, B. F., Dickson, D. W., Halliday, G., Taylor, J. P., Weintraub, D., ... & Kosaka, K. (2017). Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. *Neurology*, *89*(1), 88–100.

McKenzie, E. L., & Brown, P. M. (2014). Nursing students’ intentions to work in dementia care: Influence of age, ageism, and perceived barriers. *Educational Gerontology*, *40*(8), 618–633.

McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, *5*(2), 148–158.

McLaren, N., Drewitt-Smith, A., Coote, G., & Fuller, K. (2019, January). NSW worker charged over alleged assaults of five elderly residents. *ABC News*. Sydney, NSW: Australian Broadcasting Corporation.

McLean, A. (2017). The therapeutic landscape of dementia care: Contours of intersubjective spaces for sustaining the person. In A. Williams (Ed.), *Therapeutic landscapes* (pp. 315–332). New York, NY: Routledge.

McPherson, S., Hiskey, S., & Alderson, Z. (2015). Distress in working on dementia wards –athreat to compassionate care: A grounded theory study. *International Journal of Nursing Studies*, *53*, 95–104. doi:10.1016/j.ijnurstu.2015.08.013

Melia, K. M. (1996). Rediscovering Glaser. *Qualitative Health Research*, *6*(3), 368–378.

Meuleners, L. B., Fraser, M. L., Bulsara, M. K., Chow, K., & Ng, J. Q. (2016). Risk factors for recurrent injurious falls that require hospitalization for older adults with dementia: A population based study. *BMC Neurology*, *16*(1), Article number: 188.

Mey, G., & Dietrich, M. (2017). From text to image–shaping a visual grounded theory methodology. *Historical Social Research/Historische Sozialforschung*, *42*(4), 280–300.

Michalowsky, B., Xie, F., Eichler, T., Kilimann, I., Teipel, S. J., Thyrian, J. R., ... & Hoffmann, W. (2018). Cost-utility analysis of dementia care management: Results of the cluster-randomized, controlled, interventional trial Delphi-MV. *Alzheimer's & Dementia*, *14*(7), P1502-P1503.

Midtbust, M. H., Alnes, R. E., Gjengedal, E., & Lykkeslet, E. (2018). Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences. *BMC Health Services Research*, *18*(1), Article number: 709.

Miller, C. A. (2018). *Nursing for wellness in older adults*. Philadelphia, PA: Lippincott Williams & Wilkins.

Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*, *15*(5), 1141–1157.

Miller, L. M., Whitlatch, C. J., Lee, C. S., & Caserta, M. S. (2018). Care values in dementia: Patterns of perception and incongruence among family care dyads. *The Gerontologist*, *59*(3), 509–518.

Miller, S., Morton, N., Ramsey, A., Roberts, K., Stumbo, B., & White, S. (2017). *Improved patient outcomes through timely response to call lights*. Morehead, KY: Morehead State University.

Milte, C. M., & McNaughton, S. A. (2016). Dietary patterns and successful ageing: A systematic review. *European Journal of Nutrition*, *55*(2), 423–450.

Milte, R., Bradley, C., Miller, M., Farrer, O., & Crotty, M. (2018). How widely are supportive and flexible food service systems and mealtime interventions used for people in residential care facilities? A comparison of dementia-specific and nonspecific facilities. *Healthcare*, *6*(4), e140.

Milte, R., Ratcliffe, J., Chen, G., & Crotty, M. (2018). What characteristics of nursing homes are most valued by consumers? A discrete choice experiment with residents and family members. *Value in Health*, *21*(7), 843–849.

Mitchell, B. (2018). Identifying institutional elder abuse in Australia through coronial and other death review processes. *Macquarie LJ, 18*, 35–56.

Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard*, *30*(7), 46–50.

Mitchell, S. L., Kiely, D. K., Miller, S. C., Connor, S. R., Spence, C., & Teno, J. M. (2007). Hospice care for patients with dementia. *Journal of Pain and Symptom Management*, *34*(1), 7–16.

Mitra, A. (2016). *Fundamentals of quality control and improvement*. Hoboken, NJ: John Wiley & Sons.

Mjørud, M., Engedal, K., Røsvik, J., & Kirkevold, M. (2017). Living with dementia in a nursing home, as described by persons with dementia: A phenomenological hermeneutic study. *BMC Health Services Research*, *17*(1), Article number: 93.

Mobily, P. R., Maas, M. L., Buckwalter, K. C., & Kelley, L. S. (1992). Staff stress on an Alzheimer's unit. *Journal of Psychosocial Nursing and Mental Health Services*, *30*(9), 25–31.

Mohammed, K., Nolan, M. B., Rajjo, T., Shah, N. D., Prokop, L. J., Varkey, P., & Murad, M. H. (2016). Creating a patient-centered health care delivery system: Asystematic review of health care quality from the patient perspective. *American Journal of Medical Quality*, *31*(1), 12–21.

Mole, L., Kent, B., Abbott, R., Wood, C., & Hickson, M. (2018). The nutritional care of people living with dementia at home: A scoping review. *Health & Social Care in the Community*, *26*(4), e485–e496.

Monroe, T. B., Parish, A., & Mion, L. C. (2015). Decision factors nurses use to assess pain in nursing home residents with dementia. *Archives of Psychiatric Nursing*, *29*(5), 316–320.

Monsen, C., Acosta, S., Mani, K., & Wann-Hansson, C. (2015). A randomised study of NPWT closure versus alginate dressings in peri-vascular groin infections: Quality of life, pain and cost. *Journal of Wound Care, 24*(6), 252–260.

Montague, A., Burgess, J., & Connell, J. (2015). Attracting and retaining Australia's aged care workers: Developing policy and organisational responses. *Labour & Industry: AJournal of the Social and Economic Relations of Work*, *25*(4), 293–305.

Monthaisong, D. (2018). Nurses' experiences in providing care for people with dementia: An integrative literature review. *Journal of Nursing and Care*, *7*(2), 1–6.

Moorhead, S., Johnson, M., Maas, M. L., & Swanson, E. (2018). *Nursing outcomes classification (NOC)-e-book: Measurement of health outcomes*. Oxford, UK: Elsevier Health Sciences.

Moos, I. (2011). Humour, irony and sarcasm in severe Alzheimer's dementia–A corrective to retrogenesis? *Ageing & Society*, *31*(2), 328–346.

Morgan, D. G., & Stewart, N. J. (1999). The physical environment of special care units: Needs of residents with dementia from the perspective of staff and family caregivers. *Qualitative Health Research, 9*(1), 105–118.

Morgan, D. L. (2018). Living within blurry boundaries: The value of distinguishing between qualitative and quantitative research. *Journal of Mixed Methods Research*, *12*(3), 268–279.

Morgan, J. (2018). Living well with dementia. *The Lancet Neurology*, *17*(4), 306–307.

Morgan-Brown, M., Brangan, J., McMahon, R., & Murphy, B. (2019). Engagement and social interaction in dementia care settings: A call for occupational and social justice. *Health & Social Care in the Community*, *27*(2), 400–408.

Morrison, K. B., & Korol, S. A. (2014). Nurses' perceived and actual caregiving roles: Identifying factors that can contribute to job satisfaction. *Journal of Clinical Nursing, 23,* 3468–3477.

Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice*, *24*(1), 9–18.

Moser, S. J. (2019). Wandering in dementia and trust as an anticipatory action. *Medical Anthropology*, *38*(1), 59–70.

Moss, H., & O'Neill, D. (2019). Narratives of health and illness: Arts-based research capturing the lived experience of dementia. *Dementia*, *18*(6), 2008-2017.

Moyle, W., El Saifi, N., Draper, B., Jones, C., Beattie, E., Shum, D., ... & Dwyer, S. (2017). Pharmacotherapy of persons with dementia in long-term care in Australia: A descriptive audit of central nervous system medications. *Current Drug Safety*, *12*(2), 95–102.

Mozley, C., Sutcliffe, C., Bagley, H., Cordingley, L., Challis, D., Huxley, P., & Burns, A. (2017). *Towards quality care: Outcomes for older people in care homes*. Abingdon, UK: Routledge.

Mruck, K., & Mey, G. (2019). Grounded theory methodology and self-reflexivity in the qualitative research process. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of current developments in grounded theory* (pp. 470–496). Thousand Oaks, CA: Sage Publications, Inc.

Mueller, C., Ballard, C., Corbett, A., & Aarsland, D. (2017). The prognosis of dementia with Lewy bodies. *The Lancet Neurology*, *16*(5), 390–398.

Mueller, C., Molokhia, M., Perera, G., Veronese, N., Stubbs, B., Shetty, H., ... & Stewart, R. (2018). Polypharmacy in people with dementia: Associations with adverse health outcomes. *Experimental Gerontology, 106*, 240–245.

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: Approaches and goals. *Aging Health*, *8*(4), 377–386.

Mukaetova-Ladinska, E. B., Cosker, G., Chan, M., Coppock, M., Scully, A., Kim, S. Y., ... & Teodorczuk, A. (2019). Delirium stigma among nursing and medical staff. *Geriatrics, 4*(1), 6.

Mulders, A. J., Fick, I. W., Bor, H., Verhey, F. R., Zuidema, S. U., & Koopmans, R. T. (2016). Prevalence and correlates of neuropsychiatric symptoms in nursing home patients with young-onset dementia: The BEYOnD Study. *Journal of the American Medical Directors Association, 17*(6), 495–500.

Murphy, A. M., & Shwartz, J. L. (2018). Innovative treatment models for Alzheimer’s disease and dementia care. *Journal of Health Care Finance*, *44*(3), 1–16.

Mulders, A. J., Smalbrugge, M., Zwijsen, S. A., Appelhof, B., Zuidema, S. U., de Vugt, M. E., ... & Koopmans, R. T. (2018). Nursing staff distress associated with neuropsychiatric symptoms in young-onset dementia and late-onset dementia. *Journal of the American Medical Directors Association*, *19*(7), 627–632.

Mulders, A. J., Zuidema, S. U., Leeuwis, R., Bor, H., Verhey, F. R., & Koopmans, R. T. (2019). Prevalence and correlates of psychotropic drug use in Dutch nursing home patients with young-onset dementia. *International Journal of Geriatric Psychiatry, 34*(8), 1185–1193.

Nadeau, K., Pinner, K., Murphy, K., & Belderson, K. M. (2017). Perceptions of a primary nursing care model in a pediatric hematology/oncology unit. *Journal of Pediatric Oncology Nursing*, *34*(1), 28–34.

Nagaratnam, K., & Nagaratnam, N. (2019). Elderly abuse and neglect. In N. Nagaratnam, K. Nagaratnam, & G. Cheuk (Eds.), *Advanced age geriatric care: A comprehensive guide* (pp. 19–24). Cham, Switzerland: Springer International Publishing.

Naidoo, Y. (2019). Comparing the implications of expanded income-based measures of living standards with an application to older Australians. *Journal of Social Policy*, *48*(1), 83–105.

Nair, N. P., Chalmers, L., Peterson, G. M., Bereznicki, B. J., Castelino, R. L., & Bereznicki, L. R. (2016). Hospitalization in older patients due to adverse drug reactions–The need for a prediction tool. *Clinical Interventions in Aging*, *11*, 497–505.

Nakashima, T., Young, Y., & Hsu, W. H. (2019). Do nursing home residents with dementia receive pain interventions? *American Journal of Alzheimer’s Disease & Other Dementias*, *34*(3), 193–198.

Nakrem, S., Vinsnes, A. G., Harkless, G. E., Paulsen, B., & Seim, A. (2013). Ambiguities: Residents’ experience of “nursing home as my home”. *International Journal of Older People Nursing*, *8*(3), 216–225.

Nazir, A., Arling, G., Perkins, A. J., & Boustani, M. (2011). Monitoring quality of care for nursing home residents with behavioural and psychological symptoms related to dementia. *Journal of the American Medical Directors Association, 12*(9), 660–667.

Needleman, J., Buerhaus, P., Mattke, S., Stewart, M., & Zelevinsky, K. (2002). Nurse-staffing levels and the quality of care in hospitals. *New England Journal of Medicine*, *346*(22), 1715–1722.

Nell, D., Neville, S., Bellew, R., O'Leary, C., & Beck, K. L. (2016). Factors affecting optimal nutrition and hydration for people living in specialised dementia care units: A qualitative study of staff caregivers' perceptions. *Australasian Journal on Ageing*, *35*(4), E1–E6.

Nelson, S. T., & Flynn, L. (2015). Relationship between missed care and urinary tract infections in nursing homes. *Geriatric Nursing*, *36*(2), 126–130.

Nembhard, I. M., Yuan, C. T., Shabanova, V., & Cleary, P. D. (2015). The relationship between voice climate and patients' experience of timely care in primary care clinics. *Health Care Management Review*, *40*(2), 104–115.

Netten, A., & Beecham, J. (2018). *Costing community care: Theory and practice*. Abingdon, UK: Routledge.

Ng, A. S., Rademakers, R., & Miller, B. L. (2015). Frontotemporal dementia: A bridge between dementia and neuromuscular disease. *Annals of the New York Academy of Sciences, 1338*(1), 71–93.

Nichols, K., Tomas, M., Chen, B., Kalev, D., Kraayenbrink, B., & Palestro, C. (2016). Does I-123-FP-CIT uptake absolute quantitation discriminate Lewy body dementia from Parkinsonism?*Journal of Nuclear Medicine*, *57*(Suppl_2), 1805–1805.

Nikmat, A. W., Al-Mashoor, S. H., & Hashim, N. A. (2015). Quality of life in people with cognitive impairment: Nursing homes versus home care. *International Psychogeriatrics*, *27*(5), 815–824.

Nikmat, A. W., Hawthorne, G., & Al-Mashoor, S. H. (2015). The comparison of quality of life among people with mild dementia in nursing home and home care – A preliminary report. *Dementia, 14*(1), 114–125.

Nilsson, A., Edvardsson, D., & Rushton, C. (2019). Nurses' descriptions of person-centred care for older people in an acute medical ward – On the individual, team and organisational levels. *Journal of Clinical Nursing*, *28*(7-8), 1251–1259.

Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond "person-centred" care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, *13*, 45–53.

Nordin, S., McKee, K., Wijk, H., & Elf, M. (2017). The association between the physical environment and the well-being of older people in residential care facilities: A multilevel analysis. *Journal of Advanced Nursing*, *73*(12), 2942–2952.

Nørgaard, A., Jensen-Dahm, C., Gasse, C., Hansen, E. S., & Waldemar, G. (2017). Psychotropic polypharmacy in patients with dementia: Prevalence and predictors. *Journal of Alzheimer's Disease*, *56*(2), 707–716.

Norouzinia, R., Ahmadi, M., & Seidabadi, M. (2016). Knowledge and clinical competence of medical emergencies students in facing trauma. *Ṭibb-i urzhāns-i Īrān*, *3*(2), 73–77. Retrieved from https://doaj.org/article/a7b2f0090aa242569d2179bfa834e5ab

Nuñez, M. T., & Chana-Cuevas, P. (2018). New perspectives in iron chelation therapy for the treatment of neurodegenerative diseases. *Pharmaceuticals*, *11*(4), E109.

Nursing and Midwifery Board of Australia. (2018). *Professional standards*. Retrieved from https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Professional-standards.aspx

O'Brien, J. T., Holmes, C., Jones, M., Jones, R., Livingston, G., McKeith, I., ... & Sampson, E. L. (2017). Clinical practice with anti-dementia drugs: A revised (third) consensus statement from the British Association for Psychopharmacology. *Journal of Psychopharmacology*, *31*(2), 147–168.

O'Brien, J. T., & Thomas, A. (2015). Vascular dementia. *The Lancet*, *386*(10004), 1698–1706.

O'Brien, M. E. (2018). *Spirituality in nursing: Standing on holy ground* (6th ed.). Burlington, MA: Jones & Bartlett Learning.

O'Brien, W. H., Horan, K. A., Singh, S. R., Moeller, M. M., Wasson, R. S., Jex, S. M., ...& Barratt, C. L. (2019). Relationships among training, mindfulness, and workplace injuries among nurse aides working in long-term care settings. *Occupational Health Science, 3*(1), 45–58.

O'Connell, B., Hawkins, M., Ostaszkiewicz, J., & Millar, L. (2012). Carers' perspectives of respite care in Australia: An evaluative study. *Contemporary Nurse*, *41*(1), 111–119.

O'Connell, B. O., & Ostaszkiewicz, J. (2005). Sink or swim – Ageing in Australia. *Australian Health Review*, *29*(2), 146–150.

O'Connell, B., Orr, J., Ostaszkiewicz, J., & Gaskin, C. J. (2011). Nursing care needs of patients with and without dementia admitted to hospital with fractured neck of femur. *International Journal of Orthopaedic and Trauma Nursing*, *15*(3), 136–144.

O'Connor, D. W., D'Cunha, C., Clifton, T., Huppert, D., Lowy, H., Macfarlane, S., ... & White, E. (2018). Quality indicators of psychotropic prescribing to people with dementia in aged psychiatry inpatient units. *Aging & Mental Health*, *22*(11), 1432–1437.

O'Loughlin, K., Barrie, H., & Kendig, H. (2018). Australia's baby boomers as the future older generation. In T. R. Klassen, M. Higo, N. S. Dhirathiti, & T. W. Devasahayam (Eds.), *Ageing in Asia–Pacific: Interdisciplinary and comparative perspectives* (pp. 237–255). Abingdon, UK: Routledge.

O'Rourke, H. M., Duggleby, W., Fraser, K. D., & Jerke, L. (2015). Factors that affect quality of life from the perspective of people with dementia: A metasynthesis. *Journal of the American Geriatrics Society*, *63*(1), 24–38.

Ofori-Asenso, R., Zomer, E., Curtis, A. J., Zoungas, S., & Gambhir, M. (2018). Measures of population ageing in Australia from 1950 to 2050. *Journal of Population Ageing*, *11*(4), 367–385.

Ogden, J. (2017). Rising cost of dementia care risks social care funding crisis. *Progress in Neurology and Psychiatry*, *21*(1), 5–32.

Ohta, R. J., & Ohta, B. M. (1988). Special units for Alzheimer's disease patients: A critical look. *The Gerontologist*, *28*(6), 803–808.

Oliveira, C., & Tariman, J. D. (2017). Barriers to the patient advocacy role: An integrative review of the literature. *Journal of Nursing Practice Applications & Reviews of Research*, *7*(2), 7–12.

Oliveira, F. F. D., Almeida, S. S. D., Chen, E. S., Smith, M. C., Naffah-Mazzacoratti, M. D. G., & Bertolucci, P. H. F. (2018). Lifetime risk factors for functional and cognitive outcomes in patients with Alzheimer’s disease. *Journal of Alzheimer’s Disease,* (Preprint), 1–17.

Olney, N. T., Spina, S., & Miller, B. L. (2017). Frontotemporal dementia. *Neurologic Clinics*, *35*(2), 339–374.

Olson, K. (2016). *Essentials of qualitative interviewing*. Abingdon, UK: Routledge.

Olsson, A., Engström, M., Skovdahl, K., & Lampic, C. (2012). My, your and our needs for safety and security: Relatives’ reflections on using information and communication technology in dementia care. *Scandinavian Journal of Caring Sciences*, *26*(1), 104–112.

Omranifard, V., Haghighizadeh, E., & Akouchekian, S. (2018). Depression in main caregivers of dementia patients: Prevalence and predictors. *Advanced Biomedical Research*, *7*, 34.

Orrell, M. (2016). Access to timely formal care in dementia: Baseline results of the Actifcare cohort study with a focus on the Portuguese sample. In J.-A. Michel (Ed.), *12th International Congress of the European Union Geriatric Medicine Society* (p. S58), Lisbon, Portugal: European Union Geriatric Medicine Society.

Osborn, R., Moulds, D., Schneider, E. C., Doty, M. M., Squires, D., & Sarnak, D. O. (2015). Primary care physicians in ten countries report challenges caring for patients with complex health needs. *Health Affairs*, *34*(12), 2104–2112.

Ostaszkiewicz, J. (2018). A conceptual model of the risk of elder abuse posed by incontinence and care dependence. *International Journal of Older People Nursing*, *13*(2), e12182.

Ostaszkiewicz, J., Lakhan, P., O’Connell, B., & Hawkins, M. (2015). Ongoing challenges responding to behavioural and psychological symptoms of dementia. *International Nursing Review*, *62*(4), 506–516.

Ostaszkiewicz, J., O’Connell, B., & Dunning, T. (2014). Ethical challenges associated with providing continence care in residential aged care facilities: Findings from a grounded theory study. *Australian and New Zealand Continence Journal*, *20*(4), 179–186.

Ostaszkiewicz, J., O’Connell, B., & Dunning, T. (2016). “We just do the dirty work”: Dealing with incontinence, courtesy stigma and the low occupational status of carework in long-term aged care facilities. *Journal of Clinical Nursing*, *25*(17–18), 2528–2541.

Owens, L. D., & Koch, R. W. (2015). Understanding quality patient care and the role of the practicing nurse. *Nursing Clinics*, *50*(1), 33–43.

Palesi, F., De Rinaldis, A., Vitali, P., Castellazzi, G., Casiraghi, L., Germani, G., ... & Micieli, G. (2018). Specific patterns of white matter alterations help distinguishing Alzheimer’s and vascular dementia. *Frontiers in Neuroscience*, *12*, Article number: 274.

Pandit, N. R. (1996). The creation of theory: A recent application of the grounded theory method. *The Qualitative Report*, *2*(4), 1–15.

Park, A. Y. (2018). A study of knowledge about dementia, empathy and attitudes toward dementia in caregivers of older adults with dementia. *Journal of Digital Convergence*, *16*(1), 389–397.

Parke, B., Hunter, K. F., Schulz, M. E., & Jouanne, L. (2019). Know me – A new person-centered approach for dementia-friendly emergency department care. *Dementia*, *18*(2), 432–447.

Parker, J., & Penhale, B. (2018). *Forgotten people: Positive approaches to dementia care*. Abingdon, UK: Routledge.

Parker, V., Engle, R. L., Afable, M. K., Tyler, D. A., Gormley, K., Stolzmann, K., ...& Sullivan, J. L. (2019). Staff-perceived conflict between resident-centered care and quality in the skilled nursing facility: Are both possible? *Clinical Gerontologist*, *42*(3), 267–276.

Parsons, C. (2017). Polypharmacy and inappropriate medication use in patients with dementia: An under-researched problem. *Therapeutic Advances in Drug Safety*, *8*(1), 31–46.

Payne, S. (2007). Grounded theory. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 65–86). London, UK: Sage Publications Ltd.

Pearson, A., & Chalmers, J. (2004). Oral hygiene care for adults with dementia in residential aged care facilities. *JBI Reports*, *2*(3), 65–113.

Pearson, A., Hegney, D., & Donnelly, P. (2018). Serving the community: The rural general practice nurse. In M. Gott (Ed.), *Nursing practice, policy and change* (pp. 143–160). Boca Raton, FL: CRC Press.

Peeters, G. G., Gardiner, P. A., Dobson, A. J., & Brown, W. J. (2018). Associations between physical activity, medical costs and hospitalisations in older Australian women: Results from the Australian Longitudinal Study on Women's Health. *Journal of Science and Medicine in Sport*, *21*(6), 604–608.

Peng, R., & Anstey, K. J. (2019). Longitudinal study of factors associated with informal care provision: Evidence from older Australians. *Australasian Journal on Ageing*, *38*(2), 98–106.

Peri, K., Kerse, N., Moyes, S., Scahill, S., Chen, C., Hong, J. B., & Hughes, C. M. (2015). Is psychotropic medication use related to organisational and treatment culture in residential care. *Journal of Health Organization and Management*, *29*(7), 1065–1079.

Person, M., & Hanssen, I. (2015). Joy, happiness, and humor in dementia care: A qualitative study. *Creative Nursing*, *21*(1), 47–52.

Peters, R., Booth, A., Rockwood, K., Peters, J., D'Este, C., & Anstey, K. J. (2019). Combining modifiable risk factors and risk of dementia: A systematic review and meta-analysis. *BMJ Open*, *9*(1), e022846.

Petersen, R. C., Lundt, E. S., Therneau, T. M., Weigand, S. D., Knopman, D. S., Mielke, M. M., ... & Jack, C. R. Jr. (2019). Predicting progression to mild cognitive impairment. *Annals of Neurology*, *85*(1), 155–160.

Petrucci, C., Calandro, M. T., Tresulti, F., Baldacchini, A., & Lancia, L. (2015). Relationship between nurse staffing and nursing outcomes: Anarrative review of literature. *Professioni infermieristiche*, *68*(4), 195–202.

Phillips, C. D., Sloane, P. D., Hawes, C., Koch, G., Han, J., Spry, K., ... & Williams, R. L. (1997). Effects of residence in Alzheimer disease special care units on functional outcomes. *JAMA*, *278*(16), 1340–1344.

Phillipson, L., Goodenough, B., Reis, S., & Fleming, R. (2016). Applying knowledge translation concepts and strategies in dementia care education for health professionals: Recommendations from a narrative literature review. *Journal of Continuing Education in the Health Professions*, *36*(1), 74–81.

Pickett, J., Bird, C., Ballard, C., Banerjee, S., Brayne, C., Cowan, K., ... & Walton, C. (2018). A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International Journal of Geriatric Psychiatry*, *33*(7), 900–906.

Pierce, H., Perry, L., Gallagher, R., & Chiarelli, P. (2017). Urinary incontinence, work, and intention to leave current job: A cross sectional survey of the Australian nursing and midwifery workforce. *Neurourology and Urodynamics*, *36*(7), 1876–1883.

Pierre, J. S., & Conley, D. M. (2017). Introduction to gerontological nursing. In K. L. Mauk (Ed.), *Gerontological nursing: Competencies for care* (pp. 3–28). Burlington, MA: Jones & Bartlett Learning.

Piersma, D., Fuermaier, A. B., De Waard, D., Davidse, R. J., De Groot, J., Doumen, M. J., ... & Tucha, O. (2018). Assessing fitness to drive in patients with different types of dementia. *Alzheimer Disease and Associated Disorders*, *32*(1), 70–75.

Piggott, J. (2016). Population ageing in Australia – National policy challenges and future directions. In K. Hendig, P. McDonald, & J. Piggott (Eds.), *Population ageing and Australia's future* (pp. 47–62). Canberra, ACT: ANU Press.

Pijl-Zieber, E. M., Awosoga, O., Spenceley, S., Hagen, B., Hall, B., & Lapins, J. (2018). Caring in the wake of the rising tide: Moral distress in residential nursing care of people living with dementia. *Dementia*, *17*(3), 315–336.

Pillemer, K., Burnes, D., Riffin, C., & Lachs, M. S. (2016). Elder abuse: Global situation, risk factors, and prevention strategies. *The Gerontologist*, *56*(Suppl_2), S194–S205.

Pini, S., Ingleson, E., Megson, M., Clare, L., Wright, P., & Oyebode, J. R. (2017). A needs-led framework for understanding the impact of caring for a family member with dementia. *The Gerontologist*, *58*(2), e68–e77.

Pink, J., O'Brien, J., Robinson, L., & Longson, D. (2018). Dementia –assessment, management and support: Summary of updated NICE guidance. *BMJ*, *361*, k2438.

Pinkert, C., Faul, E., Saxer, S., Burgstaller, M., Kamleitner, D., & Mayer, H. (2018). Experiences of nurses with the care of patients with dementia in acute hospitals: A secondary analysis. *Journal of Clinical Nursing*, *27*(1-2), 162–172.

Poikkeus, T., Suhonen, R., Katajisto, J., & Leino-Kilpi, H. (2020). Relationships between organizational and individual support, nurses' ethical competence, ethical safety, and work satisfaction. *Health Care Management Review*, *45*(1), 83–93.

Polis, S., Higgs, M., Manning, V., Netto, G., & Fernandez, R. (2015). Factors contributing to nursing team work in an acute care tertiary hospital. *Collegian, 24*(1), 19–25. doi:10.1016/j.colegn.2015.09.002

Pomey, M. P., Hihat, H., Khalifa, M., Lebel, P., Néron, A., & Dumez, V. (2015). Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced. *Patient Experience Journal*, *2*(1), 29–42.

Powell, T. (2018). "Tho'much is taken, much abides": A good life within dementia. *TheHastings Center Report*, *48*(S3), S71–S74.

Power, E., Mee, K., & Horrocks, J. (2018). Housing: An infrastructure of care. *Housing Studies*. doi:10.1080/02673037.2019.1612038

Prince, M. (2017). Progress on dementia – Leaving no one behind. *The Lancet, 390*(10113), e51–e53.

Prince, M., Acosta, D., Ferri, C. P., Guerra, M., Huang, Y., Rodriguez, J. J. L., ... & Acosta, I. (2012). Dementia incidence and mortality in middle-income countries, and associations with indicators of cognitive reserve: A 10/66 Dementia Research Group population-based cohort study. *The Lancet, 380*(9836), 50-58.

Prince, M., Ali, G. C., Guerchet, M., Prina, A. M., Albanese, E., & Wu, Y. T. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's Research & Therapy*, *8*(1), Article number: 23.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's & Dementia*, *9*(1), 63–75.

Prince, M., Bryce, R., & Ferri, C. (2011). *World Alzheimer Report 2011: The benefits of early diagnosis and intervention.* A report prepared for Alzheimer's Disease International. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf

Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). *World Alzheimer Report 2016: Improving healthcare for people living with dementia – coverage, quality and costs now and in the future*. A report prepared for Alzheimer's Disease International. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf

Prince, M., Guerchet, M., & Prina, M. (2013). *The global impact of dementia 2013–2050*. A report prepared for Alzheimer's Disease International. Retrieved from https://www.alz.co.uk/research/GlobalImpactDementia2013.pdf

Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer Report 2015: The global impact of dementia – an analysis of prevalence, incidence, cost and trends*. A report prepared for Alzheimer's Disease International. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf

Prizer, L. P., & Zimmerman, S. (2018). Progressive support for activities of daily living for persons living with dementia. *The Gerontologist*, *58*(suppl_1), S74–S87.

Pulsford, D. (2016). *Promoting cognitive security among people with dementia through empathy, person-centred attitudes and a compassionate approach*. (Doctoral dissertation). University of Central Lancashire, Preston, UK.

Pulsford, D., Duxbury, J., & Carter, B. (2016). Personal qualities necessary to care for people with dementia. *Nursing Standard*, *30*(37), 38–44.

Pulsford, D., Hope, K., & Thompson, R. (2007). Higher education provision for professionals working with people with dementia: A scoping exercise. *Nurse Education Today*, *27*(1), 5–13.

Qizilbash, N., Gregson, J., Johnson, M. E., Pearce, N., Douglas, I., Wing, K., ... & Pocock, S. J. (2015). BMI and risk of dementia in two million people over two decades: A retrospective cohort study. *The Lancet. Diabetes & Endocrinology*, *3*(6), 431–436.

Radford, K., Lavrencic, L. M., Delbaere, K., Draper, B., Cumming, R., Daylight, G., ... & Broe, G. A. (2018). Factors associated with the high prevalence of dementia in older Aboriginal Australians. *Journal of Alzheimer's Disease,* (Preprint), 1–11.

Ralph, K. (2019). *"Navigational leadership" through our multi-generational healthcare workforce*. Houston, TX: Elsevier-Houston.

Ranabhat, C. L., Atkinson, J., Park, M. B., Kim, C. B., & Jakovljevic, M. (2018). The influence of universal health coverage on life expectancy at birth (LEAB) and healthy life expectancy (HALE): A multi-country cross-sectional study. *Frontiers in Pharmacology*, *9,* 960.

Rasmussen, P., Henderson, A., Andrew, N., & Conroy, T. (2018). Factors influencing registered nurses' perceptions of their professional identity: An integrative literature review. *The Journal of Continuing Education in Nursing*, *49*(5), 225–232.

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review. *Dementia*, *18*(7–8), 3091–3112.

Raviv, A. (2014). Humor in the "twilight zone": My work as a medical clown with patients with dementia. *Journal of Holistic Nursing*, *32*(3), 226–231.

Ray, M. A. (2016). *Transcultural caring dynamics in nursing and health care*. Philadelphia, PA: F. A Davis Company.

Reay, G., Rankin, J. A., & Then, K. L. (2016). Momentary fitting in a fluid environment: A grounded theory of triage nurse decision making. *International Emergency Nursing*, *26*, 8–13.

Reese, T. R., Thiel, D. J., & Cocker, K. E. (2016). Behavioral disorders in dementia: Appropriate non-drug interventions and antipsychotic use. *American Family Physician*, *94*(4), 276–282.

Reid, R. C., & Chappell, N. L. (2017). Family involvement in nursing homes: Are family caregivers getting what they want? *Journal of Applied Gerontology*, *36*(8), 993–1015.

Renolen, Å., & Hjälmhult, E. (2015). Nurses' experience of using scientific knowledge in clinical practice: A grounded theory study. *Scandinavian Journal of Caring Sciences*, *29*(4), 633–641.

Reynolds, W. J. (2017). *The measurement and development of empathy in nursing*. Abingdon, UK: Routledge.

Rheaume, Y., Riley, M. E., & Volicer, L. (1988). Meeting nutritional needs of Alzheimer patients who pace constantly. *Journal of Nutrition for the Elderly*, *7*(1), 43–52.

Richards, K. A. R., Killian, C. M., Graber, K. C., & Kern, B. D. (2019). Chapter 4: Studying recruitment and retention in PETE: Qualitative and quantitative research methods. *Journal of Teaching in Physical Education*, *38*(1), 22–36.

Richards, L. (2014). *Handling qualitative data: A practical guide*. London, UK: Sage Publications Ltd.

Richter, J. P., McAlearney, A. S., & Pennell, M. L. (2016). The influence of organizational factors on patient safety: Examining successful handoffs in health care. *Health Care Management Review*, *41*(1), 32–41.

Riesch, J., Meyer, L., Lehr, B., & Severin, T. (2018). Dementia-specific training for nursing home staff. *Zeitschrift für Gerontologie und Geriatrie*, *51*(5), 523–529.

Rijnaard, M. D., Van Hoof, J., Janssen, B. M., Verbeek, H., Pocornie, W., Eijkelenboom, A., ... & Wouters, E. J. M. (2016). The factors influencing the sense of home in nursing homes: A systematic review from the perspective of residents. *Journal of Aging Research*, *2016*, Article ID: 6143645.

Riter, R. N., & Fries, B. E. (1992). Predictors of the placement of cognitively impaired residents on special care units. *The Gerontologist*, *32*(2), 184–190.

Rizzi, L., Rosset, I., & Roriz-Cruz, M. (2014). Global epidemiology of dementia: Alzheimer’s and vascular types. *BioMed Research International*, *3,* 908915.

Roach, P., Drummond, N., & Keady, J. (2016). “Nobody would say that it is Alzheimer’s or dementia at this age”: Family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies*, *36,* 26–32.

Roberto, K. A. (2016). The complexities of elder abuse. *American Psychologist, 71*(4), 302–311.

Roberts, B. W., Walton, K. E., & Viechtbauer, W. (2006). Patterns of mean-level change in personality traits across the life course: A meta-analysis of longitudinal studies. *Psychological Bulletin, 132*(1), 1–25.

Roberts, G., Morley, C., Walters, W., Malta, S., & Doyle, C. (2015). Caring for people with dementia in residential aged care: Successes with a composite person-centered care model featuring Montessori-based activities. *Geriatric Nursing, 36*(2), 106–110.

Roberts, T., & Bowers, B. (2015). How nursing home residents develop relationships with peers and staff: A grounded theory study. *International Journal of Nursing Studies*, *52*(1), 57–67.

Robertshaw, D., & Cross, A. (2019). Roles and responsibilities in integrated care for dementia. *Journal of Integrated Care*, *27*(2), 131–140.

Robertson, S., Cooper, C., Hoe, J., Lord, K., Rapaport, P., Marston, L., ... & Livingston, G. (2019). Comparing proxy rated quality of life of people living with dementia in care homes. *Psychological Medicine, 29,* 1–10.

Robinson, L., Tang, E., & Taylor, J. P. (2015). Dementia: Timely diagnosis and early intervention. *BMJ*, *350,* h3029.

Rodríguez-Martín, B. (2019). Individualised nursing care in older people care. In R. Suhonen, M. Stolt, & E. Papastavrou (Eds.), *Individualized care: Theory, measurement, research and practice* (pp. 121–130). Cham, Switzerland: Springer International Publishing.

Rokstad, A. M. M., Røsvik, J., Kirkevold, O., Selbaek, G., SalyyteBenth, J., & Engedal, K. (2013). The effect of person centred dementia care to prevent agitation and other neuropsychiatric symptoms and enhance quality of life in nursing home patients: A 10-month randomised controlled trial. *Dementia and Geriatric Cognitive Disorders, 36*(5), 340–353.

Rokstad, A. M. M., Vatne, S., Engedal, K., & Selbæk, G. (2015). The role of leadership in the implementation of person-centred care using dementia care mapping: A study in three nursing homes. *Journal of Nursing Management*, *23*(1), 15–26.

Romeo, R., Zala, D., Knapp, M., Orrell, M., Fossey, J., & Ballard, C. (2018). Improving the quality of life of care home residents with dementia: Cost-effectiveness of an optimized intervention for residents with clinically significant agitation in dementia. *Alzheimer's & Dementia, 15*(2), 282–291.

Ronch, J. L. (1987). Specialized Alzheimer's units in nursing homes: Pros and cons. *American Journal of Alzheimer's Care and Related Disorders & Research*, *2*(4), 10–19.

Rose, K., & Webb, C. (1998). Analyzing data: Maintaining rigor in a qualitative study. *Qualitative Health Research*, *8*(4), 556–562.

Rose, V. L. (2018). Cameras in long-term care: Monitoring, surveillance, and risk management concerns. *Annals of Long-Term Care*, *26*(4), 9–11.

Roselle, A. (2018). Using the patient–family–nurse triad to improve advocacy and patient care. *Journal of Psychosocial Nursing and Mental Health Services*, *56*(9), 2–3.

Ross, H., Tod, A. M., & Clarke, A. (2015). Understanding and achieving person-centred care: The nurse perspective. *Journal of Clinical Nursing*, *24*(9–10), 1223–1233.

Rostad, H. M., Utne, I., Grov, E. K., Småstuen, M. C., Puts, M., & Halvorsrud, L. (2018). The impact of a pain assessment intervention on pain score and analgesic use in older nursing home residents with severe dementia: A cluster randomised controlled trial. *International Journal of Nursing Studies*, *84*, 52–60.

Røsvik, J., Brooker, D., Mjorud, M., & Kirkevold, Ø. (2013). What is person-centred care in dementia? Clinical reviews into practice: The development of the VIPS practice model. *Reviews in Clinical Gerontology*, *23*(2), 155–163.

Røsvik, J., Kirkevold, M., Engedal, K., Brooker, D., & Kirkevold, Ø. (2011). A model for using the VIPS framework for person-centred care for persons with dementia in nursing homes: A qualitative evaluative study. *International Journal of Older People Nursing*, *6*(3), 227–236.

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, *55*(2), 309–319.

Rowland, C., Hanratty, B., Pilling, M., van den Berg, B., & Grande, G. (2017). The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliative Medicine*, *31*(4), 346–355.

Royal Commission into Aged Care Quality and Safety. (2019). *Interim report*. Retrieved from https://agedcare.royalcommission.gov.au/publications/Pages/interim-report.aspx?utm_source=National_Seniors_Australia&utm_medium=Email&utm_campaign=Royal%20Commission%20into%20Aged%20Care%20Quality%20and%20Safety&utm_content=Royal%20Commission%20into%20Aged%20Care%20Quality%20and%20Safety%3A%20191119

Royston, C., Mitchell, G., Sheeran, C., Strain, J., & Goldsmith, S. (2017). Optimisation of dementia care in care homes: Dementia care framework (innovative practice). *Dementia*, 1471301217740009.

Russell, D. J., Zhao, Y., Guthridge, S., Ramjan, M., Jones, M. P., Humphreys, J. S., & Wakerman, J. (2017). Patterns of resident health workforce turnover and retention in remote communities of the Northern Territory of Australia, 2013–2015. *Human Resources for Health*, *15*(1), Article number: 52.

Rutten, J. L. (2017). Prevention is better than cure: Can exercise prevent dementia? *Maastricht Student Journal of Psychology & Neuroscience*, *6*(1), 1–12.

Sadowsky, C. H., & Galvin, J. E. (2012). Guidelines for the management of cognitive and behavioral problems in dementia. *The Journal of the American Board of Family Medicine*, *25*(3), 350–366.

Sagbakken, M., Nåden, D., Ulstein, I., Kvaal, K., Langhammer, B., & Rognstad, M. K. (2017). Dignity in people with frontotemporal dementia and similar disorders: A qualitative study of the perspective of family caregivers. *BMC Health Services Research*, *17*(1), Article number: 432.

Samus, Q. M., Black, B. S., Bovenkamp, D., Buckley, M., Callahan, C., Davis, K., ... & Lyketsos, C. G. (2018). Home is where the future is: The BrightFocus Foundation consensus panel on dementia care. *Alzheimer's & Dementia*, *14*(1), 104–114.

Sanders, K. (2019). Media review: Research design: Quantitative, qualitative, mixed methods, arts-based, and community-based participatory research approaches. *Journal of Mixed Methods Research, 13*(2), 263–265.

Scales, K., Bailey, S., Middleton, J., & Schneider, J. (2017). Power, empowerment, and person-centred care: Using ethnography to examine the everyday practice of unregistered dementia care staff. *Sociology of Health & Illness*, *39*(2), 227–243.

Scerri, A., Innes, A., & Scerri, C. (2015). Discovering what works well: Exploring quality dementia care in hospital wards using an appreciative inquiry approach. *Journal of Clinical Nursing*, *24*(13–14), 1916–1925.

Scerri, A., Innes, A., & Scerri, C. (2019). Using appreciative inquiry to implement person-centred dementia care in hospital wards. *Dementia*, *18*(1), 190–209.

Schaller, S., Mauskopf, J., Kriza, C., Wahlster, P., & Kolominsky-Rabas, P. L. (2015). The main cost drivers in dementia: A systematic review. *International Journal of Geriatric Psychiatry*, *30*(2), 111–129.

Schacht, E., & Ringe, J. D. (2011). Risk reduction of falls and fractures, reduction of back pain and safety in elderly high risk patients receiving combined therapy with alfacalcidol and alendronate: A prospective study. *Arzneimittelforschung*, *61*(01), 40–54.

Schat, A. C. H., & Frone, M. R. (2011). Exposure to psychological aggression at work and job performance: The mediating role of job attitudes and personal health. *Work & Stress, 25*(1), 23–40.

Schmidt, K., & Diestal, S. (2013). Job demands and personal resources in their relations to indicators of job strain among nurses for older people. *Journal of Advanced Nursing*, *69*(10), 2185–2195.

Schmitz, H., & Westphal, M. (2015). Short-and medium-term effects of informal care provision on female caregivers' health. *Journal of Health Economics*, *42*, 174–185.

Schwarz, B., Chaudhury, H., & Tofle, R. B. (2004). Effect of design interventions on a dementia care setting. *American Journal of Alzheimer's Disease & Other Dementias*, *19*(3), 172–176.

Scott, P. A., Harvey, C., Felzmann, H., Suhonen, R., Habermann, M., Halvorsen, K., ... & Papastavrou, E. (2018). Resource allocation and rationing in nursing care: A discussion paper. *Nursing Ethics*, *26*(5), 1528–1539.

Scott, S. C. E., & Kidd, A. C. (2016). A scoping review of music and anxiety, depression and agitation in older people with dementia in residential facilities and specialist care units. *European Geriatric Medicine*, *7*(5), 488–491.

Seale, D. E., LeRouge, C. M., Ohs, J. E., Tao, D., Lach, H. W., Jupka, K., & Wray, R. (2019). Exploring early adopter baby boomers' approach to managing their health and healthcare. *International Journal of E-Health and Medical Communications*, *10*(1), 94–117.

Sellevold, G. S., Egede-Nissen, V., Jakobsen, R., & Sørlie, V. (2019). Quality dementia care: Prerequisites and relational ethics among multicultural healthcare providers. *Nursing Ethics*, *26*(2), 504–514.

Shamian, J., Kerr, M. S., Laschinger, H. K. S., & Thomson, D. (2016). A hospital-level analysis of the work environment and workforce health indicators for registered nurses in Ontario's acute-care hospitals. *Canadian Journal of Nursing Research Archive*, *33*(4), 35–50.

Sharma, J., & Dhar, R. L. (2016). Factors influencing job performance of nursing staff: Mediating role of affective commitment. *Personnel Review*, *45*(1), 161–182.

Sharp, C. A., Moore, J. S. S., & McLaws, M. L. (2019). Two-hourly repositioning for prevention of pressure ulcers in the elderly: Patient safety or elder abuse? *Journal of Bioethical Inquiry*, *16*(1), 17–34.

Sharp, S., McAllister, M., & Broadbent, M. (2016). The vital blend of clinical competence and compassion: How patients experience person-centred care. *Contemporary Nurse*, *52*(2–3), 300–312.

Sharp, S., McAllister, M., & Broadbent, M. (2018). The tension between person centred and task focused care in an acute surgical setting: A critical ethnography. *Collegian*, *25*(1), 11–17.

Shatenstein, B., & Barberger-Gateau, P. (2015). Prevention of age-related cognitive decline: Which strategies, when, and forwhom?*Journal of Alzheimer's Disease*, *48*(1), 35–53.

Shen, A. (2018). Religious attendance, healthy lifestyles, and perceived health: A comparison of baby boomers with the silent generation. *Journal of Religion and Health*, *58*(4), 1235–1245.

Sherwood, G., & Barnsteiner, J. (Eds.). (2017). *Quality and safety in nursing: A competency approach to improving outcomes*. Chichester, UK: John Wiley & Sons.

Shi, L., Chen, S. J., Ma, M. Y., Bao, Y. P., Han, Y., Wang, Y. M., ... & Lu, L. (2018). Sleep disturbances increase the risk of dementia: A systematic review and meta-analysis. *Sleep Medicine Reviews*, *40*, 4–16.

Shield, R. R. (2018). *Uneasy endings: Daily life in an American nursing home*. Ithaca, NY: Cornell University Press.

Shin, H. Y., Gadzhanova, S., Roughead, E. E., Ward, M. B., & Pont, L. G. (2016). The use of antipsychotics among people treated with medications for dementia in residential aged care facilities. *International Psychogeriatrics*, *28*(6), 977–982.

Shin, J. H. (2013). Relationship between nursing staffing and quality of life in nursing homes. *Contemporary Nurse*, *44*(2), 133–143.

Shukla, R. K. (1983). All-RN model of nursing care delivery: A cost-benefit evaluation. *Inquiry*, *20*(2), 173–184.

Silva, V. (2019). *Navigating family caregiving for dementia: The joint actions and projects of family members*. (Doctoral dissertation). University of British Columbia, Vancouver, Canada.

Silvester, K. M., Mohammed, M. A., Harriman, P., Girolami, A., & Downes, T. W. (2013). Timely care for frail older people referred to hospital improves efficiency and reduces mortality without the need for extra resources. *Age and Ageing*, *43*(4), 472–477.

Simmons, S. F., Coelho, C. S., Sandler, A., & Schnelle, J. F. (2018). A system for managing staff and quality of dementia care in assisted living facilities. *Journal of the American Geriatrics Society, 66*(8), 1632–1637.

Simone, L., Wettstein, A., Senn, O., Rosemann, T., & Hasler, S. (2016). Types of abuse and risk factors associated with elder abuse. *Swiss Medical Weekly, 146,* w14273.

Sinclair, A. J., Gadsby, R., Abdelhafiz, A. H., & Kennedy, M. (2018). Failing to meet the needs of generations of care home residents with diabetes: A review of the literature and a call for action. *Diabetic Medicine*, *35*(9), 1144–1156.

Singh, A., & Prasher, A. (2019). Measuring healthcare service quality from patients' perspective: Using fuzzy AHP application. *Total Quality Management & Business Excellence*, *30*(3–4), 284–300.

Sjögren, K., Lindkvist, M., Sandman, P. O., Zingmark, K., & Edvardsson, D. (2012). Psychometric evaluation of the Swedish version of the person-centered care assessment tool (P-CAT). *International Psychogeriatrics*, *24*(3), 406–415.

Sjögren, K., Lindkvist, M., Sandman, O., Zingmark, K & Edvardsson, D. (2013). Person-centredness and its association with resident wellbeing in dementia care units. *Journal of Advanced Nursing*, *69*(10), 2196–2206.

Sjögren, K., Lindkvist, M., Sandman, P. O., Zingmark, K., & Edvardsson, D. (2015). To what extent is the work environment of staff related to person-centred care? A cross-sectional study of residential aged care. *Journal of Clinical Nursing*, *24*(9–10), 1310–1319.

Sjögren, K., Lindkvist, M., Sandman, P. O., Zingmark, K., & Edvardsson, D. (2017). Organisational and environmental characteristics of residential aged care units providing highly person-centred care: A cross sectional study. *BMC Nursing*, *16*(1), Article number: 44.

Skoog, I., & Aevarsson, O. (2019). Epidemiology of vascular dementia in Europe. InJ. O'Brien, D. Ames, L. Gustafson, M. Folstein, & E. Chiu (Eds.), *Cerebrovascular disease and dementia*: *Pathology, neuropsychiatry and management* (2nd ed., pp. 54–68). London, UK: Taylor and Francis Group.

Skoog, J., Kern, S., Zettergren, A., Zetterberg, H., Blennow, K., Johansson, B., ... & Skoog, I. (2018). Poor sleep is associated with CSF-markers of Alzheimer’s disease in 70-year-olds without dementia. *Alzheimer’s & Dementia*, *14*(7), P265.

Slatyer, S., Coventry, L. L., Twigg, D., & Davis, S. (2016). Professional practice models for nursing: A review of the literature and synthesis of key components. *Journal of Nursing Management*, *24*(2), 139–150.

Sloane, P. D., Mathew, L. J., Scarborough, M., Desai, J. R., Koch, G. G., & Tangen, C. (1991). Physical and pharmacologic restraint of nursing home patients with dementia: Impact of specialized units. *JAMA*, *265*(10), 1278–1282.

Smalbrugge, M., Zwijsen, S. A., Koopmans, R. C., & Gerritsen, D. L. (2017). Challenging behavior in nursing home residents with dementia. In S. Schüssler & C. Lohrmann (Eds.), *Dementia in nursing homes* (pp. 55–66). Cham, Switzerland: Springer International Publishing.

Smit, D., De Lange, J., Willemse, B., Twisk, J., & Pot, A. M. (2016). Activity involvement and quality of life of people at different stages of dementia in long term care facilities. *Aging & Mental Health*, *20*(1), 100–109.

Smith, D., Cunningham, N., Willoughby, M., Young, C., Odell, M., Ibrahim, J., & Bugeja, L. (2019). The epidemiology of sexual assault of older female nursing home residents, in Victoria Australia, between 2000 and 2015. *Legal Medicine*, *36*, 89–95.

Smith, G. D., Gelling, L., Haigh, C., Barnason, S., Allan, H. T., & Jackson, D. (2018). The position of reporting guidelines in qualitative nursing research. *Journal of Clinical Nursing*, *27*(5–6), 889–891.

Smith, G. E. (2016). Healthy cognitive aging and dementia prevention. *American Psychologist*, *71*(4), 268–275.

Smith, R., Fleming, R., Chenoweth, L., Jeon, Y., Stein-Parbury, J., & Brodaty, H. (2012). Validation of the environmental audit tool in both purpose-built and non-purpose-built dementia care setting. *Australasian Journal on Ageing*, *32*(3), 159–163.

Smits, L. L., van Harten, A. C., Pijnenburg, Y. A., Koedam, E. L., Bouwman, F. H., Sistermans, N., ... & van der Flier, W. M. (2015). Trajectories of cognitive decline in different types of dementia. *Psychological Medicine*, *45*(5), 1051–1059.

Smolowitz, J., Speakman, E., Wojnar, D., Whelan, E. M., Ulrich, S., Hayes, C., & Wood, L. (2015). Role of the registered nurse in primary health care: Meeting health care needs in the 21st century. *Nursing Outlook*, *63*(2), 130–136.

Smythe, A., Jenkins, C., Galant-Miecznikowska, M., Bentham, P., & Oyebode, J. (2017). A qualitative study investigating training requirements of nurses working with people with dementia in nursing homes. *Nurse Education Today*, *50*, 119–123.

Snyder, L. (2006). Personhood and interpersonal communication in dementia. In J. C. Hughes, S. J. Louw, & S. R. Sabat (Eds.), *Dementia: Mind, meaning, and the person* (pp. 259–276). Oxford, UK: Oxford University Press.

Song, R., Daly, B. J., Rudy, E. B., Douglas, S., & Dyer, M. A. (1997). Nurses’ job satisfaction, absenteeism, and turnover after implementing a special care unit practice model. *Research in Nursing & Health*, *20*(5), 443–452.

Soto-Gordoa, M., Arrospide, A., Moreno-Izco, F., Martinez-Lage, P., Castilla, I., & Mar, J. (2015). Projecting burden of dementia in Spain, 2010–2050: Impact of modifying risk factors. *Journal of Alzheimer’s Disease*, *48*(3), 721–730.

Spector, A., Revolta, C., & Orrell, M. (2016). The impact of staff training on staff outcomes in dementia care: A systematic review. *International Journal of Geriatric Psychiatry*, *31*(11), 1172–1187.

Spector, P. E. (1985). Measurement of human service staff satisfaction: Development of the job satisfaction survey. *American Journal of Community Psychology*, *13*(6), 693–713.

Spenceley, S., Witcher, C. S., Hagen, B., Hall, B., & Kardolus-Wilson, A. (2017). Sources of moral distress for nursing staff providing care to residents with dementia. *Dementia*, *16*(7), 815–834.

Spencer, S. J., D’Angelo, H., Soch, A., Watkins, L. R., Maier, S. F., & Barrientos, R. M. (2017). High-fat diet and aging interact to produce neuroinflammation and impair hippocampal-and amygdalar-dependent memory. *Neurobiology of Aging*, *58*, 88–101.

Spilsury, K., Hewitt, C., Stirk, L., & Bowman, C. (2011). The relationship between nurse staffing and quality of care in nursing homes: A systematic review. *International Journal of Nursing Studies, 48*(6), 732–750.

Splaine, M. (2008). Campaign advocacy in brief: Dementia care policy strategies and recommendations. *Alzheimer's Care Today*, *9*(2), 145–146.

Spreadbury, J. H., & Kipps, C. (2019). Measuring younger onset dementia: What the qualitative literature reveals about the "lived experience" for patients and caregivers. *Dementia*, *18*(2), 579–598.

Srivastava, G., Tripathi, R. K., Tiwari, S. C., Singh, B., & Tripathi, S. M. (2016). Caregiver burden and quality of life of key caregivers of patients with dementia. *Indian Journal of Psychological Medicine, 38*(2), 133–136.

Stanyon, M. R., Goldberg, S. E., Astle, A., Griffiths, A., & Gordon, A. L. (2017). The competencies of registered nurses working in care homes: A modified Delphi study. *Age and Ageing*, *46*(4), 582–588.

Stanyon, M. R., Griffiths, A., Thomas, S. A., & Gordon, A. L. (2016). The facilitators of communication with people with dementia in a care setting: an interview study with healthcare workers. *Age and Ageing*, *45*(1), 164–170.

Steptoe, A., Deaton, A., & Stone, A. A. (2015). Subjective wellbeing, health, and ageing. *The Lancet*, *385*(9968), 640–648.

Stepurko, T., Pavlova, M., Gryga, I., Murauskiene, L., & Groot, W. (2015). Informal payments for health care services: The case of Lithuania, Poland and Ukraine. *Journal of Eurasian Studies*, *6*(1), 46–58.

Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. *Image*, *12*(1), 20–23.

Stern, P. N. (2007). On solid ground: Essential properties for growing grounded theory. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 114–126). London, UK: Sage Publications Ltd.

Stevens, J. (2012). Stand up for dementia: Performance, improvisation and stand up comedy as therapy for people with dementia: A qualitative study. *Dementia*, *11*(1), 61–73.

Stockwell-Smith, G., Jones, C., & Moyle, W. (2011). “You’ve got to keep account of heads all the time”: Staff perceptions of caring for people with dementia. *Journal of Research in Nursing*, *16*(5), 400–412.

Stokes, G. (2017). *Challenging behaviour in dementia: A person-centred approach*. Abingdon, UK: Routledge.

Stokin, G. B. (2019). Advocacy in dementia. In W. Grisold, W. Struhal, & T. Grisold (Eds.), *Advocacy in neurology* (pp. 291–302). Oxford, UK: Oxford University Press.

Strauss, A. L. (1967). A sociological view of normality. *Archives of General Psychiatry, 17*(3), 265–270.

Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Thousand Oaks, CA: Sage Publications, Inc.

Strubel, D., Leroy, M., Pasquier, F., & Lebert, F. (2016). Young onset demented patients in French cognitive-behavioral specialized units. *Geriatrie et Psychologie Neuropsychiatrie du Vieillissement*, *14*(2), 194–200.

Stutte, K., Hahn, S., Fierz, K., & Zúñiga, F. (2017). Factors associated with aggressive behavior between residents and staff in nursing homes. *Geriatric Nursing*, *38*(5), 398–405.

Suhonen, R., Charalambous, A., Stolt, M., Katajisto, J., & Puro, M. (2013). Caregivers’ work satisfaction and individualised care in care settings for older people. *Journal of Clinical Nursing*, *22*(3-4), 479–490.

Suhonen, R., Stolt, M., & Papastavrou, E. (Eds.). (2019). *Individualized care: Theory measurement, research and practice*. Cham, Switzerland: Springer International Publishing.

Sullivan, D. O., Mannix, M., & Timmons, S. (2017). Integrated care pathways and care bundles for dementia in acute care: Concept versus evidence. *American Journal of Alzheimer’s Disease & Other Dementias*, *32*(4), 189–193.

Sun, M. K. (2018). Potential therapeutics for vascular cognitive impairment and dementia. *Current Neuropharmacology*, *16*(7), 1036–1044.

Sun, M., Mainland, B. J., Ornstein, T. J., Mallya, S., Fiocco, A. J., Sin, G. L., ...& Herrmann, N. (2018). The association between cognitive fluctuations and activities of daily living and quality of life among institutionalized patients with dementia. *International Journal of Geriatric Psychiatry, 33*(2), e280–e285.

Surr, C. A., Gates, C., Irving, D., Oyebode, J., Smith, S. J., Parveen, S., ...& Dennison, A. (2017). Effective dementia education and training for the health and social care workforce: A systematic review of the literature. *Review of Educational Research*, *87*(5), 966–1002.

Surr, C. A., Smith, S. J., Crossland, J., & Robins, J. (2016). Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: A repeated measures study. *International Journal of Nursing Studies*, *53*, 144–151.

Surr, C. A., Walwyn, R. E., Lilley-Kelly, A., Cicero, R., Meads, D., Ballard, C., ... & Wallace, D. (2016). Evaluating the effectiveness and cost-effectiveness of dementia care mappingto enable person-centred care for people with dementia and their carers (DCM-EPIC) in care homes: Study protocol for a randomised controlled trial. *Trials*, *17*(1), Article number: 300.

Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia, 13*(6), 709–716.

Swaffer, K. (2016). Living beyond dementia. *Lamp, The*, *73*(8), 24–25.

Sykes, L., Nipah, R., Kalra, P., & Green, D. (2018). A narrative review of the impact of interventions in acute kidney injury. *Journal of Nephrology*, *31*(4), 523–535.

Szebehely, M. (2017). Residential care for older people: Are there lessons to be learned from Sweden? *Journal of Canadian Studies*, *50*(2), 499–507.

Tak, S. H., Kedia, S., Tongumpun, T. M., & Hong, S. H. (2015). Activity engagement: Perspectives from nursing home residents with dementia. *Educational Gerontology*, *41*(3), 182–192.

Talbot, R., & Brewer, G. (2016). Care assistant experiences of dementia care in long-term nursing and residential care environments. *Dementia*, *15*(6), 1737–1754.

Talebzadeh, A., & Lang, A. (2017). *Sensory for dementia, light and sound in long term care environment.* Retrieved from http://openresearch.ocadu.ca/id/eprint/2194/1/Talebzadeh_Poster_2018.pdf

Tan, Z. S., Damron-Rodriguez, J., Cadogan, M., Gans, D., Price, R. M., Merkin, S. S., ... & Chodosh, J. (2017). Team-based interprofessional competency training for dementia screening and management. *Journal of the American Geriatrics Society*, *65*(1), 207–211.

Tang, M. M., Wollsen, M. G., & Aagaard, L. (2016). Pain monitoring and medication assessment in elderly nursing home residents with dementia. *Journal of Research in Pharmacy Practice, 5*(2), 126–131.

Tarzia, L., Fetherstonhaugh, D., Bauer, M., Beattie, E., & Nav, R. (2015). “We have to work within the system!” Staff perceptions of organisational barriers to decision making for older adults with dementia in Australian aged care facilities. *Research in Gerontological Nursing*, *1*(7), 11–13.

Taylor, J., Marjanovic, S., Nolte, E., Pollitt, A., & Rubin, J. (2015). *Treatment for dementia: Learning from breakthroughs for other conditions.* Cambridge, UK: Rand Corporation.

Temple, J. B., & Williams, R. (2018). Multiple health conditions and barriers to healthcare among older Australians: Prevalence, reasons and types of barriers. *Australian Journal of Primary Health, 24*(1), 82–89.

Teresi, J. A., Holmes, D., Benenson, E., Monaco, C., Barrett, V., Ramirez, M., & Koren, M. J. (1993). A primary care nursing model in long-term care facilities: Evaluation of impact on affect, behavior, and socialization. *The Gerontologist, 33*(5), 667–674.

Teresi, J. A., Ramirez, M., Fulmer, T., Ellis, J., Silver, S., Kong, J., ...& Pillemer, K. (2018). Resident-to-resident mistreatment: Evaluation of a staff training program in the reduction of falls and injuries. *Journal of Gerontological Nursing*, *44*(6), 15–23.

Teri, L., McKenzie, G., & Coulter, C. A. (2016). Psychosocial interventions for older adults with dementia and their caregivers. In K. Warner Schaie & S. L. Willis

(Eds.), *Handbook of the psychology of aging* (8th ed., pp. 447–474). London, UK: Academic Press.

Tesad, I., Corbett, A., Aarsland, D., Lexow, K. O., Fossey, J., & Woods, B. (2014). The value of personalised psychological interventions to address behavioural and psychological symptoms in people with dementia living in care home settings: A systematic review. *International Psychogeriatrics*, *26*(7), 1083–1098.

Tesfaye, W. H., Wimmer, B. C., Peterson, G. M., Castelino, R. L., Jose, M. D., McKercher, C., & Zaidi, S. T. R. (2019). The effect of hospitalization on potentially inappropriate medication use in older adults with chronic kidney disease. *Current Medical Research and Opinion*, *35*(6), 1119–1126.

Testad, I., Mekki, T. E., Førland, O., Øye, C., Tveit, E. M., Jacobsen, F., & Kirkevold, Ø. (2016). Modeling and evaluating evidence-based continuing education program in nursing home dementia care (MEDCED) – training of care home staff to reduce use of restraint in care home residents with dementia: A cluster randomized controlled trial. *International Journal of Geriatric Psychiatry*, *31*(1), 24–32.

The Guardian. (2018, September 6). Sydney aged-care worker arrested for allegedly assaulting elderly man. Retrieved from https://www.theguardian.com/australia-news/2018/sep/06/sydney-aged-care-worker-arrested-for-allegedly-assaulting-elderly-man

Theurer, K., Mortenson, W. B., Stone, R., Suto, M., Timonen, V., & Rozanova, J. (2015). The need for a social revolution in residential care. *Journal of Aging Studies*, *35*, 201–210.

Thomas, L. H. (1992). Qualified nurse and nursing auxiliary perceptions of their work environment in primary, team and functional nursing wards. *Journal of Advanced Nursing*, *17*(3), 373–382.

Thompson, M., & Walton-Roberts, M. (2018). International nurse migration from India and the Philippines: The challenge of meeting the sustainable development goals in training, orderly migration and healthcare worker retention. *Journal of Ethnic and Migration Studies*, *45*(14), Special Issue 1, 2583–2599.

Thorkildsen, K. M., Eriksson, K., & Råholm, M. B. (2015). The core of love when caring for patients suffering from addiction. *Scandinavian Journal of Caring Sciences*, *29*(2), 353–360.

Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research*, *56*(3), 243–259.

Thornberg, R. (2017). Grounded theory. In D. Wyse, N. Selwyn, E. Smith, & L. E. Suter (Eds.), *The Bera/Sage handbook of educational research* (pp. 355–375). London, UK: Sage Publications Ltd.

Tible, O. P., Riese, F., Savaskan, E., & von Gunten, A. (2017). Best practice in the management of behavioural and psychological symptoms of dementia. *Therapeutic Advances in Neurological Disorders, 10*(8), 297–309.

Tiedeman, M. E., & Lookinland, S. (2004). Traditional models of care delivery: What have we learned? *The Journal of Nursing Administration, 34*(6), 291–297.

Timmons, S., O’Shea, E., O’Neill, D., Gallagher, P., de Siún, A., McArdle, D., ... & Kennelly, S. (2016). Acute hospital dementia care: Results from a national audit. *BMC Geriatrics, 16*(1), Article number: 113.

Timonen, V., Foley, G., & Conlon, C. (2018). Challenges when using grounded theory: A pragmatic introduction to doing GT research. *International Journal of Qualitative Methods*, *17*(1), 1609406918758086.

Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., & Chaboyer, W. (2015). Nurses’ views of patient participation in nursing care. *Journal of Advanced Nursing*, *71*(12), 2741–2752.

Tonetti, M. S., Bottenberg, P., Conrads, G., Eickholz, P., Heasman, P., Huysmans, M. C., ... & Paris, S. (2017). Dental caries and periodontal diseases in the ageing population: Call to action to protect and enhance oral health and well-being as an essential component of healthy ageing – Consensus report of group 4 of the joint EFP/ORCA workshop on the boundaries between caries and periodontal diseases. *Journal of Clinical Periodontology*, *44*, S135–S144.

Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: A systematic review and meta-analysis. *International Psychogeriatrics*, *29*(2), 195–208.

Trahan, L. M., Spiers, J. A., & Cummings, G. G. (2016). Decisions to transfer nursing home residents to emergency departments: A scoping review of contributing factors and staff perspectives. *Journal of the American Medical Directors Association*, *17*(11), 994–1005.

Traynor, V., Inoue, K., & Crookes, P. (2011). Literature review: Understanding nursing competence in dementia care. *Journal of Clinical Nursing, 20*(13-14), 1948–1960.

Treadaway, C., Fennell, J., Kenning, G., Prytherch, D., & Walters, A. (2016, September). *Designing for wellbeing in late stage dementia.* Paper presented at Third International Conference Exploring the Multi-Dimensions of Well-Being: Co-Creating Pathways to Well-Being, Birmingham, UK.

Treadaway, C., Prytherch, D., Kenning, G., & Fennell, J. (2016, June). *In the moment: Designing for late stage dementia.* Paper presented at Design Research Society – 50th Anniversary Conference, Brighton, UK.

Tremayne, P. (2014). Using humour to enhance the nurse–patient relationship. *Nursing Standard, 28*(30), 37–40.

Tropea, J., LoGiudice, D., Liew, D., Gorelik, A., & Brand, C. (2017). Poorer outcomes and greater healthcare costs for hospitalised older people with dementia and delirium: A retrospective cohort study. *International Journal of Geriatric Psychiatry*, *32*(5), 539–547.

Tsoi, K. K., Hirai, H. W., Chan, F. C., Griffiths, S., & Sung, J. J. (2016). Cancer burden with ageing population in urban regions in China: Projection on cancer registry data from World Health Organization. *British Medical Bulletin*, *121*(1), 83–94.

Tuinman, A., de Greef, M. H., Krijnen, W. P., Nieweg, R. M., & Roodbol, P. F. (2016). Examining time use of Dutch nursing staff in long-term institutional care: A time-motion study. *Journal of the American Medical Directors Association*, *17*(2), 148–154.

Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore. *Journal of Cross-Cultural Gerontology, 31*(2), 157–172.

Tyler, D. A., Gadbois, E. A., McHugh, J. P., Shield, R. R., Winblad, U., & Mor, V. (2017). Patients are not given quality-of-care data about skilled nursing facilities when discharged from hospitals. *Health Affairs*, *36*(8), 1385–1391.

Urquhart, C. (2007). The evolving nature of grounded theory method: The case of the information systems discipline. InA. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 339–360). London, UK: Sage Publications Ltd.

Van Alphen, H. J., Hortobagyi, T., & van Heuvelen, M. J. (2016). Barriers, motivators, and facilitators of physical activity in dementia patients: A systematic review. *Archives of Gerontology and Geriatrics*, *66*, 109–118.

Van Baal, P., Morton, A., Meltzer, D., & Brouwer, W. (2019). Future unrelated medical costs need to be considered in cost effectiveness analysis. *The European Journal of Health Economics*, *20*(1), 1–5.

Van de Ven, G., Draskovic, I., Adang, E. M. M., Donders, R. A. R. T., Post, A., Zuidema, S.U., … & Vernooij-Dassen, M. J. F. J. (2012). Improving person-centred care in nursing homes through dementia-care mapping: Design of a cluster-randomised controlled trial. *Geriatrics, 12*(1), 2–9.

Van der Spek, K., Gerritsen, D. L., Smalbrugge, M., Nelissen-Vrancken, M. H., Wetzels, R. B., Smeets, C. H., ... & Koopmans, R. T. (2016). Only 10% of the psychotropic drug use for neuropsychiatric symptoms in patients with dementia is fully appropriate. The PROPER I-study. *International Psychogeriatrics*, *28*(10), 1589–1595.

Van der Spek, K., Koopmans, R. T., Smalbrugge, M., Nelissen-Vrancken, M. H., Wetzels, R. B., Smeets, C. H., ... & Gerritsen, D. L. (2018). The effect of biannual medication reviews on the appropriateness of psychotropic drug use for neuropsychiatric symptoms in patients with dementia: A randomised controlled trial. *Age and Ageing*, *47*(3), 430–437.

Van Deun, B., Van Den Noortgate, N., Van Bladel, A., Palmans, T., & Cambier, D. (2019). The impact of paratonia on fine and gross motor function in older adults with mild and moderate dementia. *Alzheimer Disease & Associated Disorders*, *33*(1), 54–61.

Van Hecke, L., Van Steenwinkel, I., & Heylighen, A. (2019). How enclosure and spatial organization affect residents' use and experience of a dementia special care unit: A case study. *Health Environments Research & Design*, *12*(1), 145–159.

Van Kooten, J., Delwel, S., Binnekade, T. T., Smalbrugge, M., van der Wouden, J. C., Perez, R. S., ... & Scherder, E. J. A. (2015). Pain in dementia: Prevalence and associated factors – protocol of a multidisciplinary study. *BMC Geriatrics*, *15*(1), Article number: 29.

Van Kooten, J., van der Wouden, J. C., Sikkes, S. A., Smalbrugge, M., Hertogh, C. M., & Stek, M. L. (2017). Pain, neuropsychiatric symptoms, and quality of life of nursing home residents with advanced dementia in the Netherlands. *Alzheimer Disease & Associated Disorders*, *31*(4), 315–321.

Vassbø, T. K., Kirkevold, M., Edvardsson, D., Sjögren, K., Lood, Q., Sandman, P. O., & Bergland, Å. (2019). Associations between job satisfaction, person-centredness, and ethically difficult situations in nursing homes – A cross-sectional study. *Journal of Advanced Nursing*, *75*(5), 979–988.

Verbeek, H. (2017). Inclusion and support of family members in nursing homes. In S. Schüssler & C. Lohrmann (Eds.), *Dementia in nursing homes* (pp. 67–76). Cham, Switzerland: Springer International Publishing.

Verbeek, H., Van Rossum, E., Zwakhalen, S. M., Kempen, G. I., & Hamers, J. P. (2009). Small, homelike care environments for older people with dementia: A literature review. *International Psychogeriatrics*, *21*(2), 252–264.

Vernooij-Dassen, M., & Moniz-Cook, E. (2016). Person-centred dementia care: Moving beyond caregiving. *Aging & Mental Health*, *20*(7), 667–668.

Vinoo, D., Vinoo, D., Santos, J., & Amin, R. (2018). Reduction of unnecessary usage of antipsychotics, physical altercations and falls in memory care units by implementing person centered comfort care. *Journal of the American Medical Directors Association*, *19*(3), B22.

Vinters, H. V., Zarow, C., Borys, E., Whitman, J. D., Tung, S., Ellis, W. G., ... & Chui, H. C. (2018). Vascular dementia: Clinicopathologic and genetic considerations. *Neuropathology and Applied Neurobiology*, *44*(3), 247–266.

Vogel, B., De Geest, S., Fierz, K., Beckmann, S., & Zúñiga, F. (2017). Dementia care worker stress associations with unit type, resident, and work environment characteristics: A cross-sectional secondary data analysis of the Swiss Nursing Homes Human Resources Project (SHURP). *International Psychogeriatrics, 29*(3), 441–454.

Vogenberg, F. R., & Santilli, J. (2018). Healthcare trends for 2018. *American Health & Drug Benefits*, *11*(1), 48–54.

Volicer, L., Citrome, L., & Volavka, J. (2017). Measurement of agitation and aggression in adult and aged neuropsychiatric patients: Review of definitions and frequently used measurement scales. *CNS Spectrums*, *22*(5), 407–414.

Voutilainen, A., Pitkäaho, T., Kvist, T., & Vehviläinen-Julkunen, K. (2016). How to ask about patient satisfaction? The visual analogue scale is less vulnerable to confounding factors and ceiling effect than a symmetric Likert scale. *Journal of Advanced Nursing*, *72*(4), 946–957.

Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research, 16*(4), 547–559.

Walker, Z., Possin, K. L., Boeve, B. F., & Aarsland, D. (2015). Lewy body dementias. *The Lancet*, *386*(10004), 1683–1697.

Wallin, A. O., Jakobsson, U., & Edberg, A. K. (2012). Job satisfaction and associated variables among nurse assistants working in residential care. *International Psychogeriatrics*, *24*(12), 1904–1918.

Walmsley, B., & McCormack, L. (2016). Shame, hope, intimacy and growth: Dementia distress and growth in families from the perspective of senior aged care professionals. *Dementia*, *15*(6), 1666–1684.

Wan, L. (2019). *Dealing with wandering in dementia care: A developmental story of designing a GPS monitoring system and its challenges in a wider context.* (Doctoral dissertation). University of Siegen, Siegen, Germany.

Wandelt, M. A., & Stewart, D. S. (1975). *Slater nursing competencies rating scale.* New York, NY: Appleton-Century-Crofts.

Wang, S. H., Hsiao, P. C., Yeh, L. L., Liu, C. M., Liu, C. C., Hwang, T. J., ... & Chen, W. J. (2018). Polygenic risk for schizophrenia and neurocognitive performance in patients with schizophrenia. *Genes, Brain and Behavior, 17*(1), 49–55.

Wang, Y., Xiao, L. D., Ullah, S., He, G. P., & De Bellis, A. (2017). Evaluation of a nurse-led dementia education and knowledge translation programme in primary care: A cluster randomized controlled trial. *Nurse Education Today*, *49*, 1–7.

Wang, X., Liu, L., Zou, F., Hao, J., & Wu, H. (2017). Associations of occupational stressors, perceived organizational support, and psychological capital with work engagement among Chinese female nurses. *BioMed Research International*, *2017,* Article ID: 5284628.

Wangmo, T., Nordström, K., & Kressig, R. W. (2017). Preventing elder abuse and neglect in geriatric institutions: Solutions from nursing care providers. *Geriatric Nursing*, *38*(5), 385–392.

Waring, J., Allen, D., Braithwaite, J., & Sandall, J. (2016). Healthcare quality and safety: A review of policy, practice and research. *Sociology of Health & Illness*, *38*(2), 198–215.

Weaver, J. (2015). Dementia: Empathy is key to alleviating worrying behaviours. *Australian Ageing Agenda*, (May/June 2015), 48–49.

Webster, L., Groskreutz, D., Grinbergs-Saull, A., Howard, R., O’Brien, J. T., Mountain, G., ... & Livingston, G. (2017). Core outcome measures for interventions to prevent or slow the progress of dementia for people living with mild to moderate dementia: Systematic review and consensus recommendations. *PLoS One*, *12*(6), e0179521.

Wells, Y., & Jorm, A. F. (1987). Evaluation of a special nursing home unit for dementia sufferers: A randomised controlled comparison with community care. *Australian & New Zealand Journal of Psychiatry*, *21*(4), 524–531.

Wells, Y., Brooke, E., & Solly, K. N. (2019). Quality and safety in aged care virtual issue: What Australian research published in the *Australasian Journal on Ageing* tells us. *Australasian Journal on Ageing*, *38*(1), E1–E6.

White, E., Aiken, L., & Aiken, M. (2018). The impact of registered nurse work environment on care quality in nursing homes. *Innovation in Aging*, *2*(suppl_1), 1018–1019.

White-Chu, E. F., Graves, W. J., Godfrey, S. M., Bonner, A., & Sloane, P. (2009). Beyond the medical model: The culture change revolution in long-term care. *Journal of the American Medical Directors Association*, *10*(6), 370–378.

Whitlatch, C. J., & Orsulic-Jeras, S. (2018). Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *The Gerontologist*, *58*(suppl_1), S58–S73.

Wiechula, R., Conroy, T., Kitson, A. L., Marshall, R. J., Whitaker, N., & Rasmussen, P. (2016). Umbrella review of the evidence: What factors influence the caring relationship between a nurse and patient? *Journal of Advanced Nursing*, *72*(4), 723–734.

Willemse, B. M., Downs, M., Arnold, L., Smit, D., de Lange, J., & Pot, A. M. (2015). Staff-resident interactions in long-term care for people with dementia: The role of meeting psychological needs in achieving residents' well-being. *Aging and Mental Health, 19*(5):444–452. doi:10.1080/13607863.2014.944088

Willetts, G., Aberdeen, S., Hood, K., & Cross, W. (2017). The dynamic role of the graduate nurse in aged care: An Australian experience of delivering an aged care graduate nurse program. *Collegian, 24*(4), 397–402.

Willis, E., Reynolds, L., & Keleher, H. (Eds.). (2016). *Understanding the Australian health care system*. Sydney, NSW: Elsevier Health Sciences.

Wimo, A., Guerchet, M., Ali, G. C., Wu, Y. T., Prina, A. M., Winblad, B., ... & Prince, M. (2017). The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimer's & Dementia*, *13*(1), 1–7.

Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., ... & Zetterberg, H. (2016). Defeating Alzheimer's disease and other dementias: A priority for European science and society. *The Lancet Neurology*, *15*(5), 455–532.

Winslow, S., Cook, C., Eisner, W., Hahn, D., Maduro, R., & Morgan, K. (2019). Care delivery models: Challenge to change. *Journal of Nursing Management, 27*(7), 1438–1444.

Winterton, R., Knight, K., Morley, C., & Walters, W. (2018). Residential models of dementia care in rural Australian communities. In G. Halseth, S. Markey, & L. Ryser (Eds.), *Service provision and rural sustainability: Infrastructure and innovation* (pp. 95–108). Abingdon, UK: Routledge.

Woodbridge, R., Sullivan, M. P., Harding, E., Crutch, S., Gilhooly, K. J., Gilhooly, M. L. M., ...& Wilson, L. (2018). Use of the physical environment to support everyday activities for people with dementia: A systematic review. *Dementia*, *17*(5), 533–572.

Woodhead, E. L., Northrop, L., & Edelstein, B. (2016). Stress, social support, and burnout among long-term care nursing staff. *Journal of Applied Gerontology*, *35*(1), 84–105.

Woods, M., Phibbs, S., & Severinsen, C. (2017). “When morals and markets collide”: Challenges to an ethic of care in aged residential care. *Ethics and Social Welfare, 11*(4), 365–381.

World Health Organization and Alzheimer’s Disease International. (2012). *Dementia: A public health priority*. Retrieved from https://www.who.int/mental_health/publications/dementia_report_2012/en/

World Health Organization. (2017a). *Elder abuse.* Retrieved from https://www.who.int/ageing/projects/elder_abuse/en/

World Health Organization. (2017b). *Global health and ageing*.Retrieved from https://www.who.int/ageing/publications/global_health.pdf

Wübker, A., Zwakhalen, S. M., Challis, D., Suhonen, R., Karlsson, S., Zabalegui, A., ... & Sauerland, D. (2015). Costs of care for people with dementia just before and after nursing home placement: Primary data from eight European countries. *The European Journal of Health Economics*, *16*(7), 689–707.

Xu, J., Wang, J., Wimo, A., Fratiglioni, L., & Qiu, C. (2017). The economic burden of dementia in China, 1990–2030: Implications for health policy. *Bulletin of the World Health Organization*, *95*(1), 18–26.

Yaffe, K. (2018). Modifiable risk factors and prevention of dementia: What is the latest evidence? *JAMA Internal Medicine*, *178*(2), 281–282.

Yamakawa, M., Suto, S., Shigenobu, K., Kunimoto, K., & Makimoto, K. (2012). Comparing dementia patients’ nighttime objective movement indicators with staff observations. *Psychogeriatrics*, *12*(1), 18–26.

Yan, E., Chan, K. L., & Tiwari, A. (2015). A systematic review of prevalence and risk factors for elder abuse in Asia. *Trauma, Violence, & Abuse*, *16*(2), 199–219.

Yang, H., Lv, J., Zhou, X., Liu, H., & Mi, B. (2017). Validation of work pressure and associated factors influencing hospital nurse turnover: A cross-sectional investigation in Shaanxi Province, China. *BMC Health Services Research*, *17*(1), Article number: 112.

Ye, F., Luo, Y. J., Xiao, J., Yu, N. W., & Yi, G. (2016). Impact of insulin sensitizers on the incidence of dementia: A meta-analysis. *Dementia and Geriatric Cognitive Disorders*, *41*(5–6), 251–260.

Young, J., & Swaffer, K. (2018). Kate Swaffer, What the hell happened to my brain? Living beyond dementia [Blog post]. Retrieved from https://www.jessicaanneyoung.com/blog-1/2018/3/18/new-publication-book-review-of-what-the-hell-happened-to-my-brain-by-kate-swaffer-with-a-response-from-the-author

Zadeh, R. S., Eshelman, P., Setla, J., Kennedy, L., Hon, E., & Basara, A. (2018). Environmental design for end-of-life care: An integrative review on improving the quality of life and managing symptoms for patients in institutional settings. *Journal of Pain and Symptom Management*, *55*(3), 1018–1034.

Zamanzadeh, V., Valizadeh, L., Rahmani, A., Cingel, M., & Ghafourifard, M. (2018). Factors facilitating nurses to deliver compassionate care: A qualitative study. *Scandinavian Journal of Caring Sciences*, *32*(1), 92–97. doi:10.1111/scs.12434

Zarowitz, B. J., Resnick, B., & Ouslander, J. G. (2018). Quality clinical care in nursing facilities. *Journal of the American Medical Directors Association*, *19*(10), 833–839.

Zeisel, J., Hyde, J., & Levkoff, S. (1994). Best practices: An environment behavior (EB) model for Alzheimer special care units. *American Journal of Alzheimer’s Care and Related Disorders & Research*, *9*(2), 4–21.

Zhao, J., Gao, S., Wang, J., Liu, X., & Hao, Y. (2016). Differentiation between two healthcare concepts: Person-centered and patient-centered care. *JournalofNursing*, *2352*, 0132.

Zhao, Y., Russell, D. J., Guthridge, S., Ramjan, M., Jones, M. P., Humphreys, J. S., & Wakerman, J. (2019). Costs and effects of higher turnover of nurses and Aboriginal health practitioners and higher use of short-term nurses in remote Australian primary care services: An observational cohort study. *BMJ Open*, *9*(2), e023906.

Zhu, C. W., Cosentino, S., Ornstein, K., Gu, Y., Andrews, H., & Stern, Y. (2015). Use and cost of hospitalization in dementia: Longitudinal results from a community-based study. *International Journal of Geriatric Psychiatry*, *30*(8), 833–841.

Zhu, C. W., Bruinsma, B., & Stern, Y. (2018). Utility of the Dependence Scale in dementia: Validity, meaningfulness, and health economic considerations. *Alzheimer's Research & Therapy, 10*, Article number: 78.

Zhu, C. W., Scarmeas, N., Ornstein, K., Albert, M., Brandt, J., Blacker, D., ...& Stern, Y. (2015). Health-care use and cost in dementia caregivers: Longitudinal results from the Predictors Caregiver Study. *Alzheimer's & Dementia*, *11*(4), 444–454.

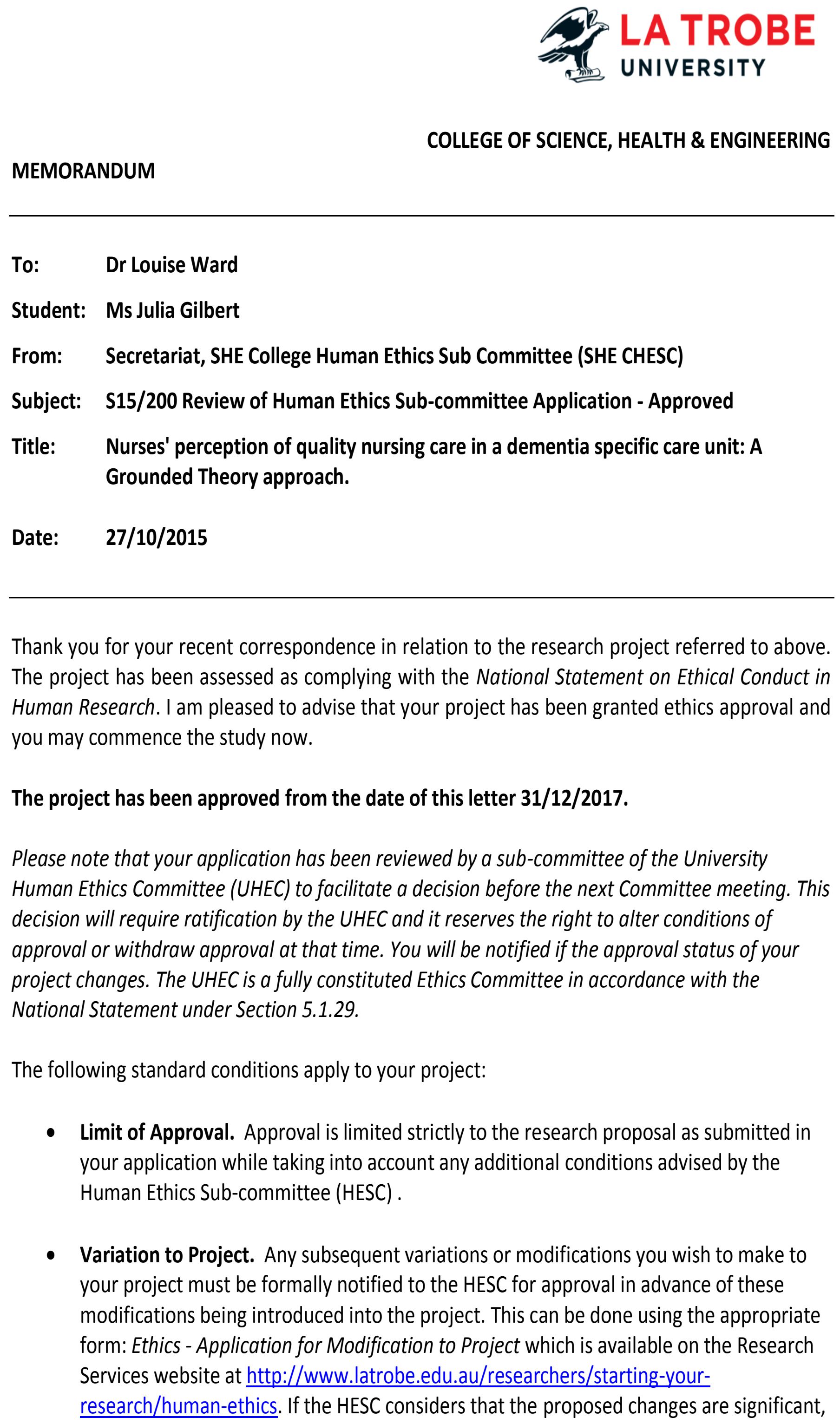
Zimmerman, S. I., & Sloane, P. D. (1999). Optimum residential care for people with dementia. *Generations*, *23*(3), 62–68.

Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., & Sloane, P. D. (2005). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*, *45*(suppl_1), 96–105.

Zúñiga, F., Ausserhofer, D., Hamers, J. P., Engberg, S., Simon, M., & Schwendimann, R. (2015). Are staffing, work environment, work stressors, and rationing of care related to care workers'perception of quality of care? A cross-sectional study. *Journal of the American Medical Directors Association*, *16*(10), 860–866.

Appendices

Appendix A – Ethics Approval



LA TROBE UNIVERSITY

COLLEGE OF SCIENCE, HEALTH & ENGINEERING

MEMORANDUM

To:	**Dr Louise Ward**
Student:	**Ms Julia Gilbert**
From:	**Secretariat, SHE College Human Ethics Sub Committee (SHE CHESC)**
Subject:	**S15/200 Review of Human Ethics Sub-committee Application - Approved**
Title:	**Nurses' perception of quality nursing care in a dementia specific care unit: A Grounded Theory approach.**
Date:	**27/10/2015**

Thank you for your recent correspondence in relation to the research project referred to above. The project has been assessed as complying with the *National Statement on Ethical Conduct in Human Research*. I am pleased to advise that your project has been granted ethics approval and you may commence the study now.

The project has been approved from the date of this letter 31/12/2017.

Please note that your application has been reviewed by a sub-committee of the University Human Ethics Committee (UHEC) to facilitate a decision before the next Committee meeting. This decision will require ratification by the UHEC and it reserves the right to alter conditions of approval or withdraw approval at that time. You will be notified if the approval status of your project changes. The UHEC is a fully constituted Ethics Committee in accordance with the National Statement under Section 5.1.29.

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the Human Ethics Sub-committee (HESC) .

- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the HESC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate form: *Ethics - Application for Modification to Project* which is available on the Research Services website at http://www.latrobe.edu.au/researchers/starting-your-research/human-ethics. If the HESC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.

- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the HESC Secretary on at hesc.she@latrobe.edu.au. Any complaints about the project received by the researchers must also be referred immediately to the HESC Secretary.

- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you must advise the HESC and clarify the circumstances.

- **Monitoring.** All projects are subject to monitoring at any time by the Human Ethics Sub-committee.

- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit an *Ethics - Progress/Final Report Form* annually, **on or just prior to 12 February**. The form is available on the Research Services website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse.

- **Auditing**. An audit of the project may be conducted by members of the HESC.

- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project**.**

If you have any queries on the information above or require further clarification please contact me at hesc.she@latrobe.edu.au.

On behalf of the Faculty of Health Sciences Faculty Human Ethics Committee, best wishes with your research!

Ms. Kate Ferris
Human Ethics Officer
Secretariat – SHE College Human Ethics Sub-Committee
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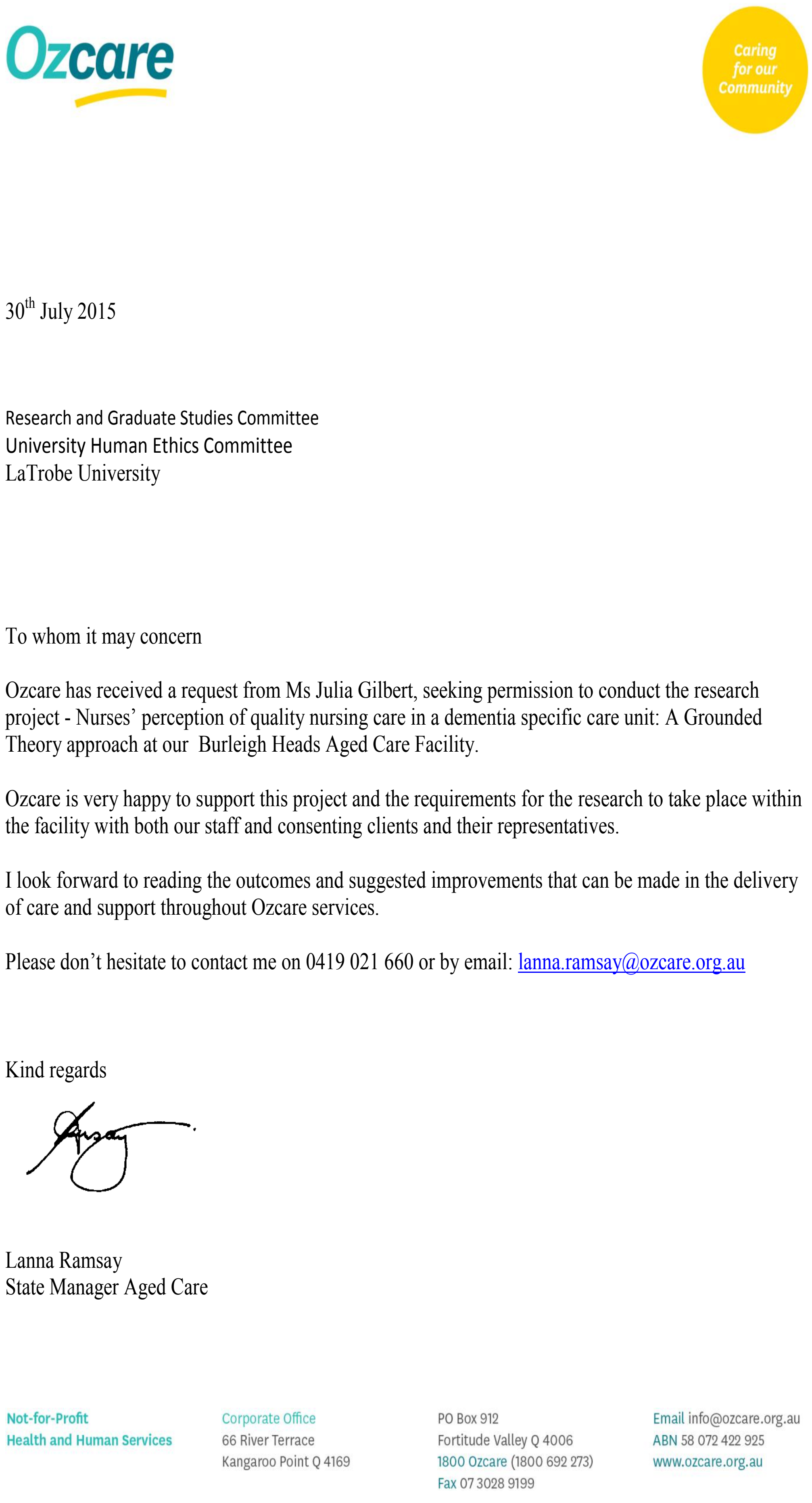
Appendix B – Approval from Facility Manager



Ozcare

Caring for our Community

30th July 2015

Research and Graduate Studies Committee
University Human Ethics Committee
LaTrobe University

To whom it may concern

Ozcare has received a request from Ms Julia Gilbert, seeking permission to conduct the research project - Nurses' perception of quality nursing care in a dementia specific care unit: A Grounded Theory approach at our Burleigh Heads Aged Care Facility.

Ozcare is very happy to support this project and the requirements for the research to take place within the facility with both our staff and consenting clients and their representatives.

I look forward to reading the outcomes and suggested improvements that can be made in the delivery of care and support throughout Ozcare services.

Please don't hesitate to contact me on 0419 021 660 or by email: lanna.ramsay@ozcare.org.au

Kind regards

Lanna Ramsay
State Manager Aged Care

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Appendix C – Participant Information Statement

COLLEGE OF SCIENCE HEALTH AND ENGINEERING

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Participant Information Statement

NURSES' PERCEPTION OF QUALITY NURSING CARE IN A DEMENTIA SPECIFIC CARE UNIT: A GROUNDED THEORY APPROACH.

We want to know the perceptions of nurses regarding quality nursing care within a dementia specific care unit. That is why we are inviting you to take part in this study.

Participation in this project is entirely voluntary. Whether you decide to participate or not will ***not*** affect your current employment or your relationship with your employer or registering authority. If you do decide to participate, you are free to withdraw at any time without giving a reason.

Before you decide if you would like to participate, it is important to understand why the research is being done and what it would involve.

Please take the time to read the following information carefully.

Who are the researchers?

The researchers are Dr Louise Ward from the LaTrobe University School of Nursing and Midwifery, Dr Karleen Gwinner, from Queensland Institute of Technology and Ms Julia Gilbert from the LaTrobe University School of Nursing and Midwifery. The study is a project for Julia Gilbert's Doctor of Philosophy degree at LaTrobe University. Dr Ward and Dr Gwinner are supervising the research.

Why are we carrying out this study?

The aim of this study is to explore and understand the perceptions that nurses have of quality care within a dementia specific care unit. Findings from this study may help highlight the challenges and issues faced by nurses working within the dementia specific care unit.

Why have I been invited to participate?

You have been invited to participate because you are a nurse working within the dementia specific care unit environment.

What do I need to do to be in the research project?

If you agree to participate, I will ask to interview you for about 60 minutes to ask you about your thoughts and perceptions regarding quality care delivery in a dementia specific care unit. During the interview I will ask you to talk about the issues and problems you experience and what you think constitutes quality care in a dementia specific care unit. The interview will be audio taped and the information obtained will be kept confidential and transcribed by the researchers following the interview.

What are the risks to me?

There are some very unlikely risks to you if you participate in this study. These risks include:

- It is possible that you could experience unpleasant or upsetting emotions when discussing what is quality nursing care in the dementia specific care unit. You will be provided with support via the facility Employee Counselling Service if you do experience any of these emotions.

What will be done to make sure the information is confidential?

In this study we will be collecting information from you which will only be used for this research study. All information records, including interview notes and audio recordings, will be kept private and confidential.

Once interview data is obtained, it will be de-identified and transcribed into the electronic data analysis format. The researchers will ensure electronic data will be stored in a password protected computer in a password protected file, only accessible to the research team. Paper copies, such as hand written notes will be stored in a locked cabinet in a locked office at the University and will only be accessible to the research team.

The only situation when we will provide anyone else with information is the unlikely situation where we are required by law to report information to meet government, legal or other regulatory requirements.

Data collected in this study will be kept securely for five years following completion of the study, following which it will be destroyed by the research team. We hope to report and publish the results of our study in Ms Gilberts' doctoral dissertation which is made publicly available on-line through the LaTrobe University Library, conferences and scientific publications. The researchers will ensure that no information that could identify you is included, and the participating agency will not be named.

As all information gathered will be collated, it will not be possible to provide a copy of your personal data collected in the course of this research.

What are the benefits for me if I decide to participate?

As a participant in this research study you will not receive any monetary compensation or other incentives to participate. You will, however, have the opportunity to reflect on and discuss your perceptions of what quality nursing care within a dementia secure unit entails. Information obtained from this research may benefit nurses working in a dementia specific care unit, agencies, managers, stakeholders and policy makers who seek to provide safe and high quality care within dementia specific care units.

What happens if I want to withdraw as a participant from the research?

You have the right to withdraw from active participation in this project giving four weeks' notice to the researchers of your wish to withdraw. You may also request that data arising from your participation are not used in the research project provided that this right is exercised within four weeks of the completion of your participation in the project. You are asked to complete the "Withdrawal of Consent Form" or to notify the researcher by email or telephone that you wish to withdraw your consent for your data to be used in this research project.

Any questions regarding this project may be directed to the investigators

Julia Gilbert of the School of Nursing and Midwifery, LaTrobe University on (07) 55527292 or **Julia.gilbert@latrobe.edu.au**

Louise Ward of the School of Nursing and Midwifery, LaTrobe University on louise.ward@latrobe.edu.au

Karleen Gwinner from Queensland University of Technology on karleen.gwinner@qut.edu.au

If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086 (P: 03 9479 1443, E: humanethics@latrobe.edu.au). Please quote the application reference number S15/200WARD/Gilbert.

Appendix D – Consent and Withdrawal of Consent Forms

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Mailing address
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E health@latrobe.edu.au
latrobe.edu.au/health

MELBOURNE CAMPUSES
Bundoora
Collins Street CBD
Franklin Street CBD

Consent Form

NURSES' PERCEPTION OF QUALITY NURSING CARE IN A DEMENTIA SPECIFIC CARE UNIT: A GROUNDED THEORY APPROACH.

I ____________________ have read and understood the participant information statement and consent form, and any questions I have asked have been answered to my satisfaction. I agree to participate in the project, realizing that I may withdraw at any time before the start of data collection. I agree that research data provided by me or with my permission during the project may be included in a thesis, presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used. I am aware that I may request that research data provided by me will be withdrawn from the project within four weeks of providing this data.

I give permission to be audio recorded in the individual interview. Please tick ☐

Name of Participant (block letters):
Signature:
Date:

Name of Chief Investigator (block letters): Dr. Louise Ward
Signature:
Date:

Name of Co-Investigator (block letters): Dr. Karleen Gwinner
Signature:
Date:

Name of Co-Investigator (block letters): Ms Julia Gilbert
Signature:
Date:

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WITHDRAWAL OF CONSENT FORM

NURSES' PERCEPTION OF QUALITY NURSING CARE IN A DEMENTIA SPECIFIC CARE UNIT: A GROUNDED THEORY APPROACH.

1. *I have read the Participation Information Statement for this study and understand its contents. I have had the nature and purposes of the research project, so far as it affects me, fully explained to my satisfaction by the Participation Information Statement and have had the opportunity to discuss any concerns I might have with the researchers.*
2. *I, …………………………………………………………………………wish to withdraw from active participation in this project effective immediately.*
3. *I understand that I do not have to provide any reason for my withdrawal from this study.*
4. *I understand that it is not possible to withdraw my individual data from information collected during the research study.*
5. *I agree to complete this form and email it to a researcher within seven days.*

Name of Participant (block letters):
Signature:
Date:

Name of Chief Investigator (block letters): Dr. Louise Ward
Signature:
Date:

Name of Co-Investigator (block letters): Dr. Karleen Gwinner
Signature:
Date:

Name of Co-Investigator (block letters): Ms Julia Gilbert
Signature:
Date:

Appendix E – Research Interview Protocol

In line with Glaser's concepts of 'atmosphering' I will seek to create an environment in which the participant feels comfortable and willing to share their experiences relating to this research question. As a constructivist grounded theorist, I consider the interview to be the starting point to explore the problem with the data collected as the individual view taken in context. The purpose of the interviews is to identify the key events, their contexts and the processes shaping the events. The focus of the interview for me is on the participant's definitions of terms, situations and events along with their assumptions and meanings to obtain rich material without imposing pre conceived concepts.

I will use a conversational tone to facilitate feelings of safety and respect in the participant.

The interviews will be conducted face to face in a comfortable location, preferably a neutral location or one selected by the participant. I will have a copy of the interview schedule in front of me to keep the interview on track. I will present as relaxed, affirmative and as natural as I can, asking the questions as though they had just occurred to me, and will utilise active listening and responding to verbal and non verbal cues. I will try and understand what I am hearing, seek clarity and a deeper understanding from the participant throughout the interview and remain a listener.

As these interviews are semi-structured, the questions may be re-ordered during the interview to seek clarification and additional questions may be added if appropriate. The level of language may be adjusted for each participant.

Some probing questions may be utilised if necessary to obtain more information eg if the participant just gives yes or no answers.

' you mentioned_________________, tell me more about that'

'you mentioned ___________________, what was that like for you?"

'what else happened?'

'what were your feelings about that?'

'can you elaborate on that idea?'

'would you explain that further?'

The interview will begin with the following:

Introduction:

Hello, my name is Julia and I am researching the perceptions of nurses regarding quality nursing care within a dementia specific care unit. I will not be using your name or including any details which could identify you in the information I collect today from our conversation. All interview data will be coded in a way that cannot be connected to you. I am particularly interested in your experiences in the delivery of quality nursing care within a dementia specific care unit.

If, at any time in the interview, you feel uncomfortable, you are free to end your participation in the research and all notes and the recording will be destroyed.

The interview is really just a conversation that will allow you to share your experience with me. Before we begin, do you have any questions for me?

So,….

‘ Are you a Registered Nurse or an Enrolled Nurse?’

‘How long have you worked in the dementia secure unit?’

‘Can you tell me a little about what it’s like working in the unit?’

‘Can you describe a typical day for you in the dementia unit?’

‘How would you describe ‘quality nursing care?’

‘What kinds of nursing care activities have you seen in the unit that you consider to be quality nursing care?’

‘What do you think are the most important elements of quality nursing care?’ ‘Why?’

‘Do you encounter problems in providing quality nursing care in the unit?’

‘If so, how did you overcome those problems?’

‘As you look back on your time working in the dementia specific care unit, are there any events relating to nursing care that stand out in your mind?’

‘Could you describe each one?’

‘How did you respond to them?’

‘Is there anything that you might not have thought about before that occurred to you during this interview?’

‘Is there anything you would like to ask me?’

I will offer participants the opportunity for follow-up interviews to discuss and clarify any new questions. I am anticipating that new questions will arise as the interviews are conducted and I talk to more participants and I would welcome the opportunity to go back and ask earlier participants about the new areas identified. This strategy would assist me to correct any earlier errors and omissions and construct a denser, more complex analysis of the information. The interview captures the participants’ views at just that time and follow up interviews can provide depth and detail to their experiences based on growing trust between the participant and myself.

Appendix F – Analysis Codes and Categories

Codes

- Tasks
- Jobs
- Hard work
- Pressure
- The coalface
- Relentless
- Patient behaviours
- Documentation
- Job satisfaction
- Love
- Caring
- Persistence
- Compassion
- Engagement
- Humour
- Advocacy
- Empathy
- Documentation completion
- Timeframes
- Management stress
- Cost containment

Subcategories

- Ticking things off a list
- Task-based care
- Loving care
- Therapeutic touch
- The patient as an individual
- Meeting managerial goals and expectations
- Cost management

Categories

- Task-based scheduled care
- Warm, loving care
- Making a difference
- Keep your head down
- Stressed, diminished and devalued