

**Registered Nurses' Experiences of Caring for People with
Dementia at the End of Life in Nursing Homes During the COVID-
19 Pandemic: A Grounded Theory Study**

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**A thesis submitted for the degree of
Doctor of Philosophy**

Cardiff University

April 2026

Abstract

People living with dementia often present with complex care needs as they approach the end of life, which can necessitate nursing home admission. In the United Kingdom (UK) Registered nurses are pivotal in providing and coordinating end-of-life care for people living with dementia. However, little is known about the experiences of registered nurses of caring for people living with dementia at the end of life in nursing homes. Therefore, it is difficult to understand the challenges the nurses encounter in the delivery of end-of-life care for people living with dementia in nursing homes. This thesis aims to explore the experiences of registered nurses in providing end-of-life care for people living with dementia in nursing homes. A qualitative Straussian grounded theory (Strauss and Corbin 1998) study was conducted involving four nursing homes in South Wales. Eighteen registered nurses were recruited for this study using purposive and theoretical sampling approaches. Data was collected between February and December 2021 using semi-structured in-depth interviews. Interview transcripts, field notes and memos were analysed using constant comparative analysis. The analysis, assisted by NVIVO software, integrated open, axial, and selective codes which assisted in the development of main categories and grounded theory for this study. Three main categories were generated from the data which included the participants' experiences of residents' 'end-of-life care wishes and preferences', the 'organisation and delivery of end-of-life care', and 'moral distress'. The core category of 'interpersonal relationships' led to the generation of the grounded theory which carries implications that extend well beyond the pandemic context. The findings of this study reveal a Relational Paradox; the quality of interpersonal relationships that existed among nurses, residents, and families, enabled good care but also caused moral distress when that care was constrained. The COVID-19 pandemic disrupted these relational foundations, severing the connections upon which quality care depended. This study, therefore, recommends structural changes that value relational continuity, invest in workforce stability, create robust systems of emotional support for staff, and ensure that the relational dimensions of care are protected even under conditions of crisis. Given, that the grounded theory in this study is new and original, it needs to be tested, developed, and refined through further research.

Keywords: dementia, end-of-life care, experiences, registered nurses, nursing homes, qualitative, grounded theory, interpersonal relationships, moral distress, relational paradox.

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Acknowledgements

I would like to thank the registered nurses who took part in this study. These nurses provided valuable insights about end-of-life care for people living with dementia in nursing homes. I am also grateful to the managers of the nursing homes involved in this study for their help as gatekeepers during the recruitment of the participants, for granting me access into the nursing homes, and for helping in organising the interview dates and venues.

I would also like to thank my academic supervisors Professor Jane Hopkinson, Dr Raymond Samuriwo, Dr Sarah Fry, Dr Tessa Watts, and Dr Dominic Roche for their support, guidance, and encouragement. Without their expert advice and constructive feedback this project would not have been a success.

I will forever be grateful to my late Dad for believing in me and teaching me the value of education and resilience. My daughter Taonga, my son Alex, and my grandson Leon- thank you for your unwavering love, patience, and support. You have been so understanding despite my divided attention during the period of my study. My sister Pastor Siyileni Malinki, I appreciate your love, prayers, and pastoral support, and Jo Solomon for your support.

I will also forever be indebted to the Worshipful Company of Barbers (WCOB) for awarding me two consecutive Clinical Nursing Scholarships which funded the tuition fees for my fourth and fifth years of my PhD programme. I am also grateful to the WCOB for allowing me the opportunity to attend the annual awards luncheon at the Barber-Surgeons' Hall in Barbican, London on two occasions as an award recipient. The memories created from these experiences will last a lifetime- not to mention the finest food and wine, and the elegant Barber-Surgeons' Hall. I had the privilege to meet my fellow awards recipients, the Master, Wardens, Clerk, and Assistant Clerk of the company, also Professor Sally Hardy from University of East Anglia who administered the Clinical Nursing Scholarship funded by the WCOB. The networks I established will be useful throughout my career.

Thank you to the Student Loans Company for the Loan which helped me to fund part of my PhD and provide financial maintenance during this period.

My gratitude also extends to the Cardiff University Aspire Digital Capability Scheme for providing funds which helped me to purchase a new laptop for my project and other educational materials such as USB sticks that I used to store some of my work.

Thank you to the TP Transcription Limited for your help transcribing my interviews, and to my cousin Brenda, friends Lusungu and Jean for helping to pay for my transcription fees.

Also, a massive thank you to the rugby, football, and basketball mums and dads, not forgetting the lads and coaches for being there for Alex and offering lifts when I was stuck writing up my thesis.

Dr Idesi Chilinda and Dr Emmie Malewezi- thank you for your mentoring.

My fellow PhD students at School of Healthcare Sciences- thank you for your peer support.

I will never forget the rest of my family, friends, line Manager, colleagues, neighbours, Ararat Baptist Church and Boys Brigade for the support, encouragement, and remaining with me throughout this tough but incredible journey.

To the Healthcare Research Support Office staff Michelle, Marie, and Claire, thank you so much for your help and support. You do an amazing job!

Nick Russell- I appreciate your IT support to manage my long word document.

Dr Fintan Nagle, thank you so much for proof-reading my thesis.

Finally, I would also like to express my gratitude to Cardiff University students support services for the mentoring sessions and assisting me to access the DSA support I required for my studies.

Dedication

For my late Dad

Chapter 1: Introduction to the study

1.1: Introduction

This chapter introduces the study by providing an overview of the topic, outlining my professional background and interest in conducting the research, and presenting the overall structure of the thesis. It establishes the context of dementia care in the UK, explains the significance of registered nurses (RNs) role in end-of-life care, and highlights the rationale for exploring their experiences in nursing home settings.

The population of the United Kingdom (UK) is both growing and ageing (Office of National Statistics (ONS) 2024). In 2022, approximately 12.7 million people in the UK were aged 65 years or over, representing 19% of the population. This figure is projected to increase to 22.1 million (27% of the population) by 2072, compared with 7.5 million (13% of the population) in 1972 (ONS 2024). Increasing age consequently predisposes a population to conditions such as dementia and other neurodegenerative diseases (Dementia Research Institute 2024). Furthermore, the ageing population represents a significant global challenge for future end-of-life care (Bone et al. 2018).

Dementia is an umbrella term used to describe progressive and debilitating symptoms resulting from disorders of the nervous system (Coope 2020, Coope and Richards 2020). It is a life-limiting and incurable condition that affects memory, cognition, behaviour, and daily functioning (National Institute for Health and Care Excellence (NICE) 2024). Dementia leads to substantial disability and dependency, reduces quality of life, and places a considerable burden on families, communities, and governments (World Health Organisation (WHO) 2023).

Globally, more than 55 million people currently live with dementia, and this figure is expected to rise to 150 million by 2050 (GBD 2019 Dementia Forecasting Collaborators). Almost 10 million new cases are reported each year (WHO 2023), establishing dementia as a major global public health concern. In the UK, approximately one million people are currently living with dementia, and this is projected to rise to 1.4 million by 2040 (Dementia Research Institute 2024). Dementia is now the leading cause of death in the UK: of the 581,363 deaths registered in England and Wales in 2023, 66,876 (11.6%) were attributed to dementia and Alzheimer's disease (ONS 2024).

1.2: Care homes as a setting for advanced dementia care

In 2021, 278,946 people aged 65 years and over were living in long-term care settings in England and Wales, primarily in nursing or residential care homes (ONS 2023). In the UK, the term *care home* refers to institutional care for older adults requiring 24-hour support with personal care and daily activities (NHS 2026). Care homes include residential homes, which provide personal care delivered by care workers, and nursing homes, which additionally provide 24-hour nursing care delivered by RNs (Sanford et al. 2015, Oliver 2016, NHS 2026, Comas-Herrera et al. 2021, Age UK 2022). While the terms *care home* and *nursing home* are sometimes used interchangeably (Sanford et al. 2015), the distinction is important for understanding the role of nursing care.

When people with advanced dementia are admitted to nursing homes, they require specialist multidisciplinary care to address the complex health and social needs associated with advanced illness (Kinnaird 2015). Within these teams, RNs play a vital role in organising, assessing, planning, leading, supervising, and delivering end-of-life care (NHS England 2019). They ensure that care is person-centred and aligned with residents' wishes (Royal College of Nursing (RCN) 2019). In the UK, RNs are formally trained and registered professionals responsible for assessment, care planning, care delivery, health promotion, education, leadership, and coordination of care (Nursing and Midwifery Council (NMC) 2018). They are also responsible for ongoing assessment of residents' needs, monitoring changes in condition, and evaluating care outcomes, skills essential for high-quality end-of-life care.

The NMC (2019) emphasises the need for RNs to provide compassionate, person-centred end-of-life care tailored to individual needs, preferences, values, and beliefs. This includes symptom management, medication monitoring, the use of clinical devices, advance care planning, and facilitating end-of-life discussions with residents and families. The RN's proximity to residents at the end-of-life places them in a unique position to identify unmet needs and ensure dignity in dying (RCN 2019).

Nursing homes are increasingly becoming common places of death for people with dementia (Darsch et al. 2018, Wiggins et al. 2019). Given the high prevalence of dementia, its progressive nature, and the complexity of associated care needs, there is a growing demand for end-of-life care in nursing homes (Harrison Denning 2023). Exploring the experiences of RNs who provide this care is therefore crucial. Understanding their perspectives can help identify challenges, training needs, and opportunities to improve care delivery. Ultimately,

this research seeks to inform strategies that enhance the quality of end-of-life care for residents with dementia and support the RNs delivering that care.

Conducting research in nursing homes presents distinct challenges, including issues of consent and capacity (Lam et al. 2018, Johnstone and Donaldson 2019), ethical approval, participant recruitment and retention (Jenkins et al. 2016), and organisational constraints such as limited resources, high staff turnover, and competing priorities (Lam et al. 2018). Despite these barriers, nursing home research offers significant benefits, including staff training and empowerment, improved care standards, networking opportunities, and the generation of knowledge to advance care practice (Jenkins et al. 2016).

1.3: Researcher's professional background and interest

My interest in end-of-life care for people living with dementia is rooted in both professional and personal experience. I worked as an RN in UK nursing homes for five years, followed by three years as a registered manager. During this time, I provided direct care to residents at the end of life, as well as to those living with dementia, and developed a strong appreciation for the importance of dignified, person-centred care.

I subsequently worked for seven years as a Nurse Assessor for a local Health Board in Wales. In this role, I was responsible for commissioning and monitoring primary and community-based care services, including care provided in nursing homes. This position required me to evaluate standards of dementia care, provide expert advice to nursing home staff, and ensure that residents, particularly those nearing the end of life, received high-quality, safe, and compassionate care. This experience heightened my awareness of the challenges RNs face in delivering end-of-life care and strengthened my interest in understanding their experiences in depth.

On a personal level, caring for dying relatives and observing the care provided to close friends reinforced my belief in the importance of respecting individual wishes at the end of life. These experiences further motivated me to explore the realities of RN practice in supporting people with dementia as they approach death.

Together, my professional and personal experiences inspired this study. They shaped my commitment to advancing understanding of RN experiences and to identifying ways to support them in delivering high-quality end-of-life care for people with dementia.

1.4: Structure of the thesis

This grounded theory study explores the experiences of RNs in caring for people with dementia at the end of life in UK nursing homes during the COVID-19 pandemic. The thesis is organised as follows:

- Chapter 1 introduces the study, background, rationale, and structure.
- Chapter 2 contextualises the research by outlining relevant background literature and the rationale for the study.
- Chapter 3 presents a scoping review of existing research on RNs' experiences of end-of-life dementia care in nursing homes and identifies gaps in the literature.
- Chapter 4 describes the grounded theory methodology, provides a rationale for its selection.
- Chapter 5 explains the study methods.
- Chapter 6 presents the ethical principles underpinning the study and how these were applied.
- Chapters 7 and 8 present the findings, including the three major categories and the core category developed from the data.
- Chapter 9 introduces the grounded theory for this study.
- Chapter 10 discusses the findings in relation to existing literature, and highlights the contributions, limitations, and implications for practice, policy, research, and education. The chapter concludes with reflections and final remarks.

The next section presents the background chapter.

Chapter 2: Background

2.1: Introduction

This chapter introduces the core concepts and context of this study in terms of dementia, palliative and end-of-life care, nursing homes, and registered nurses. The chapter further presents the COVID-19 pandemic as the context in which this study was conducted. The justification for conducting this study has been presented at the end of this chapter.

2.2: Dementia

Dementia is an umbrella term describing progressive and debilitating symptoms caused by the impairment of the nervous system (Coope 2020, Coope and Richards 2020). It is a life-limiting, incurable condition (NICE 2024) which can result in significant disability and dependency, poor quality of life and a considerable burden on families, communities, and governments (WHO 2023).

The exact cause of dementia is unknown (Earlstein 2016). However, Theodoulou and Jaswal (2020) identified several risk factors including hearing loss, gender, genetics, high cholesterol, excessive alcohol consumption, smoking, obesity, poor diet/nutritional deficiencies and conditions including heart diseases, hypertension, diabetes, stroke, depression, Parkinson's disease, Huntington's disease, HIV infection, and severe head injury. Further risk factors include age, being physically inactive, and social isolation (WHO 2025).

Individuals living with dementia may experience problems with their memory, particularly short-term, processing information, disorientation to place, time, and persons (Andrews 2020). In addition, they may also display some changes in behaviour such as agitation and may present with conditions such as anxiety and depression (Warner and Graham 2018). According to Warner and Graham (2018), these symptoms manifest across all forms of dementia although some may be specific to certain types and disease stage. Moreover, multiple symptoms may coexist when an individual has a mixed dementia (WHO 2025).

The four main forms of dementia are Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies (Warner and Graham 2018). Alzheimer's disease is the most prevalent form of dementia accounting for almost 60-70% of all cases of dementia (WHO 2025). It is estimated that 22% of all persons aged 50 and above globally have Alzheimer's disease (Gustavsson et al. 2023).

Furthermore, dementia is classified either according to stages as early, middle, and late/final or advanced stage (Warner and Graham 2018), or based on severity as mild, moderate, and severe (Earlstein 2016). The early stage is associated with mild, gradually developing symptoms such as forgetfulness, poor concentration, and reduced motivation which may be dismissed as being a normal part of ageing (Warner and Graham 2018). The middle stage is associated with moderate symptoms. At this stage individuals may display clear changes in their behaviours, demeanour, memory impairment, poor judgement, and difficulties managing day-to-day tasks independently (Earlstein 2016). The late stage is also classed as the final or advanced stage of dementia. Advanced dementia is characterised by complex needs, distressing physical, behavioural, and psychological symptoms (Koppitz et al. 2015, Sampson et al. 2018), considerable limitations in terms of cognitive and physical functioning (Eisenmann et al. 2020) and high dependency levels (Earlstein 2016). This increased dependency often results from impaired mobility, continence, communication, and oral intake/swallowing problems (Midtbust et al. 2018). Individuals with advanced dementia may also experience repeated infections, agitation, mood disorders, weight loss, and are at considerable risk of developing pressure sores (Sampson et al. 2018). More severe symptoms may manifest as the terminal phase approaches including prolonged drowsiness, reduced levels of consciousness, diminished urine output, cyanosis, and bronchial secretions with gurgling or rattling (Duckworth 2018). This late stage of dementia can last for years (Warner and Graham 2018).

It has been suggested that the prevalence and burden of problematic symptoms experienced by people with advanced dementia can be similar for individuals with cancer (Moens et al. 2014). Furthermore, older and frail individuals are said to be at a higher risk of multiple comorbidities, complex needs, and death from the disease (Etkind et al. 2017, Yorganci and Sleeman 2023). Arguably, early initiation of a palliative approach to care or referral to palliative care services might enhance the quality and experience of living and dying with advanced dementia for individuals and those important to them and is therefore beneficial. Nevertheless, evidence suggests that for a range of reasons access to palliative and end of life care is suboptimal (Erel et al. 2017, Mataqi and Aslanpour 2020, Fox et al. 2018,

Sampson et al. 2018, Ding et al. 2020). Furthermore, it is estimated that every year 100,000 people with dementia in the UK die needing but not receiving palliative care (Dudley and Mutebi 2022). This evidence supports the need to improve palliative and end-of-life care for people with dementia (Harrison Denning 2023), making it a global priority (Triandafilidis et al. 2024).

2.3: Palliative care and end-of-life care

The terms palliative care and end-of-life care are often used interchangeably in clinical practice and literature, yet, they have different meanings (Russell 2015). There is a general misconception amongst health care professionals that palliative care is only valid in the terminal phase of an illness (Mitchell et al. 2016). However, palliative care is intended to relate to the whole patient journey (Russell 2015), from the point of diagnosis of an incurable, life-limiting illness (Mitchell et al. 2016).

The WHO (2023) definition of palliative care is widely used (NHS England 2024). The WHO (2023) define palliative care as holistic (physical, psychological, social, and spiritual) care and support offered to people (and those close to them) with life-threatening conditions, at any stage of an illness, regardless of the diagnosis or prognosis. Palliative care aims to control symptoms and support people with advanced progressive illness to live as comfortably as possible (NICE 2023). It also seeks to improve quality of life for individuals and families facing problems associated with life-limiting illness through the prevention and relief of suffering (WHO 2024).

Historically, palliative care focused on people with cancer but in recent times has been expanded to encompass non-malignant illnesses such as dementia and chronic obstructive pulmonary disease (COPD) (WHO and Worldwide Hospice Palliative Care Alliance (WHPCA) 2020). The WHO and WHPCA (2020) have estimated that globally over 56.8 million people require palliative care annually. This includes 31.1 million people living prior to and 25.7 million approaching the end of life. The majority (67.1%) are adults over 50 years old living with chronic, life-limiting illnesses including cardiac problems, dementia, HIV/AIDS, and cancer.

The unmet need for palliative care for chronic life-limiting health problems in most parts of the world is substantial (WHO and WHPCA 2020). Furthermore, palliative care for older people is a global public health concern. This is due to the ageing society and inadequate

services available to cater for older people's complex health and care needs. The WHO (2024) has predicted that by 2050, the world's population of people aged 60 years and older will double (2.1 billion). Furthermore, the number of persons aged 80 years or older is expected to triple between 2020 and 2050 and reach 426 million. This increase in age is anticipated to bring about an increased level of ill health and disability (Rechel et al. 2020), age-related and life-limiting conditions, including dementia (Sampson and Harrison Denning 2020), and a corresponding need for palliative care (Harrison Denning 2023). Accordingly, raising awareness of the need for better palliative care and integration into primary health services is important (Johansson et al. 2024, Triandafilidis et al. 2024).

The term end-of-life care is often used synonymously with palliative care, particularly in North America. However, when a person in the UK is described as at the end of life it is often understood that they are in the last year of their life (Duckworth 2018, NICE 2021 General Medical Council (GMC) 2022). End-of-life care is aimed at supporting individuals during the advanced stages of life-limiting illness, to enable them to live as well as possible until death (NICE 2021). Often considered part of palliative care, in UK policies, strategic initiatives and guidance, end-of-life care is often defined in line with the NICE (2021) definition as care for those "approaching the end of life" when they are likely to die within the next 12 months and including those whose death is imminent'. This definition of the end-of-life is used in this thesis.

2.3.1: End-of-life care and dementia

In recent years there has been increased attention to end-of-life care for people living with dementia. In part this is due to the increasing dementia prevalence, progressive neurodegeneration in many dementias and rising mortality rates (WHO 2024). The Global Action Plan on the public health response to dementia 2017-2025 (WHO 2017) for example, has been instrumental in laying out strategies to improve the lives of people living with dementia and their families, including those approaching the very end of their lives. Published in 2015, the then Prime Minister's Challenge on dementia 2020 highlighted the importance of good quality care from the point of diagnosis to the very end-of-life (Department of Health and Social Care 2015, Care Quality Commission 2016). Current NICE guidelines emphasise the importance of timely, ongoing advance care planning, early adoption of palliative care and relevant guidelines and co-ordinated working between health and social care (NICE 2018), all of which align with UK strategy directions.

Nevertheless, Murphy et al. (2016) and Sampson et al. (2018) argued that palliative and end-of-life care for people living with dementia remain inadequate compared to those living with other terminal illnesses. Specific problems identified include inadequate symptom control, access to palliative care interventions and specialist palliative care (Lee et al. 2017, Martinsson et al. 2018, Lundin and Godskesen 2021) together with increased, sometimes unnecessary hospitalisation (Lee et al. 2017) where they may be subjected to intrusive and painful interventions.

Several reasons for this inadequacy have been suggested. Bolt et al. (2018) allude to the fact that some health care professionals are insufficiently equipped with the appropriate and adequate knowledge, skills, and confidence to provide safe and effective end-of-life care for individuals dying with dementia. This has related to insufficient appropriate training and support (van Der Steen et al. 2017). Ultimately limited knowledge, skills, and confidence for delivering end-of-life care for individuals with advanced dementia could compromise end of life care quality (Browne et al. 2021).

To be able to identify when a person is in the final stages of their illness it is important that healthcare professionals can recognise symptoms of end of life. In dementia this is far from straightforward for as previously mentioned, advanced dementia may persist for several years (Browne et al. 2021), the dementia illness trajectory is complex, and it is difficult to both prognosticate and identify the end-of-life phase with any degree of certainty. Yet prognostic uncertainty may result in delays in initiating timely end-of-life care, unmet needs, and symptoms which are undertreated, not detected, or inappropriately managed (Mitchell et al. 2016, Browne et al. 2021). In addition, several authors have argued that health and social care professionals do not always recognise dementia as a progressive, terminal, life-limiting illness (Broady et al. 2018, Schmidt et al. 2018, Annear et al. 2020, Mataqi and Aslanpour 2020). Consequently, individuals may not be offered the opportunity to engage in timely advance care planning (ACP) for their future healthcare.

2.3.2: Long term care and advanced dementia

At times, the complex needs of people living with advanced dementia due to cognitive and functional impairment, render continuing care at home unsustainable, hence increasing the necessity for longer term care in either residential or nursing care homes (Mitchell et al. 2016, Wiggins et al. 2019, Croft et al. 2023, Schmidt et al. 2018). International evidence

indicates that people with dementia are more likely to die in hospital or care homes rather than in their own homes (Sleeman et al. 2014, Reyniers et al. 2015, Wiggins et al. 2019). Furthermore, dementia and Alzheimer's Disease have been the leading causes of death in UK care home residents since 2015 (ONS 2024) and arguably care homes, both residential and nursing, may be perceived as important providers of end-of-life care.

However, nursing homes are not always equipped to provide proactive, coordinated end of life care (Davies et al. 2014), either for older residents or those with dementia. To address this deficit the need for and importance of implementing educational and organisational interventions to enhance end of life care delivery has been recognised (O'Brien et al. 2016, Collingridge-Moore et al. 2020).

2.3.3: Enhancing end-of-life care in the UK

The national End of Life Care Strategy (Department of Health (DOH) 2008) highlighted the gaps in the provision of optimal end-of-life care and aimed to enhance end-of-life care and enable people to die in their preferred place by providing a comprehensive framework for quality end-of-life care. This first national End of Life Care Strategy was the impetus for improving end-of-life care and since then, and sometimes in response to reports highlighting inadequate end-of-life care, for example, the independent Neuberger Review of the Liverpool Care Pathway (DOH 2013), other nation-specific strategies, guidance and initiatives have followed. In England examples include: the Five Priorities for Care (Leadership Alliance for the Care of Dying People 2014) which focused on enhancing person-centred care outcomes for all those at the very end of life; Actions for End-of-Life Care: 2014-2016 (NHS England 2014) which was developed to build on the success of the 2008 End of Life Care Strategy and meet the challenges of achieving quality end of life care in the changing landscape of health and social care and population needs (NHS England 2014) and the 'Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026'. The co-produced Ambitions framework was initially launched in 2015 and relaunched in 2021 and provides a vision for high-quality local level palliative and end of life care across England for everyone with advanced, progressive, life-limiting illness to optimise care experiences throughout their remaining life, and in death (Wee 2016). The NICE guidance (NG142) (NICE 2019) and Quality Standard for End-of-Life Care (QS13) (NICE 2021) covers care for adults aged 18 years and above with a life-limiting condition who are in the last twelve

months of their life in health and social care settings and describes high-quality care in priority areas for improvement, including support for dying individuals' families and/or carers.

Devolution means that in the UK different legislatures and executives exist each with a different range of powers and devolved nations are responsible for developing their own policies in certain areas. Welsh Government is the executive arm of devolved government of Wales and has the powers to independently make decisions about Welsh health and social care services (Government of Wales Act 2006). As such, service delivery may differ from the other UK nations. For example, in Wales dying individuals are referred to specialist palliative care services on the basis of need using a standard All Wales Palliative Care Team referral form.

The sustained focus on improving end-of-life care in Wales during the early twenty first century can be traced back to the Welsh Government commissioned Sugar report in 2008 (Sugar 2008). This Report set the agenda for enhancing palliative care in Wales, with a broad objective of a one Wales approach to achieve equitable access to services, reduce inequalities and raise care standards. Implementation of the recommendations of the Sugar Report was the business of a newly established End of life Care Implementation Board supported by £6.4 million Welsh Government funding. Recommendations included an all-Wales review of the templates used for individual care pathways and patient pathway through services which, in the aftermath of the Neuberger Review (DOH 2013), evolved into the Care Decisions Guidance (2015). In 2017 the Palliative and End of Life Care Delivery Plan (2017) was published and subsequently extended to 2022. Informed by the Quality Statement for Palliative and End of Life Care for Wales (Welsh Government 2021), the recently established National Palliative and End of life Care Programme focuses on a broader agenda for person-centred end of life care and a one Wales approach, notably in terms of Advance and Future Care Plans, care decisions for the last days of life, All Wales Specialist Palliative Care Referrals and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR).

Despite abundant guidance for providing good end-of-life care and the implementation of established evidence-based initiatives such as Advance care planning, the Gold Standards Framework, and the Namaste care programme, there are significant variations in the quality of end-of-life care across the UK (Collingridge-Moore et al. 2020, National Palliative and End of Life Care Partnership 2021, Wu et al. 2024, Office for Health Improvement & Disparities 2025). Concerns about the quality of end-of-life care were heightened during the COVID-19

pandemic, which resulted in high numbers of deaths, shifted patterns of care for people approaching the end of life, intensified pressure on community services and increased inequalities in end-of-life care (Johansson et al. 2024). Furthermore, in England, most deaths in the initial phase of COVID-19, between January and August 2020, occurred within nursing homes for older people including those living with dementia (Morciano et al. 2021).

2.3.3.1: Advance care planning and dementia

Promoted through National Health Service End of Life Care Programmes (NHS England 2021, NHS Wales 2025) and national strategic documents such as the End-of-Life Care Strategy (DOH 2008), Advance Care Planning for now and the Future (DOH Northern Ireland (2022) and in Wales, the Quality Statement for Palliative and End of Life Care (Welsh Government 2022), ACP has become integral to end-of-life care provision in the United Kingdom.

Definitions of ACP have evolved over time. ACP is now broadly defined as a voluntary, ongoing, person-led process that involves meaningful, holistic discussions between an individual and their care providers about their values, goals, preferences and priorities for their future care, treatment and end of life wishes (Rietjens et al. 2017, NHS England 2021, NHS Wales 2025), and their documentation, while they have the ability to communicate and mental capacity to do so (NICE 2021). This process is continued when an individual's ability to make their own decisions is impaired (van der Steen et al. 2024). ACP includes various aspects of decisions such as advance statement of wishes, preferences and priorities, Advance Decision to Refuse Treatment/ Advance directives, and nomination of an LPA Health and welfare.

According to Rietjens et al. (2017), Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions (Rietjens et al. 2017). Comprehensive Advance Care Planning, when adhered to, may ensure that an individual's end-of-life care preferences are respected, reduce unnecessary and potentially futile and invasive interventions or hospital admission, improve the quality of end-of-life care, help those important to individuals in

bereavement and benefit healthcare systems in terms of resource utilisation and associated costs (Hamilton 2017, Kelly et al. 2019, Kernick et al. 2018, Jimenez et al. 2019, Wendrich-van Dael et al. 2020, Burghout et al. 2023).

Despite these purported benefits, the literature suggests that several barriers to successful ACP for people living with dementia exist (Phenwan et al. 2020, Flaherty et al. 2023). Initiating and engaging in ACP discussion, particularly in relation to end of life matters, can be challenging for both healthcare professionals and patients (Simon et al. 2015). For patients this may be for a range of interconnected reasons which appear to centre on the notion of 'death talk.' International evidence suggests reasons include an unwillingness to discuss end of life care matters, social and cultural norms and beliefs around death talk, fear of losing control of emotions, mistrust and insufficient knowledge of ACP, concern about the impact of engaging in ACP on family dynamics, a perception that ACP is not a priority, appropriate or beneficial and that ACP is a doctor's, rather than patient responsibility (Canny et al. 2023, Goodwin et al. 2021, Graham- Wisner et al. 2022, Bernard et al. 2020, Simon et al. 2015). For healthcare professionals, barriers to engaging in ACP conversations include inadequate education, insufficient time, discomfort with initiating and engaging in end-of-life care conversations, prognostic uncertainty, competing priorities and role ambiguity in terms of responsibility for initiating ACP conversations (Canny et al. 2023, Blackwood et al. 2019, Jimenez et al. 2019). In addition, insufficient readily accessible, understandable ACP information in a range of formats has also been identified (Canny et al. 2023, Goodwin et al. 2021, Bernard et al. 2020).

The dementia illness trajectory, while variable between individuals and often protracted, is one of progressive, unpredictable decline which may vary across different dementia types (Lillyman and Bruce 2016, Melis et al. 2019). Figure1 illustrates a general dementia trajectory.

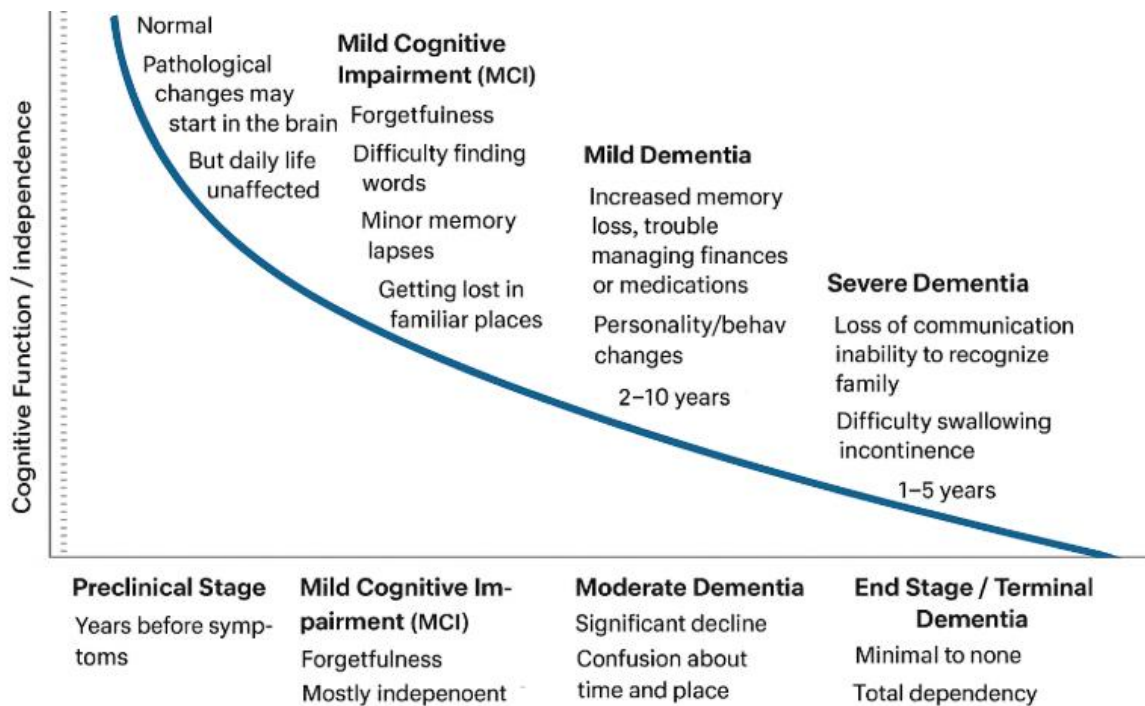


Figure 1: Dementia disease trajectory

This decline is often insidious and characterised by uncertainty, progressive decrease in cognitive and communicative ability, and is invariably punctuated by acute events and associated emergency hospital admissions, which may increase as individuals approach the very end of life (Yorganci et al. 2023). As the end of life in dementia remains ill-defined (Browne et al. 2021), timely ACP is fundamental in ensuring a basis for supporting decisional autonomy in the event of future mental incapacity, delivering and improving end-of-life care for individuals living with dementia, and those important to them (Dixon et al. 2018, NHS England 2018, Harrison Denning et al. 2019, NICE 2019, Harrison Denning 2023).

The body of evidence regarding ACP in dementia is growing. Systematic reviews of international studies have focused on effectiveness, facilitators and barriers and perspectives on and experiences of ACP in the context of dementia and have pointed to benefits in terms of reduced hospitalisations and increased concordance between preferences and care received dementia (Wendrich-van Dael et al. 2020). Nonetheless, it has recently been suggested that ACP may be under used in dementia (Bryant et al. 2021). A range of reasons for underuse have been identified including individuals' insufficient knowledge about ACP, denial or reluctance to acknowledge a dementia diagnosis, and unwillingness to engage in the ACP process, difficulties determining optimal timing of ACP conversations, and healthcare professionals' limited knowledge of dementia illness

trajectories and low self-efficacy in initiating and engaging in quality conversations (Bryant et al. 2021, Tilburgs et al. 2018, Harrison-Dening et al. 2019).

It has been suggested that advance care planning is particularly relevant for nursing home residents in view of the prevalence of comorbidities, increasing cognitive and social decline and associated frailty (Gilissen et al. 2017). Indeed, recent data indicates that in England 169,500 (34%) people with a formal diagnosis of dementia currently reside in either a residential or nursing care home (NHS England 2024). Nursing homes are hence seen as being conducive environments for ACP conversations because staff are believed to have more time and a personal connection with residents from regular and close contact (Sævareid et al. 2019; 2020).

Despite nursing homes being mandated to offer ACP, nurses are not always adequately prepared or confident to initiate and facilitate timely ACP discussions with individuals living with dementia and their families (Poveda-Moral et al. 2021, Konno et al. 2024). Research has also reported low implementation and uptake of advance care planning in nursing homes (Mignani et al. 2017, Gilissen et al. 2018, Andreassen et al. 2019). A number of reasons for the limited implementation of advance care planning in nursing homes and for residents affected by dementia have been identified. These include roles and responsibilities, organisational hierarchy, reluctance and insufficient time, staff knowledge, training and confidence to engage in meaningful and sensitive advance care planning conversations with residents living with dementia either for fear of causing distress and confusion or perceptions of insufficient mental capacity (Spacey et al. 2021, Ampe et al. 2017). Strategies to improve ACP in nursing homes have therefore been recommended for example designing ACP implementation tools (Wendrich-van Dael et al. 2021), training and support for staff (Wendrich-van Dael et al. 2022), and conducting nurse-led facilitation projects (NHS England 2019).

2.3.3.2: The Gold Standards Framework

Developed in 2000 and recommended by the End-of-Life Care Strategy (Department of Health 2008), the Gold Standards Framework (GSF) is an evidence-based, systematic approach to improving end of life care in any UK setting (Shaw et al. 2010). While the GSF has evolved over time, its overarching aim is to achieve a 'gold standard' of end-of-life care for all dying individuals, irrespective of diagnosis (Walshe et al. 2008). The practical GSF Proactive Identification Guide (2017), updated in 2022, helps staff identify patients' end-of-

life status and triggers the GSF process, in terms of person-centred needs and preferences assessment and care planning if appropriate (Thomas et al. 2022).

The Gold Standards Framework in Care Homes programme (GSFCHP) was developed in 2004 in response to the growing recognition of the need to improve end-of-life care in care homes through staff education and training (Gold Standards Framework Care Homes (GSFCH) 2021, GSF 2025). The GSFCH is a three-phase, system-based organisational approach to optimising the end-of-life care provision in care homes (Kinley et al. 2018). The programme comprises a structured curriculum and accreditation. Care homes are required to pay a fee to undertake the GSFCH training programme which includes a designated external training facilitator, learning resources, and training workshops. To be accredited care homes are assessed against twenty standards of best practice. Re-appraisal occurs annually and re-accreditation every 3 years.

Currently, there are about 16, 444 care homes in the UK (11,375 residential care homes and 5069 nursing homes) (Berg 2025). Of these, the GSF reports about 3,000 who have engaged in the GSFCH in England. Thus, it would seem that the majority of care homes in England have not engaged in the GSF training programme. To date no care homes are accredited in Wales (Gold Standards Framework 2025).

Research has found that a benefit of the GSFCH training programme is enhanced confidence and competence of care home workers in identifying the end-of-life care phase and delivering end-of-life care (Nash and Fitzpatrick 2015). Despite the highlighted benefits of the GSFCH training programme, not all care homes commencing the training programme complete it, thereby raising questions regarding implementation (Kinley et al. 2018). Kinley et al.'s (2018) mixed methods study involving thirty-eight care homes in South-East London aimed to identify the type, role, impact, and cost of facilitation when implementing the GSFCH programme into nursing care home practice. Kinley et al. (2018) recommended multi-layered, and timely, tailored training to ensure a successful implementation of the GSFCH.

2.3.3.3: Namaste Care

The Namaste Care programme was designed to improve quality of life and end-of-life care for nursing home residents living with advanced dementia. Through an enhanced person-centred multi-sensory nursing programme, this care programme focuses on creating a peaceful end-of-life experience by reducing distressing symptoms such as anxiety and

agitation through individualised meaningful activities, sensory input, comfort and pleasure and family support (Stacpoole et al. 2016). Small-scale studies have indicated that the programme confers observable benefits to residents in terms of reducing behavioural and psychological symptoms (Stacpoole et al. 2016) and improved social engagement (Latham et al. 2020).

2.4: Study context: The COVID-19 pandemic

This study commenced before the COVID-19 pandemic. However, data collection fell within the duration of the pandemic. As such, the pandemic forms part of the context for this study. The COVID-19 pandemic had a devastating impact on the delivery of end-of-life care in nursing homes around the world (Hendricksen et al. 2022). The outbreak placed prolonged physical and emotional strain on care home residents, their families, and staff (Galik 2021). Spacey et al. (2021) found that end-of-life care in nursing homes was disrupted by the pandemic, and that the previously obscure issues such as staffing levels, well-being, and motivation became starkly visible and highlighted. Disruption in daily working routines (Lombardo et al. 2020, Hanna et al. 2022) and fundamentals of end-of-life care such as enabling residents to die in the company of their loved ones, and symptom management, were all reported (Strang et al. 2020, Thompson et al. 2020).

During the COVID-19 pandemic, the UK government imposed three national lockdown periods (March 2020, November 2020, and January 2021) in an attempt to control the spread of the Coronavirus (House of Commons House of Lords Joint Committee on Human Rights Care Homes 2021, Department of Health and Social Care and UK Health Security Agency 2023). Wales, however, mandated three additional short 'firebreak' lockdowns in September, October, and December 2020. Thereafter, local restrictions continued in the UK regions throughout 2021 and 2022. Figure 2 illustrates the timeline of the COVID-19 pandemic in terms of lockdowns, declarations, and milestones including those specific to Wales and in relation to this study.

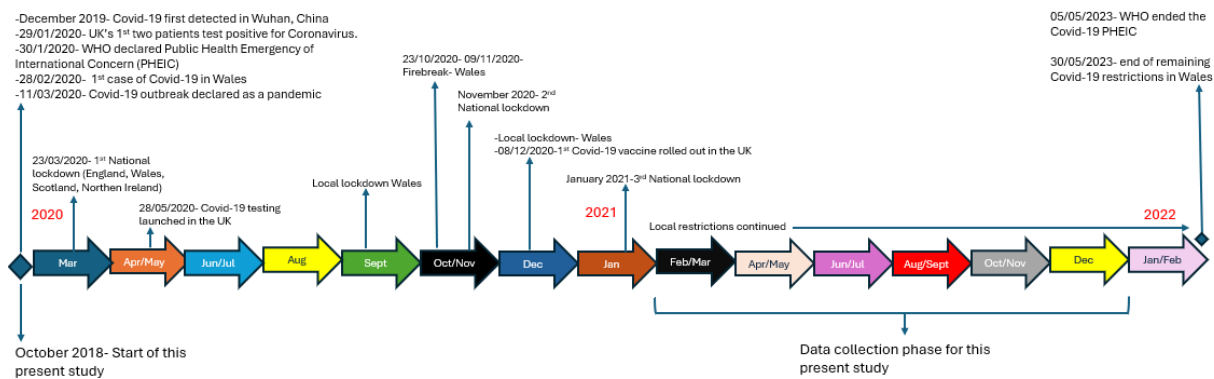


Figure 2: COVID-19 timeline in Wales: lockdowns, declarations, milestones, and data collection

Globally, care homes, both nursing and residential were significantly affected by the COVID-19 virus, particularly during the first wave of the pandemic (Dixon et al. 2023) (it is important to note that there was no established vaccine against the virus in this phase of the pandemic). In England and Wales an increase in deaths of approximately 79% was reported among care home residents in the initial phase of the COVID-19 pandemic between March 2nd, 2020, and June 12th, 2020, as compared with 2015-2019 (ONS 2020). Furthermore, UK care home mortality rates were higher than many European countries (Dixon et al. 2023). This increase in mortality has been attributed to residents' vulnerability associated with increased frailty, old age, and multiple comorbidities (Spacey et al. 2021, WHO 2021). In addition, residents were living in close proximity to and requiring close contact from staff and other visiting healthcare professionals, hence increasing their risk of contracting the virus (Spacey et al. 2021). This was compounded by problems of access to personal protective equipment (PPE) across all social care settings in the UK and the practice of discharging patients from hospitals into nursing homes without established COVID-19 status (UK COVID-19 Inquiry 2025). Moreover, during this time nursing home residents were confined indoors where the spread of the virus was known to be rapid (Qian et al. 2021, NHS 2023).

2.4.1: COVID-19 and care home infection control measures

The Health and Social Care Act 2008: Code of Practice on the prevention and control of infections sets out what registered providers of health and adult social care services need to

do to ensure compliance with the Care Quality Commission (CQC) registration requirements for infection control. All services registered under the Health and Social Care Act 2008 are expected to have a policy for the control of infectious disease outbreaks.

When an infectious disease outbreak is suspected or declared, visitors, including healthcare professionals, are restricted entry into nursing homes to control infection spread and protect residents' safety (Department of Health (DOH) and Health Protection Agency 2013, Public Health Agency 2015, Public Health England 2020, Department of Health and Social Care 2024). During the COVID-19 pandemic the UK government initially advised against care home visiting if individuals were feeling unwell. Care home visiting guidance suggesting alternative modes of connection, for example, through telephone/video calls, garden, customised pod or window visits and the introduction of booking systems in exceptional circumstances such as end of life, was published in April 2020 following the first national lockdown (UK Parliament 2021). However, these alternative visiting arrangements may not always be suitable for many residents living with dementia, especially those with sensory and perceptual impairments, as they may find the window or video chats confusing, which may cause distress for the individuals and their relatives (Galik 2021, Giebel et al. 2023).

Within nursing homes, social isolation was initially imposed on residents to control infection spread (UK COVID Inquiry 2025). Residents were required to remain in their own rooms, thereby limiting their social interaction (Ferdous 2021). Implementing infection control measures specifically for people with advanced dementia during this period proved challenging (Hendricksen et al. 2022). For example, people with cognitive impairment such as dementia experienced distress and declining health as they were unable to understand why they were isolated (UK COVID-19 Inquiry 2025). Galik (2021) further suggested that individuals living with advanced dementia in care homes lacked the capacity to process or remember infection control information, follow physical distancing protocols, and wear face coverings correctly.

Although essential in controlling the spread of infection, face coverings presented communication challenges particularly for people with hearing impairment due to difficulties lip-reading and added confusion for people living with dementia as they were unable to recognise faces (Galik, 2021, Page et al. 2021, UK COVID-19 Inquiry 2025). The UK COVID-19 Inquiry recently published its findings on the impact of the COVID-19 pandemic on the health and social care sector in England, Wales, and Northern Ireland detailed in its latest record "Every story matter". The inquiry examined personal accounts from families,

care workers, unpaid carers and people with care and support needs from across the UK. These findings highlight the urgent need for systemic changes in the care home sector to ensure better support for residents, relatives, and staff.

In addition, physical distancing measures meant that staff and home residents were required to maintain a distance of at least two metres, except when staff were providing direct care. This posed a challenge for staff as it limited contact and meant staff found it difficult to provide emotional support and comfort care through the therapeutic use of touch or sitting close to residents (Galik 2021).

2.4.2: COVID-19 and family members of nursing home residents

It is widely accepted that family members are important collaborators in residents' care, providing emotional support (Honarmand and Mehta 2021) and assisting with personal hygiene, feeding, mobilisation and recreation activities. They are rich sources of valuable information essential for planning and delivery of timely safe and effective care (Fry et al. 2015), recognising and reporting changes in health status and offering essential support for residents and staff (Dupuis- Blanchard et al. 2021). Families can be valuable in maintaining residents' irreplaceable previous relationships and personhood (Pirhonen et al. 2015). Accordingly, their contribution should be recognised and acknowledged (Cohen-Mansfield and Meschiany 2022, Chu et al. 2023).

In most cases, families understood the rationale and accepted visiting restrictions during the pandemic (Cohen et al. 2024). However, even though they trusted the care staff to do their best, some disagreed with the separation these restrictions created (Cohen-Mansfield and Meschiany 2022). Following the House of Commons/ House of Lords Joint Committee on Human Rights Care Homes (2021), some felt that by denying families, essential care givers, the right to see their relatives, especially when they could have played a crucial role in supporting the overstretched care home staff during the crisis, Government guidance did not adequately acknowledge the importance of families to residents' well-being.

COVID-19 visiting restrictions and the resultant separation of residents in their care home bubble and from their families, loved ones and the outside world for extended periods negatively affected residents' families' wellbeing (Paananen et al. 2021, Sweeney et al. 2022). This was particularly marked among those whose family member with dementia was approaching the very end of their life (Paananen et al. 2021, Hanna et al. 2022, Sweeney et

al. 2022) as restrictive measures set limits on families spending precious time with their dying relatives and deprived them and the dying resident of solace and connectedness in the last moments of life (Honarmand and Mehta 2021). Social needs were unmet (Noten et al. 2022) and connections between residents, families and communities fractured (Saad et al. 2022). Some families were concerned about their relatives, particularly those with dementia, dying alone or in the absence of their loved ones (Cohen- Mansfield and Meschiany 2022, UK COVID inquiry 2025), resulting in trauma and ongoing mental health challenges for many family members.

Similarly, numerous studies investigating the impact of the pandemic on residents' family members, including those whose loved one with dementia was approaching the very end of life, have identified heightened levels of frustration, concern, fear, anxiety, anger, distress, grief, sadness, guilt, abandonment, distrust, loneliness, and hopelessness (Dupuis-Blanchard et al. 2021, Giebel et al. 2022, Honarmand and Mehta 2021, Paananen et al. 2021, Cohen-Mansfield and Meschiany 2022, Hanna et al. 2022, Cotterell et al. 2026, Sweeney et al. 2022, Chu et al. 2023, Cohen et al. 2024). Some family members acknowledged the difficulties facing care home workers particularly in relation to poor staffing levels and higher than normal patient care demands (Sweeney et al. 2022, Dupuis-Blanchard et al. 2021, Chu et al. 2023). However, family members also reported feeling frustrated with the inconsistent and continuously changing rules around visitations, poor communication about their relatives' welfare and updates on the COVID-19 situation within the homes (Chu et al. 2023). This left them feeling excluded and concerned about their loved ones (Giebel et al. 2021). Some family members reported feeling fearful and anxious about their relatives contracting the virus and becoming ill or dying from it whilst others expressed anger about the pandemic (Dupuis-Blanchard et al. 2021). There were reported growing concerns amongst family members about the well-being of their loved ones.

Prolonged visiting restrictions are known to impact on a dying individual's emotional well-being (Department of Health and Social Care and UK Health Security Agency 2023) and family members felt prolonged isolation could cause depression and further functional and cognitive decline (Cohen-Mansfield and Meschiany 2022, Sweeney et al. 2022, Giebel et al. 2023). Cohen-Mansfield and Meschiany (2022) reported that some families were concerned about their ill relatives dying alone and without their families. These concerns resulted in grief and sadness (Paananen et al. 2021, Cohen-Mansfield and Meschiany 2022). Some family members expressed frustration, sadness, and grief about being unable to participate in the care of their loved ones. They felt they were not recognised as part of the care team,

and their exclusion caused a disconnect in their relationship (Gaur et al. 2020, Schlaudecker 2020, Dupuis-Blanchard et al. 2021, Paananen et al. 2021, Sweeney et al. 2022, Chu et al. 2023). Cotterell et al. (2026) suggested that families had to trust care home staff and develop coping mechanisms to survive this period. Nevertheless, feelings of mistrust towards care home staff were expressed by some family members. While some families did not believe that their loved ones would receive adequate care if they were unable to regularly monitor their care and well-being (Dupuis-Blanchard et al. 2021) others doubted the credibility of the information they were being given about their loved ones by nursing home staff (Giebel et al. 2021).

In addition, the findings from the study by Dupuis-Blanchard et al. (2021) are intended to support long-term care facilities to review policies regarding restriction of visits. Stall et al. (2020) and Tupper et al. (2020) suggest more flexible policies with fewer restrictions to benefit both the family members and residents in long-term care facilities. Giebel et al. (2021) therefore advocate for increased understanding of institutional and individual responses to critical situations, such as the COVID-19 pandemic, which will inform subsequent choices and decisions, consequently useful for the creation of a balance between risks and solutions.

2.4.3: COVID-19 and nursing home staff/staffing

It is widely documented that the COVID-19 pandemic resulted in unprecedented strain for healthcare workers around the world. Rising infection rates, inadequate PPE, poor working conditions, insufficient knowledge about the virus and its management and the lack of availability of hospital beds impacted negatively on the physical and mental health of frontline healthcare staff, including those working in nursing homes (Firew et al. 2020, Sweeney et al. 2022, Gray et al. 2022).

During the pandemic, increased staff illness from the virus, together with shielding, meant nursing homes were faced with staff shortages (Giri et al. 2021, Sweeney et al. 2022, White et al. 2021, Craft Morgan et al. 2023, UK COVID-19 Inquiry 2025) and, during the height of the pandemic, use of agency workers increased (Giri et al. 2021, Brazier et al. 2023). This affected the routine care delivery (Spacey et al. 2021, Daley et al. 2022, Hanna et al. 2022, Masterson-Algar et al. 2022) and raised concerns about exposure to the virus (Nyashanu et al. 2022). The increased numbers of deaths and people infected and dying with COVID, as well as staff taking on additional roles in nursing homes during this time generated additional workload demands (WHO 2021, Gray et al. 2022, van Diepen et al. 2023). Examples include

nurses adopting additional roles such as verifying deaths and covering staff shortages in laundry and catering departments in the absence of outside agencies (Hanna et al. 2022). In addition, during this period, some nurses served in alternate roles outside their specialty or where they did not regularly work to cover critical staff shortages resulting from increased illnesses and absence, leading to additional stress and anxiety (Sweeney et al. 2022, Womack et al. 2024). The UK COVID-19 Inquiry (2025) found that during this time some staff felt helpless and frustrated providing end-of-life care without appropriate training when healthcare professionals were unable to visit. The inquiry also found that staff were working longer hours at times to ensure that residents did not die alone resulting in staff strain and increased risk of burnout.

Increased demands on care meant that staff caring for residents living with advanced dementia during the pandemic found it unique, challenging, and 'an emotional rollercoaster' due to the increased demands on care (Hendriksen et al. 2022). This was at a time when care home staff were affected emotionally due to increased exposure to death not only of residents but also of colleagues (Nyashanu et al. 2022) against a backdrop of inadequate organisational support (Spacey et al. 2021). It is of little surprise therefore that a decrease in wellbeing (van Diepen et al. 2023) and increased feelings of helplessness (Liberati et al. 2021), personal and work-related stress and even burnout (Liberati et al. 2021, Sweeney et al. 2022, Hanna et al. 2022) have all been reported. Furthermore, recent research has indicated that registered nurses working in care home settings during COVID-19 experienced moral distress (Birt et al. 2023, Cockshott et al. 2024).

Furthermore, inconsistencies in following visiting restrictions guidelines within long term care facilities, including nursing homes, posed moral dilemmas amongst staff (Giebel et al. 2021). Some care homes allowed family members to visit and spend more time with their loved one in exceptional circumstances, such as when their loved ones were dying while others placed stricter measures. At such times it was reported that family members were even allowed physical contact with their dying relatives like hand holding, as staff felt it would be inhumane to disallow such moments (Giebel et al. 2021). It is, therefore, not surprising that the nursing home nurses faced moral distress during this period due to repeated exposure to morally distressing events. Most nurses felt they had no or little control over these situations and were unable to act in accordance with their professional and ethical values (Birt et al. 2023, Cockshott et al. 2024).

The term moral distress was originally defined by Jameton in 1984 as the psychological reaction to situations when individuals believe they are doing something that is ethically wrong, contradicting their values, beliefs, or principles. Following on from Jameton (1984), Georgina Morley's work focuses on understanding nurses' ethical experiences and creating interventions aimed at minimising negative effects of moral distress. Morley et al. (2017) expanded the definition of moral distress as a situation whereby an individual makes a moral judgement but is unable to act upon it. To create sufficient conditions of moral distress, Morley et al. (2017) suggest a combination of and existence of a direct causal relation between the experience of a moral event and an experience of a psychological distress.

By affecting mental health and wellbeing, moral distress is known to impact negatively on healthcare professionals (Watts et al. 2023) and even impair their ability to perform their duties competently (Colville et al. 2019). Effects of moral distress are normally short-term and reversible. However, if they are not appropriately addressed burnout and moral injury may arise (Thomas and McCullough 2014). Contrastingly, moral injury results from an individual's own or other people's acts of omission or commission, or betrayal by a trusted person (Williamson et al. 2021) and can manifest through deep feelings of anger, guilt, shame, or loss of trust in self/others (Jinkerson 2016, Barnes et al. 2019).

Consequences of the COVID-19 pandemic on healthcare staff are evident through increased reports of mental health issues including moral distress, resulting in occupational health challenges (Greene et al. 2021, Lamb et al. 2021, Marvaldi et al. 2021, Roberts et al. 2021). Moral distress may normally occur amongst staff caring for people living with dementia (Spenceley et al. 2017, Haslam-Larmer et al. 2023). However, Haslam-Larmer et al. (2023) found the restricted family visits, insufficient staffing, and high turnover during the pandemic to exacerbate moral distress in nursing home staff.

In their qualitative study, Cockshott et al. (2024) reported care home staff experiences of anxiety and distress due to uncertainty of what to expect, dealing with increased numbers of unwell residents and deaths causing overwhelming workload, concerns regarding their own health, feeling their work was under-recognised, and lack of external healthcare support. Cockshott et al. (2024) investigated the impact on the emotional well-being of care home staff of challenges faced during the COVID-19 pandemic, and the strategies used to manage them. What Cockshott et al. (2024) found can help to inform planning for future crises including disease outbreaks and highlight the need for further work to develop pandemic preparedness in care homes and beyond.

Moral distress and moral injury are believed to have existed prior to COVID-19 in the health care sector, but the pandemic only made them more pronounced (Laher et al. 2022). As such, Laher et al. (2022) call for interventions to continue to be developed in the post-pandemic era to support nursing and care home staff.

Moral distress and moral injury consequently impact on care provision (Haslam-Larmer 2023). Colville et al. (2019) explained that some degree of moral distress is expected in day-to-day care provision but concerns only arise when a member of staff's emotional well-being is seriously compromised to a point that impacts on the quality of care of patients, morale, and staff turnover. Colville et al. (2019) therefore recommended interventions to be designed to support staff in addressing experiences or situations that expose them to emotional distress.

2.4.4: Researcher's experience of challenges faced by nursing home nurses during the pandemic

During the COVID-19 pandemic, I experienced several issues with the nursing homes I visited in my role as a Nurse Assessor. The UK government's visiting restrictions resulted in limited access to nursing homes. As Nurse Assessors we were still allowed into nursing homes. However, as our visits were limited it was difficult to review residents and monitor the standards of care. Face-to-face reviews were conducted only in cases of concern and remaining routine reviews were conducted over the telephone. Reduced visits may have resulted in delays identifying care-related issues or even missed care thus compromising the residents' care and safety. Telephone reviews also presented a risk of missing problems for residents. Direct contact with residents was limited during this period. Routine procedures such as physical skin checks and observation of care as part of residents' Funded Nursing Care (FNC) and Continuing Health Care (CHC) reviews were omitted in most cases and there was a reliance on the information provided by the nursing home staff. Thus, monitoring procedures were incomplete, and this meant resident wellbeing and safety could not be fully assessed. The relatives of the residents depended on the Nurse Assessor's visits to reassure them that their loved ones were safe and well cared for, but it was difficult for Nurse Assessors to provide full reassurance.

Poor staffing levels during the pandemic meant that I found it was often difficult to get a chance to speak to staff about the residents I was reviewing. The nursing homes were often short-staffed and the staff on duty were too busy attending to residents and could not find

time to discuss the FNC and CHC reviews with the Nurse Assessors. Staff had to rely on our written records which posed a potential risk of communication breakdown which could result in unintentional omissions or delays in care.

Agency staff were frequently employed to cover staff shortages in the nursing homes during this period. During my visits, I found obtaining information from these staff challenging. This was because most were unfamiliar with residents. Furthermore, I noted a drop in care standards during this period. One example was poor documentation. Nurses reported having no time to update daily care records, assessments, and care plans due to staff shortages, high numbers of sick residents needing more attention, and an increased number of deaths. The nurses were forced to omit routine care and address priority issues at most times.

On a couple of occasions, I found myself helping around the nursing homes and abandoning the main purpose of my visit as I was met with a staffing crisis in those homes. This situation posed a dilemma for me as this was outside my employment, but I had to exercise duty of care as a registered nurse myself and could not walk out of that situation. Being aware of these issues made me plan my research interviews in a way that did not cause disruption to care provision. The interviews were hence conducted during the times that the participants were not on duty.

2.5: Rationale for the study

Following this overview, it can be concluded that dementia remains a global challenge. It is also deduced that in most cases, people dying with dementia have complex needs requiring specialist care services which during the COVID-19 pandemic were compounded, resulting in challenges in care delivery. Furthermore, this complexity of care needs for people living with dementia necessitates admission into nursing homes which have been shown as the most preferred place of care and death for these individuals. Various efforts are being made at an international, national, and local level to improve palliative and end-of-life care services for people living with dementia. However, it has been flagged up that the care for individuals dying with dementia and their families is still sub-optimal, making palliative and end-of-life care for this population a health and social care priority (Sampson et al. 2018).

This study was therefore set to explore the registered nurse's experiences of providing end-of-life care for people living with dementia in nursing homes. The knowledge gained from the nurses' experiences was intended to assist in identifying areas of focus where strategies

could be designed to develop better end-of-life care and improve the end-of-life experiences for people with dementia and their relatives. Limited knowledge about nurses' experiences could make it difficult to understand the specific challenges that nurses encounter in the delivery of end-of-life care. Furthermore, a lack of insight into how best to deliver end-of-life care to people with dementia in nursing homes may result in unwarranted variations in care which could affect the quality of care and the way people die. A scoping review of literature was therefore conducted to systematically identify the research that has been conducted around this topic to identify any existing gaps in knowledge. This scoping review did not include COVID-19 as this study was commenced, and the scoping review was conducted prior to the COVID-19 onset.

2.6: Summary of chapter

This chapter has provided an overview of the key concepts underpinning the study including dementia, palliative and end-of-life care, long-term care settings, and the context of the COVID-19 pandemic. Dementia is presented as a progressive, incurable condition associated with complex cognitive, physical, and behavioural symptoms that intensify in the advanced stage, resulting in high dependency and significant palliative care needs. Despite increasing recognition of dementia as a terminal illness, access to appropriate palliative and end-of-life care remains inconsistent and often inadequate, with barriers linked to limited professional knowledge, prognostic uncertainty, and delayed care planning.

Nursing homes have been highlighted as critical care settings for individuals with advanced dementia, yet they often lack the resources, training, or systems required to deliver high-quality end-of-life care. Initiatives such as Advance Care Planning, the Gold Standards Framework, and the Namaste Care programme aim to improve care quality, though implementation varies across the UK, particularly in Wales.

The chapter has also highlighted how the COVID-19 pandemic profoundly exacerbated existing challenges in nursing homes. Restrictions, isolation, staffing shortages, and increased resident vulnerability significantly disrupted end-of-life care delivery, negatively affecting residents, families, and staff. The chapter concludes by emphasising the urgent need to understand RN's experiences in this environment to inform improvements in

end-of-life care for people living with dementia. The next chapter details the scoping review that was conducted in this study.

Chapter 3: Scoping review

3.1: Introduction

This chapter discusses the scoping review that was undertaken for this study. The chapter is structured based on the Arksey and O'Malley (2005) framework stages: identifying the review question; identifying relevant studies; study selection; charting the data; collating, summarising, and reporting the results.

There are several approaches to conducting evidence synthesis, including systematic reviews, literature reviews, and scoping reviews (Munn et al. 2022). Scoping reviews, also referred to as 'mapping reviews' or 'scoping studies,' are an increasingly popular approach used to systematically map and identify research completed on a particular area, topic, or field (Arksey and O'Malley 2005, Munn et al. 2022). This identified research is then used to inform subsequent research by clarifying key concepts and methods (Khalil and Tricco 2022). It has also been suggested that scoping reviews help in identifying and analysing knowledge gaps through a rapid review of evidence on emerging fields or topics (Munn et al. 2018, Peters et al. 2020).

The first methodological framework for conducting scoping reviews was published in 2005 by Arksey and O'Malley. This framework comprised six stages: identifying the review question; identifying relevant studies; study selection; charting the data; collating, summarising, and reporting the results; and consultation exercise (this last stage although considered optional, is highly recommended).

Levac et al. (2010) further refined and enhanced Arksey and O'Malley's original framework to ensure that each stage was clarified to support consistency and maximise the usefulness and rigour of scoping study findings within healthcare research and practice. Levac et al.'s (2010) enhancements included: clarifying and linking the purpose and research question for stage one; balancing feasibility with breadth and comprehensiveness of the scoping process for stage two; using an iterative team approach to selecting studies for stage three; extracting data for stage four; incorporating a numerical summary and qualitative thematic analysis, reporting results, and considering the implications of study findings to policy, practice, or research for stage five; and incorporating consultation with stakeholders as a required knowledge translation component of scoping study methodology for stage six.

Furthermore, the Joanna Briggs Institute (JBI) adopted and refined both Arksey and O'Malley (2005) and Levac et al.'s (2010) frameworks in 2013 (Peters et al. 2015). A working group from the JBI and JBI Collaboration (JBIC) produced guidance for scoping review methodology to ensure rigorous, transparent, and trustworthy processes (Peters et al. 2015). To establish consistent reporting according to the JBI scoping review methodology, the working group extended the Preferred Reporting Items for Systematic Reviews (PRISMA) Statement to scoping reviews thus creating the PRISMA-ScR (Tricco et al. 2018). The JBI methodology working groups continue to improve, update and further the science of JBI Evidence Syntheses whenever there is any notable change to a methodology (Peters et al. 2020). For the scoping review reported in this thesis, Arksey and O'Malley's (2005) framework was used. This framework was chosen because it offered a simple and easy guide, particularly for a novice researcher, as the stages were straightforward and clearly defined. Also, the first five stages of this framework were used since the sixth stage was not applicable in this case.

The idea of conducting literature reviews prior to data collection in grounded theory studies has been the subject of debate. Charmaz (2007) highlighted concerns that have arisen since the publication of 'The Discovery of Grounded Theory' (Glaser and Strauss 1967) regarding the use of existing literature when conducting a grounded theory study. Traditionally, literature reviews were not recommended prior to data collection in grounded theory studies. Rather, the idea was to allow categories to emerge naturally from the empirical data during analysis and prevent the pre-existing knowledge impacting the theory generation (Glaser and Strauss 1967). Glaser (1967), however, advocated that literature reviews were conducted prior to data collection in grounded theory studies. He argued that this was because a review was a requirement for PhD students whose research funding, ethical approval, and progression through the doctoral process may expect them to produce a detailed and systematic review of literature before collecting data. Straussian grounded theory supports literature reviews prior to data collection. However, Strauss and Corbin (1998) warned those researchers undertaking literature reviews prior to data collection to take caution that their pre-existing knowledge does not affect the theory generation which should only be based on the empirical data collected. They advise that the literature review conducted in grounded theory studies should be intended to provide baseline information only to help the researcher(s) in understanding and comparing data, creating theoretical sensitivity, and explaining results (Strauss and Corbin 1998).

3.2: Aim of the review

This scoping review aimed to identify and map the existing literature around registered nurses' experiences of caring for people living with dementia in nursing home settings. This was to identify knowledge gaps and assist to justify the choice of this topic area.

The specific objectives for the review, therefore, included to identify and summarise existing studies focused on registered nurses' experiences in this context; to provide an overview of the scope, focus, and findings of the existing literature; and to identify knowledge gaps and areas for future research.

3.3: Identifying the review question

Scoping review questions tend to be broader (Pollock et al. 2021) and use components of the Population Concept and Context (PCC) framework as a guide (Peters et al. 2020). Teixeira-Santos et al. (2022) regarded review questions as fundamental in conducting scoping reviews and advised researchers to ensure that they constructed well-built questions for their scoping reviews. The following broad question guided this scoping review:

'What is known from the existing literature about registered nurses' experiences of caring for people living with dementia in nursing home settings?'

3.3.1: Defining and aligning the objectives and questions

The PCC framework was used in this scoping review to map the concept of interest relevant to registered nurses (population) experiences of caring for people living with dementia (concept) in nursing homes (setting or context) (Peters et al. 2022). This has been illustrated in Table 1. The PCC framework was used to align the aim of this scoping review with the research question (Khalil and Tricco 2022).

Research Aim	Research/Review question	Population/Participants	Concept	Context
To map and explore the available literature on registered nurses' experiences of caring for individuals living with dementia in nursing homes	What is known from the existing literature about registered nurses' experiences of caring for people living with dementia in nursing home settings?	Registered nurses (Registered general nurses and registered mental health nurses)	End-of-life care for people living with dementia	Nursing homes

Table 1: Defining and aligning the objectives and questions

(Adapted from Kao et al. 2017, Khalil and Tricco 2022)

3.4: Identifying and selecting relevant studies

The search was conducted with the aim of identifying published and unpublished evidence related to the review question (Polit and Beck 2021). The search was limited to studies published in English due to translation constraints for studies in other languages. The search period applied from 2009 to 2019 to capture more recent studies around the topic. No geographical restrictions were applied to the search to access literature from different countries or regions.

Three stages were involved in the search process: Initial search, the second search, and the third search. The initial search involved a quick search of CINAHL, MEDLINE and Google Scholar to identify keywords and terms used in the title, abstract and index of papers which would inform the next stage of search (Burns and Grove 2009, Lacey 2010, Fleeman and Dundar 2014). To ensure a comprehensive search strategy, Watson (2020) advised the inclusion of both key words and subject headings from databases. Subject headings are

terms assigned to describe a concept that may have many alternative keywords which are brought together under the umbrella of this single term (Watson 2020). The keywords identified in this initial search included *end-of-life care*, *dementia*, *registered nurses*, *experiences*, and *nursing homes*. The use of these keywords allowed for the selection of all related studies as well as elimination of studies that were not relevant (Ferrari 2015).

During the second search the selected databases were searched comprehensively using the keywords identified in the first search (Tricco et al. 2018, Pollock et al. 2021) and subject headings (Watson 2020). The databases used included CINAHL, MEDLINE, EMBASE, PsycINFO and Web of Science which cover nursing topics. Google/Google Scholar, an increasingly popular bibliographic search engine (Polit and Beck 2021) was also used to source scholarly articles as well as grey literature. Grey literature refers to papers with limited distribution and not peer-reviewed, for example conference abstracts, theses, government reports, and clinical practice guidelines (Polit and Beck 2021, Pollock et al. 2021). Pollock et al. (2021) argued that this type of literature is a valuable research resource for raw data as it reveals findings in emerging research. It may also report research with negative results which are often not reported especially by commercial, profit-based publishers for fear of a negative impact to their intended consumers.

The third and final stage involved hand searching for nursing journal articles. Hand-searching key journals is helpful in identifying articles that could have been missed in database and reference list searches particularly in cases when electronic databases are incomplete, not up to date or when abstracting services cause variations in information (Arksey and O'Malley 2005). Back-chaining (searching reference lists of the selected studies and documents), and forward-chaining (tracing articles cited from initial source) (Tricco et al. 2018, Pollock et al. 2021) were undertaken for reference lists of selected studies. One relevant paper was identified from back-chaining.

Search strings were developed and linked together with Boolean operators 'OR'/'AND.' Boolean operator 'OR' was used to combine searches of the same concept or synonyms; whilst Boolean operator 'AND' was used to combine two or more searches of different concepts or synonyms (Glasper and Rees 2017). Furthermore, truncation using common symbols such as '*', were applied to broaden the search by adding the symbol to the root of a word (Polit and Beck 2021). MeSH terms (Medical Subject Headings) that are a major focus of the article (Polit and Beck 2021), were also used in this search but did not produce any specific results. Basic key word search is helpful in retrieving relevant articles (Ferrari

2015) as was the case in this search. Table 2 illustrates the search strings used in the search.

Search number	Search string
S1	Registered nurse* OR Qualified nurse* OR Staff nurse* OR Licenced nurse*
S2	Experience* OR view* OR perce*
S3	end of life care OR end-of-life care OR palliative care OR terminal care
S4	Dementia OR Alzheimer* OR memory loss OR cognitive* impair* OR Creutzfeldt-Jakob disease OR Lewy body disease OR frontotemporal lobar degeneration
S5	nursing home* OR care home* OR old people's home* OR Long-term care facilit*
S6	S1 AND S2 AND S3 AND S4 AND S5

Table 2: Search strings

3.4.1: Inclusion and exclusion criteria

The inclusion and exclusion criteria used to select papers/literature for this scoping review is outlined in table 3.

Inclusion criteria	Exclusion criteria
Primary research studies (qualitative, quantitative, mixed studies) Literature reviews Grey literature Studies involving registered nurses. Studies involving end-of-life care for people living with dementia residing in nursing homes. Studies/papers written in English language. Studies published/grey literature between 2009 and 2019.	Studies/papers not written in English language. Studies involving other Healthcare professionals'/students. Studies involving other care settings. Studies involving end-of-life care for other conditions/diseases. Studies/literature published/written before 2009

Table 3: Inclusion and exclusion criteria

Preference for studies published in English was necessary as there were no resources available for translation including finances and translation services. Studies involving registered nurses (both registered general nurses (RGN) and registered mental health nurses (RMN) were also included because these registrants are directly involved in the provision and coordination of end-of-life care in nursing homes. Nursing homes were included due to the numbers of people living with dementia residing in nursing homes at the end of their lives.

3.4.2: Summary of search results

The search process yielded eighty potentially relevant papers which were taken forward for close examination. The search results are detailed in Tables 4 and 5 below.

Search number	Search term (Boolean Phrase)	CINAHL Results	MEDLINE Results	EMBASE Results	PsycINFO Results
S1	Registered nurse*	55,098	15,017	18,586	6,100
S2	Qualified nurse*	2,312	1,210	1,292	339
S3	Staff nurse*	57,396	4,195	5,519	1,137
S4	Licenced nurse*	10	0	1	1
S5	S1 OR S2 OR S3 OR S4	111,014	20,031	24,936	7,393
S6	Experience*	559,527	1,417,016	2,094,021	840,019
S7	View*	143,988	572,501	785,955	351,255
S8	Perce*	496,223	1,654,310	2,179,039	963, 484
S9	S6 OR S7 OR S8	1,056,188	33,32973	4,633,426	1,829,327
S10	End of life care	52,990	14,802	22,114	6,074
S11	End-of-life care	29,435	14,802	22,114	6,074
S12	Palliative care	53,224	81,035	70,174	18,944
S13	Terminal care	27,607	33,581	45,357	5,056
S14	S10 OR S11 OR S12 OR S13	75,087	105,702	105,457	21,408
S15	dementia	78,495	166,163	265,465	70,578
S16	Alzheimer*	50,459	163,308	222,048	72,744
S17	Memory loss	7,305	6,038	9,102	3,163
S18	Cogniti* impair*	39,872	9,9983	158,859	70,704
S19	Lewy body disease	2,156	5,377	12,804	1,919
S20	Creutzfeldt-Jakob disease	1,519	6,652	14,175	1,040
S21	Frontotemporal lobar degeneration	1,404	3,557	4,968	1,829
S22	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	140,620	349,037	519,518	170,946
S23	Nursing home*	60,729	54,005	81,060	16,463
S24	Care home*	65,466	5,854	7,820	2,522
S25	Old people's home*	199	285	538	80
S26	Long term care facilit*	42,682	7,371	9,607	2,052
S27	S23 OR S24 OR S25 OR S26	136, 617	62,531	92,169	19,392
S28	S5 AND S9 AND S12 AND S20 AND S24	27	12	17	7

Table 4: Comprehensive search results

Search number	Search term	Web of Science Results
S1	(((ALL= (Registered nurse*)) AND ALL=(experiences)) AND ALL= (end of life care)) AND ALL=(dementia)) AND ALL= (nursing homes)	16

Table 5: Comprehensive search results

Screening was completed by the researcher and checked by her two supervisors. After removing duplicates and irrelevant papers, thirty-four papers remained for full text review. Studies that did not involve RNs, nursing homes, dementia, and end-of-life care were excluded. Titles and abstracts were then scrutinised and reviewed and after this process, a total of ten papers that were relevant to the topic remained. No studies or papers were identified from the search of grey literature or through hand searching. Finally, eight relevant studies were taken forward for the review. The summary of the search results is presented in Table 6.

Database	Number of references found	Number of references relevant to inclusion criteria	Number of references selected for review
CINAHL	27	9	4
MEDLINE	12	6	1
EMBASE	17	7	1
PsycINFO	7	6	0
Web of Science	16	6	1
Hand searching	0	0	0
Back-chaining	1	1	1
TOTAL	80	34	8

Table 6: Summary of comprehensive search results

A PRISMA flow diagram (Tricco et al. 2018) has been developed to illustrate a summary of the study selection process involved (see Figure 3).

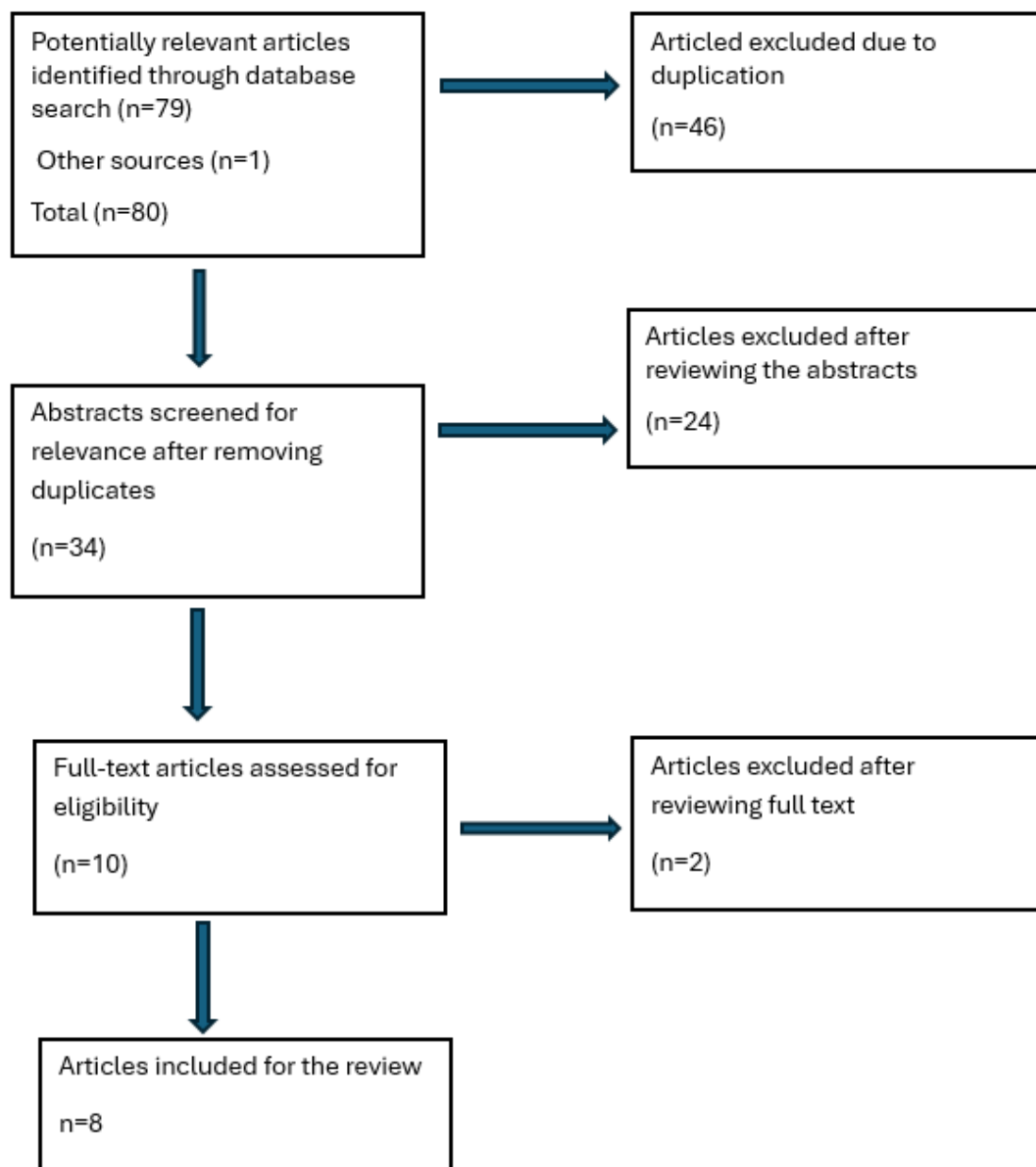


Figure 3: Prisma flow diagram illustrating the study selection process

This literature search identified some papers useful for the review. However, this search process may have been limited due to distinct types of bias such as publication, type of language and the restriction to use full-text articles only. Excluding unpublished articles may result in missing out studies reporting varied opinions as published articles tend to report positive results only (Lacey 2010). Lacey (2010) further suggested that studies published in English are often preferred by researchers due to translation issues. Consequently, selecting published articles or those written in English language only may result in missing those studies with varied opinions that are written in other languages or that are not published (Lacey 2010, Glasper and Rees 2017, Fleeman and Dundar 2014). Full text studies were used in this review to provide the researcher with more detailed information. However, Fleeman and Dundar (2014) advised against searching for full text studies only because recent studies may be missed as some up-to-date research may be reported in abstracts only such as those presented in conferences prior to submission for publication in an academic peer-reviewed journal.

3.4.3: Quality assessment of included articles

A structured quality assessment of the included studies was omitted in this scoping review since the aim of conducting the review was to identify gaps in literature and not evaluate the quality of the included studies, aligning with the Arksey and O'Malley framework. Peters et al. (2020) explain that scoping reviews do not adhere to strict methodological rules and assessment of quality of evidence making quality assessment of studies an optional process. However, Levac et al. (2010) suggested consideration of quality appraisal in scoping reviews and if conducted researchers are advised to explain the process followed, tools used and their rationale for completing the appraisal to maintain transparency and methodological rigour.

3.4.4: Data extraction

In scoping reviews, data extraction, also known as 'data charting,' is aimed at providing a logical and descriptive summary of the selected identified evidence that aligns with the scoping review question and objective (Aromataris and Munn 2020). As part of the data charting process, for this review evidence from the selected studies was extracted onto a data charting form adapted from the JBI data extraction form (Aromataris et al. 2024). Only relevant information should be extracted (Pollock et al. 2023). The key information included

on this charting form, was therefore: author; year of publication; title of article; geographical location; aim/purpose; population; sample size; methodology/ methods; key findings and conclusion/recommendations.

Following Arksey and O'Malley (2005), this form was pilot tested using two papers with a fellow PhD student to ensure consistency. The adapted data extraction form did not require any adjustments following the pilot testing as there were very minor discrepancies between the two reviewers. Following the pilot, data from the selected articles was extracted by the researcher and checked by and discussed with her two supervisors. Regular meetings between reviewers to discuss the data extraction process and any related issues is recommended to ensure rigour (Pollock et al. 2023). The populated data extraction table is provided in Appendix i (A and B).

3.5: Collating, Summarising, and reporting results

This scoping review provided insights about the studies that have been conducted around RNs' experiences of caring for people living with dementia in nursing homes at the end of life between the period of 2009 and 2019. A summary of the included studies is presented in this section highlighting key findings and gaps in the evidence.

Scoping reviews are intended to provide a map and summary of the available evidence around an area of interest but not to synthesize or aggregate findings (Pollock et al. 2023). Pollock et al. (2023) explained that advanced analysis methods were not necessary as scoping reviews do not seek to address questions of feasibility, appropriateness, meaningfulness, or effectiveness. A narrative summary of the findings, organised around the extracted data is, therefore, recommended to provide some form of analytical framework or thematic construction to be able to identify any similarities, differences, or gaps in the evidence (Arksey and O'Malley 2005). The evidence in this scoping review has been presented and organised around the following categories relevant to the review question and objectives: author, year of publication and aim; topic area, population; methodology/methods; setting and geographical location; and key findings which are presented in the section below.

3.5.1: Topic area and aim

All studies reviewed involved healthcare professionals' experiences of various aspects of palliative and end-of-life care for people living with dementia. The key aspects of care that the selected studies addressed included end-of-life care discussions, perceived barriers, and facilitators in providing palliative care, pain management, decision making, diagnosing end-of-life to provide comfort measures, and RNs' experiences of providing end-of-life care for people living with dementia.

Of the eight included studies, only one focussed on RNs' experiences of caring for people living with dementia in general (Monthaisong 2018). In this study Monthaisong (2018) sought to review the experiences of RNs in providing care for dementia patients, including theoretical perspectives that have been used to provide care for people living with dementia.

The other seven studies focussed on various aspects of end-of-life care. Huang et al. (2018) explored the factors related to the end-of-life care discussions of RNs, social workers, and physicians with people living with dementia residing in nursing homes and their families. The study conducted by Livingston et al. (2012) involved permanent staff who provided direct care for people with dementia. The aim of this study was to examine barriers and facilitators to care home staff delivering improved end-of-life care for people living with dementia. Furthermore, Midtbust et al. (2018), with a slightly different care focus from Livingston et al. (2012), explored health professionals' experiences of potential barriers and facilitators in providing palliative care for people living with severe dementia in long-term care facilities.

From a unique perspective, Bükki et al. (2016) explored staff views, attitudes, and concerns to initiate an institution-wide process to improve end-of-life care. In contrast, De Witt Jansen et al. (2016) investigated the experiences of hospice, acute-care, and nursing-home nurses in managing pain for people with advanced dementia during the final month of life, with the aim of identifying key challenges, facilitators, and areas needing further support.

Then again, the aim of the study by Koppitz et al. (2016) was to examine the decision-making process of symptom management for people living with dementia in nursing homes in their terminal phase of life, while on the other hand, Waldrop and Kirkendall (2009) set to explore how staff recognised that a resident was dying and to present a typology of comfort measures by conducting an exploratory descriptive study involving qualitative methods.

It has been suggested by the Organisation for Economic Cooperation and Development (OECD) (2018) that care services for people living with dementia are suboptimal and calls for

further investigation as to why this is the case. Surprisingly, end-of-life care for people living with dementia in nursing homes is an under-researched area (D'Astous et al. 2019) as supported by the results of this scoping review. Inadequate knowledge surrounding this area of care would, consequently, make it difficult to identify areas that require focus or improvement. As such, the need to conduct more research focussing on end-of-life care for people living with dementia was highlighted in this scoping review to explore this topic area further.

3.5.2: Population

People with advanced dementia approaching the end-of-life present with complex health and care needs hence the need to be looked after by a team of healthcare professionals from various backgrounds to ensure a holistic approach to their care (Kinnaird 2015). It was evident from the studies explored in this scoping review that viewpoints of multiple healthcare professionals involved in the care of people living with dementia residing in nursing homes were sought. Six studies reviewed explored the experiences of multiple healthcare workers including administrators (Waldrop and Kirkendall 2009), nurses (Waldrop and Kirkendall 2009, Bükki et al. 2016, Koppitz et al. 2016, Huang et al. 2018, Midtbust et al. 2018), certified nursing assistants (Waldrop and Kirkendall 2009), social workers (Waldrop and Kirkendall 2009, Huang et al. 2018), physicians (Bükki et al. 2016, Huang et al. 2018), housekeepers (Waldrop and Kirkendall 2009), care managers (Bükki et al. 2016) and staff providing direct care (Livingston et al. 2016). Only one qualitative study (De Witt Jansen et al. 2016) and a literature review (Monthaisong 2018) included in this scoping review explored the experiences of RNs exclusively.

Registered nurses are key frontline healthcare professionals who provide direct, ongoing care for people living with dementia in UK nursing homes and play a central role in assessment, care planning, coordination and symptom management (Department of Health and Social Care 2016, Bennett et al 2021, Mayo, 2022).

However, the roles of different team members in delivering end-of-life care for people living with dementia vary within the nursing homes. As such, it is necessary to explore the experiences of each group of staff separately. The unique contribution from RNs in the care of people living with dementia at the end of life is under-researched as supported by the results of this scoping review. The results of this scoping review, therefore, highlighted the need to look at the experiences of RNs exclusively to gain their separate perspectives. An understanding of the RNs' perspectives would, therefore, make a unique contribution to the

body of evidence which would assist in providing evidence to support the development of strategies addressing nurse education and support to improve end-of-life care for people living with dementia in nursing homes.

3.5.3: Methods

In conducting their research, six of the eight studies included in this scoping review used a qualitative approach. Three qualitative studies adopted a general qualitative approach (Bükki et al. 2016, De Witt Jansen et al. 2016, Livingston et al. 2016). Waldrop and Kirkendall (2009) used an exploratory descriptive qualitative approach, Koppitz et al. (2016) a qualitative constructivist grounded theory approach, and Midtbust et al. (2018) a qualitative descriptive approach.

Two included studies involved a survey (Huang et al. 2018), and an integrative literature review (Monthaisong 2018). Monthaisong (2018) in their literature review included qualitative studies (reflective journal, phenomenological, ethnographic, grounded theory, descriptive exploratory, organisational development, pragmatic exploratory, and meta-ethnographic analysis).

Individual interviews were the common data collection method in five qualitative studies included in this scoping review (Waldrop and Kirkendall 2009, Koppitz et al. 2016, Livingston et al. 2016, De Witt Jansen et al. 2016, Midtbust et al. 2018). Focus group interviews were used in Bükki et al. (2016) and Midtbust et al.'s (2018) studies, while Huang et al. (2018) collected data using self-administered standardised questionnaires.

Five of the included qualitative studies used thematic analysis (Bükki et al. 2016, Livingston et al. 2016, De Witt Jansen et al. 2016, Midtbust et al. 2018, Monthaisong 2018) and two used grounded theory (unspecified grounded theory approach-Waldrop and Kirkendall 2009, and constructivist grounded theory approach- Koppitz et al. 2016). Huang et al.'s (2018) survey used descriptive statistics: frequencies, percentages, means, standard deviations, and ranges to identify participants' demographic characteristics, discussions about EOL care, and other relevant main variables. In addition, frequency distributions of discussions about end-of-life care were measured using chi-square tests, mean-difference-related main variables with one-way analysis of variance, and Scheffe's post hoc analysis to determine any differences among the various professional groups.

Grounded theory is a type of qualitative research suitable for constructing a theory grounded in the accounts provided by participants (Corbin and Strauss 2015). Grounded theory is useful in providing insights into a variety of experiences (Bryman 2016). Furthermore, the grounded theory approach is commonly used to generate an understanding of nursing concepts including caregiving (Parahoo 2014). The results of this scoping review, however, showed a limited use of the grounded theory methodology and highlighted the need for additional grounded theory studies in this area. Only two of the qualitative studies identified in this scoping review used grounded theory as their methodology; constructivist (Koppitz et al. 2016), and grounded theory techniques (Waldrop and Kirkendall 2009). However, none of the included studies used a Straussian grounded theory method. The Straussian grounded theory methodology is said to be commonly used in nursing research to gain insights involving dynamic and new phenomena (Mohajan and Mohajan 2023).

3.5.4: Setting and geographical location

All eight studies included in this scoping review involved an aspect of care for people living with dementia who resided in nursing homes. These studies were conducted in different parts of the world which included parts of the UK such as Northern Ireland (De Witt Jansen et al. 2016) and England-London (Livingston et al. 2016), Taiwan (Huang et al. 2018), Germany (Bükki et al. 2016), Norway (Midtbust et al. 2018), Switzerland (Koppitz et al. 2016), and USA (Waldrop and Kirkendall 2009). Due to the global scale of dementia prevalence and deaths, it was therefore important to explore the concept of end-of-life care for people living with dementia residing in nursing homes from different countries and settings to gain a wider perspective of this aspect of care which would help to tailor end-of-life care services accordingly. An international perspective is useful when developing services as it enables expansion and adaptability, learning from others, and inclusivity (SMU Academy 2023).

This scoping review did not identify any study relating to the experiences of registered nurses of caring for people living with dementia in the nursing homes in South Wales, UK. It was therefore deemed necessary to conduct a study to explore RNs' experiences of caring for people living with dementia at the end-of-life in nursing homes located in South Wales. This choice of geographical location was also aimed to support the work established for improvement of services for people living with dementia in Wales. Examples of this work include Wales: A Dementia friendly Nation (2015), The National Dementia Vision for Wales: Dementia Supportive Communities, The Palliative and End-of-Life Delivery Plan (2017),

Together for a Dementia Friendly Wales (2017-2021), and Dementia Action Plan for Wales (2018-2022).

3.5.5: Key findings

This scoping review revealed key findings of the included studies which highlighted the need for ongoing improvement in end-of-life care for people living with dementia. This has been flagged up in a number of previous and recent studies including (Sampson et al. 2011, Harrison-Dening et al. 2012, Regan et al. 2014, Bamford et al. 2018, Dixon et al. 2018, Fox et al. 2018, Kaasalainen et al. 2021, Triandafilidis et al. 2024). As such, additional research is needed to explore ways of improving end-of-life care for people living with dementia (Dixon et al. 2018, Triandafilidis et al. 2024). The key findings of the studies included in this scoping review have been summarised in Table 7.

Study	Key findings
1. Huang et al. (2018) End of life care discussions for residents with dementia in Long- Term care facilities	Infrequent end-of-life care discussions; barriers to holding end-of-life care discussions including lack of confidence and communication skills in staff, attitudes, and cultural factors; and timing of conversations.
2. Midtbust et al. (2018) Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences	Poor continuity of palliative care as the main barrier resulting from time constraints, professional dilemmas, extensive use of temporary staff, staff redeployment between care facilities. Facilitator: ACP.
3. Monthaisong (2018) Nurses' experiences providing care for people with dementia: An integrative literature review	Main themes: encountering difficult emotions, working under difficult conditions, meeting holistic care needs, and lack of knowledge. Facilitators of care: forming relationships with people with dementia and effective communication. Barriers to care: staff skill shortages, lack of confidence, and staff physical and emotional strain.
4. Bükki et al. (2016) End of life care in nursing homes: Translating focus group findings into action	Key categories: workload and efficacy, aims and attitudes, leadership, and communication. Addressing team issues, fears, and avoidance was essential in promoting staff professional resilience and personal integrity.
5. De Witt Jansen et al. (2016) Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study	Core themes: challenges administering analgesia, the nurse–physician relationship, and interactive learning and practice development.
6. Koppitz et al. (2016) Decision-making in caring for people with dementia at the end of life in nursing homes	Decision-making process: 'Recount and reflect', Behaviour as a trigger. Factors influencing the decision-making process: Infrastructure, time allocated to individual residents, the attitude of the nurses and their managers towards the care of people with dementia.
7. Livingston et al. (2016) Care at the end of life for people with dementia living in a care home: a qualitative study of staff experiences and attitudes	Facilitators of care: strong caring relationships between staff and residents- 'similar to family', good knowledge/skill about recognition of end-of-life phase, understanding end-of-life religious traditions. Barriers to care: poor communication between staff and relatives, staff fear of being blamed, lack of awareness/concerns about validity of ACP, staff feeling emotionally unsupported.
8. Waldrop and Kirkendall (2009) Comfort measures: a qualitative study of nursing home-based end of life care	Physical, behavioural, and social indicators of an approaching death. Holistic and person-centred comfort care: symptom management- pain, dyspnoea, anorexia, and dry mouth, family care- emotional support, death education, interpersonal relationships with residents and family, complementarity between interdisciplinary roles.

Table 7: Key findings of included studies

3.6: Summary of chapter

This chapter has presented a scoping review exploring registered nurses' experiences of caring for people living with dementia in nursing homes, with a particular focus on end-of-life care. Using the Arksey and O'Malley (2005) framework, the review followed the stages of defining the research question, identifying studies, selecting studies, charting data, and summarising findings.

A broad search (2009-2019) across major databases identified 80 papers, which were screened down to 8 relevant studies. These studies varied in methodology and international context but collectively highlighted significant issues in dementia end-of-life care, including communication barriers, challenges in pain management, decision-making complexities, and organisational constraints.

Only two of the selected studies focused specifically on RNs, revealing a notable gap in the literature. Moreover, no studies were found from South Wales, strengthening the rationale for conducting research in this region. While this review did not include formal quality appraisal, aligning with the scoping review methodology, it effectively mapped existing evidence and identified critical gaps.

Overall, the review has shown that RNs' unique experiences are under-researched, and improvements in end-of-life dementia care remain urgently needed. These findings informed and justified the study's research question and methodological choice.

The next chapter presents a discussion on the methods used in this study.

Chapter 4: Research methodology

4.1: Introduction

This chapter provides a discussion of the methodological perspectives, and philosophical and theoretical underpinnings that informed this study. The justification for adopting the qualitative and Straussian grounded theory approaches will also be provided in this section.

Research in health and social care settings is conducted within 'paradigms' which guide or shape the researchers' understanding of a phenomenon under study (Polit and Beck 2021, William 2024). A paradigm is defined as a set of beliefs (Lincoln and Guba 2000) or a 'world view' by which a researcher studies a phenomenon guided by a set of philosophical assumptions (Simons and Lathlean 2010, Polit and Beck 2021). Thus, this world view influences what should be studied, how research should be conducted and results interpreted (Bryman 2016).

Rees (2011) described paradigms as lenses that assist researchers to focus on phenomena. Paradigms are useful in providing a framework by which a study is planned and implemented comprising four fundamental elements: ontology, epistemology, methodology, and methods (Coe 2017). These paradigms are applicable to qualitative, quantitative, and mixed methods research designs (Coe 2017) although different research paradigms may vary in their epistemological and ontological assumptions (Simons and Lathlean 2010). As such it is important for researchers to understand these essential concepts when planning and implementing their research.

Three relevant paradigms - positivist, interpretivist/constructivist, and critical, are now reviewed.

4.2: Research paradigms

Ontology is described as 'the study of being' (Bryman 2016) which involves the world view and assumptions about a phenomenon rooted in a researcher's philosophical background (Creswell 2013). As such, it is important for researchers to understand their own ontological viewpoint to support their interpretations of reality (Gray 2021). Epistemology refers to the

nature and forms of knowledge, that is, what is considered as knowledge or 'what is'/'should be' (Bryman 2016, Cohen et al. 2017) and how the knowledge is acquired, or concepts understood (Bryman 2016). Furthermore, epistemology emphasises the nature of the relationship between the researcher and the participants/objects or phenomena under study (Lincoln and Guba 2011, Creswell 2013).

Research methodology is linked closely with epistemology as both concepts are concerned with how researchers acquire knowledge (Bryman 2016). The research methodology for a particular study depends on the research question (Topping 2010) and the chosen research methodology will then influence the choice of method(s) (Bryman 2016) which are specific techniques or procedures that are used to structure a study and collecting and analysing data (Polit and Beck 2021) in both qualitative and quantitative research (Walliman 2021).

The four key paradigms involved in nursing research: positivist, interpretivist, constructivist, and critical approaches (Lincoln and Guba 2000) are presented in the following section.

4.2.1: The positivist paradigm

The positivist paradigm, also referred to as the scientific or empirical method (Topping 2010), was founded in the early 19th century by the French philosopher Auguste Comte (Holloway and Galvin 2017). Since its discovery, the methodology has dominated Health and Social sciences research (Polit and Beck 2021). According to Polit and Beck (2021), positivism is of the fundamental assumption that reality exists suggesting that there is a real world out there that is directed by real, natural causes.

The positivist approach assumes a realist ontology that the world exists independent from human perceptions of it, hence advocates the separation of researchers from the subjects under study (Parahoo 2014) to maintain objectivity and minimise or avoid biases (Holloway and Wheeler 2010, Topping 2010, Polit and Beck 2021). As such, positivists align with the objectivism (Lincoln and Guba 2011, Parahoo 2014), and an epistemology whereby the researcher believes that scientific knowledge can be proven and obtained rigorously and objectively through observation and experiments (Holloway and Wheeler 2010).

Positivism is characterised by empiricism which suggests that only what is observed by the human senses can be considered as facts (Holland and Rees 2010, Parahoo 2014). This scientific paradigm seeks cause and effect relationships hence aims to test hypotheses

through deductive processes (Topping 2010, Parahoo 2014). Therefore, positivism fits well with quantitative research designs (Polit and Beck 2021).

Due to the objectivity and generalisability of its findings and the ability to replicate the studies, positivist research is favoured and commonly used in healthcare studies (Park et al. 2019). However, the approach has been criticised for its lack of in depth understanding of human behaviour which cannot be explained via numeric applications (Panhwar et al. 2017). Moreover, positivist studies have been deemed not suitable for exploring moral or ethical issues (Polit and Beck 2021).

4.2.2: The interpretivist and constructivist paradigms

Interpretivism and constructivism are two research paradigms influential in social science research (William 2024). According to William (2024) these two paradigms whilst similar are not entirely the same. Interpretivism aims to understand human behaviour (Pulla and Carter 2018). It stems from the belief that knowledge is constructed based on an individual's unique interpretations and subjective experiences which shape how they understand the world (Parahoo 2014, William 2024). In this paradigm, the social context, cultural, historical, and social factors are key in influencing individuals' interpretations and beliefs (William 2024).

The interpretivist paradigm assumes the relativism ontology whereby reality is known through socially constructed meanings which are interpreted based on individual experiences, hence maintaining subjective and multiple perspectives (Topping 2010, Parahoo 2014). As such, interpretivist researchers use qualitative methodologies such as phenomenology, grounded theory, and case studies to understand individuals' subjective meanings and interpretations by using data collection methods such as interviews, focus groups, and observations (William 2024). However, Babones (2016) argues that interpretivism can also be applied in quantitative studies, particularly in mixed methods studies where numbers may require interpreting to understand what they mean regarding a participant's experience or a pattern of behaviour. In such cases, a researcher may use, for example, a survey with open-ended questions, or a case study with quantitative data.

The constructivist paradigm, also known as the naturalistic paradigm (Polit and Beck 2021), is considered as part of the broad interpretivist approach (Parahoo 2014). Researchers using the constructivist paradigm believe that knowledge is actively created and co-created through interactions with others and the environment (Parahoo 2014, Mohammed and Kinyo 2020). Moreover, constructivists believe in shared social meanings and interpretations,

highlighting the key role of language, culture, and social interactions in shaping individuals' understanding of the world (William 2024).

This paradigm adopts an ontological position of relativism which views reality as being subjective and varied from one person to another, hence the existence of multiple realities (Walliman 2021). Researchers using this paradigm aim to interpret findings based on the view that reality exists within a context and that many constructions are possible (Polit and Beck 2021). As such constructivist researchers are advised to remain open that the constructed realities cannot be proven true or false as there are multiple interpretations of reality that exist within people's minds (Polit and Beck 2021). In addition, reflexivity is strongly recommended in this paradigm to enable researchers to be aware of their biases and assumptions throughout the research process to help navigate the complexities of understanding socially constructed realities (William 2024).

To explore how individuals' interactions and social contexts shape their beliefs and understandings constructivist researchers use qualitative methods to gather data to capture the complexity of socially constructed realities (William 2024). Case studies, phenomenology, grounded theory, hermeneutics, and ethnography are examples of research approaches suitable for this paradigm (Adom et al. 2016, Polit and Beck 2021).

Unlike the positivist approach, both the interpretivist and constructivist paradigms advocate bringing the researcher closer to those under study through interactions to understand how and why people behave the way they do (Parahoo 2014, Polit and Beck 2021). Another key difference from positivism is that evidence in interpretivism and constructivism is obtained through inductive processes with the aim of generating hypotheses (Polit and Beck 2021).

Although studies adopting the interpretivist and constructivist paradigms are said to be sensitive to individual meanings and are suitable to understand human behaviour in social contexts, their findings have limited transferability and reproducibility due to their subjective nature (Polit and Beck 2021). Also, the small sample sizes in qualitative studies have faced criticism by other researchers, but the sizes are perfectly acceptable as it is the richness and not the quantity of data that particularly matters in this paradigm. (Polit and Beck 2021). Table 8 illustrates the key differences between the positivist and the constructivist approach according to Walliman (2021).

Topic	Positivist/Realism approach	Constructivist/Relativist approach
Philosophical stance	Realism: Reality exists independent of human existence	Idealism: There is no reality without human existence, different people construct their own world in different ways
The role of research	Seeks to explore universal laws and generalisations	To reveal different interpretations of the world as made by people
The role of the researcher	Researcher: neutral observer	Actively involved as part of the research process
Theoretical approach	Objective, Rational, deductive reasoning, scientific, value-free data	Subjective, inductive reasoning, value-laden data
Methods	Experiments, mathematical models, quantitative analysis	Surveys, observations, qualitative analysis to seek meaningful relationships and the consequences of their interactions. Analysis of language and meaning

Table 8: Comparison between the positivist and relativist approaches

4.2.3: The critical paradigm

The critical paradigm adopts the ontological position of historic realism which has the view that reality is socially constructed and is influenced by factors such as social, political, cultural, economic, ethnic and gender values (Dimock 2021, Asghar 2013). The epistemological stance for this paradigm is 'subjectivism' which is based on real world phenomena and linked with societal ideology (Egon et al. 1994, Asghar 2013). Researchers in this methodology believe that what counts as knowledge is determined by social and political positions of the ones advocating that knowledge (Cohen et al. 2007). Researchers argue that people are influenced by the culture which they are born into (Crotty 1998). This methodology aims to empower the oppressed individuals by challenging injustice and conventional social structures (Crotty 1998). For this methodology, participants are involved in the research process. The methods in this approach are often dialectical or hermeneutical (Egon et al. 1994), and examples include critical discourse, critical ethnography, and action research (Scotland 2012). Although the critical methodology is useful in critically examining realities from a cultural, historic, and political stance, the paradigm is not favoured by existing policy makers due to its political influence (Scotland 2012). According to Scotland (2012), critical methodologies are deemed to be politically sensitive by some as they can enable people to see and understand the power structures that are at play in wider society or in each situation. For example, there are some people who do not like research that is underpinned by a critical approach such as feminist research or research informed by critical race theory, which they perceive to be politically motivated.

4.3: Theoretical framework

A theoretical framework consists of the selected theory (or theories) that guides a research study determining how the phenomena will be investigated (Grant and Osanloo 2014). As such, the selection of a suitable framework, which aligns with the researcher's philosophical perspective, is important when undertaking a research study. In addition, a theoretical framework provides structure and organisation to a study which allows ideas to flow throughout the study (Varpio et al. 2020). Grant and Osanloo (2014) likened a study without

a theoretical framework to a house built without a 'blueprint' (design plan) and hence advised researchers to declare the theoretical framework that will guide their studies at the outset.

The use of theoretical frameworks is debated in qualitative studies. Garvey and Jones (2021) explained that a theoretical framework may help to provide a sense of the story emerging from the analyses but warned that the framework may prevent inductive reasoning which could result in findings incongruent to the data. Therefore, they advised researchers to be clear about the ontological and epistemological positions adopted in investigating their research topic (Grant and Osanloo 2014). Furthermore, Corbin and Strauss (2015) explained that theoretical frameworks are used in grounded theory studies to justify their choice of methodology or as a guide of their research, as opposed to structuring the analysis, building upon a research programme to extend a substantive theory developed, or offering alternative explanations where more than one theory emerges from data originating from different perspectives.

4.3.1: Constructionism and constructivism

The terms 'constructionism' and 'constructivism' are at times used interchangeably in research. However, the two concepts are not the same and are rooted in different paradigms (Rees et al. 2019). For Rees et al. (2019), constructionism is a theoretical orientation based on one or more of the following assumptions described by Varpio (2017): critique of accepted ways of understanding the world and ourselves; understandings being influenced by place and time; knowledge being constructed through social interaction, especially language; and different constructions of the world producing varied reactions or behaviours, hence acknowledging a cognitive element. Bryman (2016) added that these social processes are not permanent as they are constantly evolving depending on different circumstances or conditions. The constructionism ontology believes that multiple realities exist which are dependent on interactions between the individual and the social world, with a primary emphasis on discourse through which the individuals and the social world are engaged (Varpio 2017). Hence, constructionism is based on the epistemological belief that knowledge resides in the social world where it is constructed and reconstructed based on interactions in discourses (Varpio 2017).

Conversely, constructivism is a theoretical orientation related to how individuals understand/perceive and create their own meanings from events (Rees et al. 2019). The ontological position of constructivism also accepts the existence of multiple realities which

are, however, dependent on the individuals' construction of knowledge through their unique lived experiences (Lincoln and Guba 2011). The epistemological stand in constructivism believes that individuals construct their own knowledge from lived experiences which are shaped and influenced by researchers and displayed through the interpretation of the data collected (Lincoln and Guba 2011).

The key difference between constructivism and constructionism is therefore, that constructivism focuses on the individual understanding and creating meaning from events, whereas constructionism focusses on social interactions in the processes of constructing meaning (Rees et al. 2019). According to Rees et al. (2019) qualitative methodologies and methods align with constructionism due to the role of language in social interaction and meaning making. As such, researchers are required to be precise in the application of these two terms and interpret their findings depending on the controlling force of the construction process within the given social setting (Rees et al. 2019).

4.3.2: Epistemological and ontological approach

The choice of the methodology and methods for a study is influenced by a researcher's ontological and epistemological perspectives (Crotty 1998). A researcher's chosen methodology should, therefore, reflect the researcher's views on the nature of reality and how knowledge is acquired in relation to the phenomena under study (Al-Ababneh 2020).

A constructionist ontology aligned with this study based on my view that reality is constructed through social interaction and is subjective. This implies that the registered nurses' reality and experience would vary between individuals due to their subjective interpretation of their social setting and what is happening around them. This variation would therefore generate multiple perspectives that would provide a deeper understanding of the nurses' behaviours and actions. The interaction between the researcher and the nurses in a social setting, in this case the nursing homes, demonstrated the researcher's epistemological stand which assisted in the construction of the knowledge sought in this study. The social meanings were thus reflected in the Nurses' experiences and views in caring for the people living with dementia at the end of their lives. The nurses' individual perspectives obtained from the in-depth one to one interviews provided rich data which aided in the understanding of the nurses' experiences. A constructionist qualitative design utilising grounded theory methodology was hence deemed suitable to guide this study.

Moreover, it is suggested that end-of-life care is socially constructed and mediated and that nursing homes are specific social contexts (Bryman 2016). As such, both constructionist and constructivist approaches would have been suitable to make sense of nurses' perspectives, based on their individual perspectives as well as the interactional and structural processes within the nursing home settings in relation to the end-of-life care for people with dementia.

The constructivist epistemology was adopted for this study. Out of the multiple participants' constructions regarding their experiences of end-of-life care for people living with dementia in nursing homes, the researcher was able to construct meaning in analysing the data collected. According to Corbin and Strauss (2015), researchers using this approach actively invent concepts, models, and schemes to make sense of the participants' experiences.

4.4: Overview of qualitative research

It is important for researchers to ensure that their chosen research paradigm aligns with the research questions and goals to assist them in collecting relevant data (Rahman 2023). As such, a qualitative design was employed to explore the RNs' experiences of caring for people living with dementia at the end of life in nursing homes in this study. This approach was chosen because it is an open and flexible design which helps to collect in-depth information from a participant's perspective to explore experiences of people (Parahoo 2014).

Qualitative research investigates phenomena through narratives (Bryman 2016, Polit and Beck 2021) from a person's perspectives, using flexible, holistic, and comprehensive methods aimed at extracting meanings via interactions between researchers and participants (Parahoo 2014). Qualitative research is said to be suitable for exploring the experiences of participants and discovering the meaning or significance of such experiences (Polit and Beck 2021).

The main aim of qualitative research is to obtain rich data from an individual's point of view and explore participants' subjective perception of experience (Rees 2011, Parahoo 2014, Corbin and Strauss 2015). As such, qualitative researchers strive to extract meaning via the participants' voices with description of experience related to the research question, which is the intention of the analysis (Rees 2011). Qualitative studies can also be useful in exploring areas which have not been thoroughly investigated or topics where little is known about (Polit and Beck 2021).

Furthermore, qualitative study designs can be useful in exploring complex or subjective aspects such as feelings, thought processes, emotions and feelings which cannot be translated numerically (Topping 2010). Exploring issues surrounding death and dying can trigger emotional distress or anxiety (Pugh and Whalley 2023) and discussing end-of-life care with the nurses could have caused them some level of emotional distress. As such, a subjective and interpretive research design would be suitable to capture those different emotions and perspectives and a deeper understanding as to why they occur.

Nevertheless, qualitative research has been criticised as having several limitations. Qualitative data analysis is believed to pose a challenge for researchers due to lack of standardised procedures, which makes it difficult for researchers to describe how they analysed their data in reports resulting in the robustness of the method being questioned (Polit and Beck 2021). Polit and Beck (2021) further highlight that qualitative data analyses can be time consuming due to the page by page and line by line analysis involved to generate themes and categories. Moreover, reporting qualitative research can be challenging due to word limit restrictions whereby researchers are forced to cut down a vast amount of data to meet the stipulated word count leading to valuable data being lost or inadequately presented (Polit and Beck 2021). Being aware of these limitations helped the researcher in planning this study especially in terms of maintaining rigour and time management.

The main forms of qualitative research designs include phenomenology, ethnography, case studies, narrative studies, and grounded theory (GT) (Creswell 2013). Phenomenological research focuses on the lived experiences of people and how they express them (Parahoo 2014, Polit and Beck 2021) whereas ethnographic studies involve the study of a phenomenon within their cultural contexts and aim to understand the customs of those under study (Polit and Beck 2021). Furthermore, case studies focus on exploring events around/within specific social units such as groups, populations, or individuals (Parahoo 2014). In narrative studies the investigation focusses on the story as the main object of inquiry (Polit and Beck 2021).

The specific qualitative approach chosen for this study was the Straussian GT. This type of GT aims to explore social interactions to generate a theory or theories grounded in the data (Holloway and Todres 2010). In this study individual RNs' accounts were examined to understand their experiences in providing end-of-life care to people living with dementia in nursing homes. Using this qualitative approach, the researcher was able to identify new understanding of this aspect of healthcare and generate a theory.

4.4.1: Overview of grounded theory

Grounded Theory (GT) is a qualitative research methodology developed by Barney Glaser and Anselm Strauss through their seminal work *The Discovery of Grounded Theory* (Glaser and Strauss 1967). The primary aim of GT is to generate theory that is grounded in data collected from participants' experiences and social interactions (Corbin and Strauss 2015). While theory generation remains central to GT, controversy exists regarding whether theory development concludes at the end of a study or continues to evolve as new evidence emerges. Some scholars argue that grounded theories are continually refined and tested throughout and beyond the research process as additional data support, extend, or challenge existing interpretations (Polit and Beck 2021).

Since its development, GT has been widely applied within healthcare research, particularly nursing, where it has been used to examine social processes, patient experiences, and professional practice (Singh and Estefan 2018). The methodology is considered particularly valuable for exploring areas where limited theoretical understanding exists, enabling researchers to develop explanations grounded in participants' perspectives and experiences (Hunter et al. 2011). Although initially influential within nursing research, GT has since been adopted across a wide range of disciplines because of its ability to generate conceptual understandings and theoretical explanations of complex social phenomena (Corbin and Strauss 2015).

A defining characteristic of GT is the simultaneous process of data collection, analysis, and sampling. Following initial data collection, data are analysed and emerging concepts guide subsequent sampling decisions and data collection activities. This iterative process, known as constant comparison, continues until sufficient conceptual development is achieved (Corbin and Strauss 2015). Such flexibility allows researchers to explore emerging issues in depth and develop increasingly refined explanations of the phenomenon under investigation.

Over time, GT has evolved into several distinct methodological traditions, each underpinned by different philosophical assumptions and methodological procedures. For the purposes of this study, four major GT approaches were considered: Classical or Glaserian GT (Glaser 2002), Straussian or Interpretive GT (Corbin and Strauss 2015), Constructivist GT (Charmaz 2006), and Situational Analysis (Clarke 2005). Although all four approaches share a commitment to generating conceptual understanding from data, they differ in their philosophical orientation, treatment of prior knowledge, coding procedures, researcher involvement, and views regarding theory development.

In terms of theory emergence, Classical Grounded Theory adopts a predominantly inductive approach whereby theory emerges directly from the data with minimal influence from prior assumptions (Glaser 2002). In contrast, Straussian Grounded Theory combines inductive and deductive reasoning, allowing researchers to develop and verify relationships between categories during analysis (Corbin and Strauss 2015). Constructivist Grounded Theory extends this further through the use of inductive, deductive, and abductive reasoning, recognising theory as a co-construction between researcher and participant (Charmaz 2006). Situational Analysis retains an inductive orientation but emphasises interpretive analysis of complex social situations, discourses, and contexts (Clarke 2005). Table 9 summarises the key similarities and differences between these approaches.

The comparison of these approaches informed the methodological choice for this study. In particular, attention was paid to their philosophical compatibility with the study aims, their approach to theory generation, and the level of guidance offered during data analysis. The following sections provide a more detailed discussion of each approach and the rationale for the selection of the most appropriate grounded theory methodology for this research. These approaches are now reviewed below.

Dimension	Classical GT (Glaser)	Interpretive GT (Strauss and Corbin)	Constructivist GT (Charmaz)	Situational analysis (Clarke)
Philosophical position	Positivist/objectivist	Post-positivist	Constructivist	Constructivist/Postmodern
View of reality	Single reality	Multiple viewpoints	Multiple realities	Multiple perspectives
Theory emergence	Inductive	Inductive, deductive	Inductive, deductive, and abductive	Inductive (with constructivist interpretation)
Previous Knowledge/ experience	Not accepted to avoid guiding data collection and analysis and affecting theory generation	Allowed to strengthen the overall quality of the research, categorisation, and theoretical assumptions	Acknowledges that it is impossible to erase/escape one's previous knowledge or experience	Flexible
Literature review	After analysis	Before, during, and after data collection and analysis	Flexible	Flexible
General user friendliness	Open approach requires more understanding and experience	Step by step procedures provide an explicit guidance for data analysis- easier to use especially for novice GT researchers	Flexible. Requires more understanding and experience	Situational maps can be confusing in creating categories/ identification of themes. Requires more understanding and experience
Coding	Open, selective, theoretical.	Open, axial, and selective	Initial and focussed	Situational maps are created from codes from data
Theory outcome	Formal/substantive theory	Theory or explanatory description	Constructed theory	Situational understanding
Compatibility with contemporary thinking	Adopt the original version of GT	Original version of GT reformulated- modernised to suit current period. Post modern.	Post modern	Post-modern turn A new approach to GT theorising/ regenerated & updated GT
Researcher role	Distant and detached/ neutral observer	Active analyst	Co-Constructor	Co-Constructor

Table 9: Comparison of four Grounded Theory methodology approaches. Adapted from (Glaser 2002, Clarke 2005, Charmaz 2006, Corbin and Strauss 2015)

Each GT approach is unique and may suit some contexts better or more than others (Singh and Estefan 2018). According to Singh and Estefan (2018), what determines the choice of a GT approach is the researchers' philosophical inclinations and their understanding of the philosophical perspectives of the different grounded theory approaches. Singh and Estefan (2018) therefore suggest that a researcher's ontological and epistemological stance is key in the choice of a particular GT approach, which will aid in collecting, analysing, and interpreting the data collected in their research.

In summary, Glaser's classical grounded theory can suit those researchers who believe that there is a reality to be uncovered about a phenomenon of interest, it is within human capacity to understand the reality, and that reality can manifest itself if researchers minimise personal bias and let data speak (Glaser 2002).

Strauss and Corbin's GT best suits researchers who recognize human, practical, and pragmatic limitations to fully understanding reality as it 'really' is, accept the inevitability of personal bias of the researcher, while also seeking to limit personal bias; and who maintain an objectivist perspective by (as far as possible) controlling the inquiry and systematizing it (Strauss and Corbin 1998).

Charmaz's grounded theory perspective can be suitable for studies that aim to explore and understand local issues, which may change over time as conditions change. Furthermore, the interpretive aspect of Charmaz's approach can benefit researchers who see value in and cannot separate themselves from their personal and professional experiences as well as from existing knowledge that informs their inquiry (Charmaz 2006). On the other hand, Clarke's Situational Analysis would suit research that focuses on meaning-making that furthers a relativist/perspectival understanding (Clarke 2005).

Although GT has been widely and productively used in nursing, health and social research, the method has faced criticism by other researchers. Firstly, Charmaz (2006) challenged the trust in theory emergence in this approach. Charmaz (2006) bases their argument on the belief that theories generated via GT approach rely on constructions by researchers and participants. As such Charmaz (2006) believes that the same phenomenon studied by two different researchers would produce different theories. Secondly, Comte (2013) highlighted the confusion faced by researchers intending to use GT due to the considerable evolvement of GT literature over the years. Comte (2013) suggests that researchers require a lot of time to explore the different approaches to GT and understand the jargon that goes with the approach before choosing which approach would suit their study. Despite these opinions, the

GT methodology is deemed to offer researchers a range of alternative approaches within the same broad design, hence allowing them a wider choice (Corbin and Strauss 2015).

4.4.1.1: Justification for adopting the Straussian grounded theory

GT was selected as the methodological approach for this study because it provides a systematic process for developing theory in areas where limited knowledge exists (Charmaz 2006). Corbin and Strauss (2015) advocate GT as a robust methodology for generating theory grounded in empirical data, offering researchers a well-established framework for exploring complex social processes. Furthermore, the methodology enables phenomena to be examined from multiple perspectives, is culturally sensitive, and can be applied to individuals, organisations, and wider social contexts.

Following a review of the four major GT traditions, Classical Grounded Theory (Glaser 2002) was excluded. A key principle of the Glaserian approach is that researchers should avoid drawing upon their prior knowledge and experience during data collection and analysis to minimise the influence of preconceived ideas on theory development. However, Reay et al. (2016) argue that it is difficult for researchers to completely suspend their existing knowledge, particularly when conducting research within areas of established expertise. This limitation was particularly relevant to the present study, as the researcher recruited participants from nursing home settings within her professional remit as a Nurse Assessor and possessed extensive experience in dementia and end-of-life care. Although Glaser and Strauss (1967) contend that limiting the influence of prior knowledge helps reduce bias and allows theory to emerge directly from the data, the assumptions underpinning this approach were considered incompatible with the researcher's professional background and the practical realities of the study.

Clarke's (2005) Situational Analysis was also considered. As a contemporary development of GT, Situational Analysis seeks to account for the complexity and "messiness" of social reality through the use of situational, social worlds/arenas, and positional maps. These analytical tools are designed to stimulate deeper engagement with the data and facilitate a rich understanding of the context under investigation (Clarke 2005). One of the principal strengths of this approach is its ability to encourage researchers to immerse themselves fully in the data and examine practice within complex social systems.

Despite these strengths, Situational Analysis was not selected. As a novice grounded theory researcher, the researcher found the mapping processes conceptually complex and potentially difficult to apply in practice. Furthermore, Situational Analysis is particularly suited

to studies involving multiple interacting human and non-human actors, such as technology, policy, organisational structures, and environmental factors (Clarke 2005). In contrast, the primary aim of the present study was to explore the experiences of registered nurses caring for people living with dementia at the end of life rather than to analyse the broader complexity of the care environment. Although participants were recruited from several nursing homes, the study focused on a single phenomenon and utilised interviews as the sole method of data collection. Consequently, Situational Analysis was considered less appropriate for addressing the study aims.

Charmaz's Constructivist Grounded Theory (Charmaz 2006) was also carefully considered. This approach was attractive because it acknowledges the influence of the researcher's experiences and recognises knowledge as co-constructed through interactions between researchers and participants. Constructivist GT has been identified as particularly suitable for novice researchers who may find it difficult to separate their personal and professional experiences from the research process (Charmaz 2006). Such considerations were highly relevant given the researcher's clinical expertise in dementia and end-of-life care.

However, Constructivist Grounded Theory focuses on understanding how meaning is constructed within specific social contexts and emphasises the development of contextual and interpretive understandings rather than explanatory theory (Singh and Estefan 2018). While this orientation aligned with some aspects of the study, the researcher sought a methodology that provided a more structured analytical framework and stronger procedural guidance throughout the research process.

Following consideration of all four approaches, Straussian Grounded Theory (Strauss and Corbin 1998, Corbin and Strauss 2015) was selected as the methodological framework for this study. The approach offered a systematic yet flexible process for exploring participants' experiences while acknowledging the influence of the researcher's professional background. As a novice grounded theory researcher, the researcher considered the explicit and structured analytical procedures of Straussian GT particularly advantageous. The step-by-step guidance provided for data collection and analysis enhances methodological rigour, transparency, and credibility by clearly demonstrating how findings are derived from the data (Strauss and Corbin 1998).

The suitability of this approach for novice researchers has been highlighted by de Beer and Brysiewicz (2016), who argue that the systematic procedures associated with Straussian GT provide clear practical guidance throughout the research process. Furthermore, Singh and

Estefan (2018) suggest that the structured nature of the methodology helps maintain a degree of objectivity while recognising the interpretive role of the researcher.

Straussian Grounded Theory was also considered philosophically compatible with the researcher's position. The approach recognises that researchers are unable to fully access reality as it objectively exists and acknowledges the potential influence of personal experiences and assumptions on the research process (Singh and Estefan 2018). Rather than attempting to eliminate researcher influence entirely, Strauss and Corbin advocate reflexivity and transparency to minimise potential bias. This position aligned closely with the researcher's ontological and methodological stance and informed the use of reflective journals, field notes, and analytic memos throughout the study.

A further advantage of the Straussian approach is its acceptance of literature engagement before, during, and after data collection and analysis (Sebastian 2019). This flexibility was particularly beneficial given that a scoping literature review was undertaken at the outset of the study to establish the current state of knowledge, identify evidence gaps, and ensure that the research addressed an area requiring further investigation (Munn et al. 2022). The ability to engage with the literature throughout the study was therefore consistent with both the study design and the research objectives.

In addition, Straussian Grounded Theory recognises that researchers inevitably bring prior knowledge, expertise, and professional experience to the research process (Sebastian 2019). This was an important consideration given the researcher's extensive background in dementia and end-of-life care. To ensure methodological rigour and reduce the potential influence of bias, reflexive accounts, field notes, and analytic memos were maintained throughout the study, providing an audit trail of the researcher's thinking and decision-making processes (Strauss and Corbin 1998).

Finally, Straussian Grounded Theory is particularly useful for understanding social processes within specific contexts (Corbin and Strauss 2015). The methodology facilitates exploration of how individuals perceive, interpret, and enact their roles within complex social environments while recognising the influence of organisational, cultural, political, and policy-related factors. This focus was highly relevant to the present study, which sought to explore registered nurses' experiences of caring for people living with dementia at the end of life within nursing home settings.

The adoption of Straussian Grounded Theory therefore provided a coherent methodological framework for exploring the social interactions, experiences, and processes associated with

end-of-life dementia care in nursing homes. Although the researcher acknowledged that the findings may have limited transferability beyond the study context, it was anticipated that the insights generated would hold relevance for other nursing home settings and comparable care environments (Parahoo 2014).

4.5: Summary of chapter

This chapter outlined the philosophical foundations and methodological decisions that guided this study. The key research paradigms were introduced which included positivist, interpretivist, constructivist, critical, highlighting their assumptions about reality, knowledge, and the researcher's role. The chapter explained how constructivist and constructionist perspectives emphasise socially constructed, subjective realities and the co-creation of meaning through interaction, leading the researcher to adopt a constructionist ontology and constructivist epistemology for this study.

A qualitative design was selected for its ability to capture rich, in-depth accounts of registered nurses' experiences of end-of-life care for people with dementia in nursing homes.

The chapter has also evaluated four variants of GT; Classical, Straussian, Constructivist, and Situational Analysis, and compared their philosophical assumptions, coding processes, and use of prior knowledge. The Straussian GT approach was ultimately chosen because it aligns with the researcher's worldview, provides systematic step-by-step analytic procedures suitable for novice researchers, allows incorporation of prior knowledge, and supports rigorous, transparent theory development grounded in participants' accounts. This methodology is viewed as particularly appropriate for understanding social processes within nursing home environments, despite its limitations related to transferability in qualitative work.

The following chapter presents the methods employed in the conduct of this study.

Chapter 5: Research methods

5.1: Introduction

This chapter presents a discussion of the methods employed in this study. The discussion includes the sampling process, sample details, a description of the study settings, recruitment of study participants, and data collection and analysis. The section also outlines how theoretical saturation was achieved. A discussion of rigour of the study and reflexivity has been provided towards the end of the chapter.

Research methods are techniques and procedures/tools that are used to conduct a study (Corbin and Strauss 2015, Polit and Beck 2021, Walliman 2021) which are relevant to a research question (Polit and Beck 2021) particularly pertaining to data collection and analysis (Corbin and Strauss 2015). The methods of a study are chosen based on the study methodology which is informed by the researcher's theoretical perspectives (Crotty 1998). A discussion of the methods employed in this study is presented in the following sections which include selection of study setting, sampling and recruitment of participants, data collection, management, and analysis.

5.2: Sampling

The choice of the type of sampling depends on the study design (Lacey 2010). Qualitative research focuses on identifying key individuals, events, or settings to obtain rich data (Procter et al. 2010). As such, this study aimed to explore the experiences of RNs in caring for people living with dementia at the end of life. Staying in line with GT approach, purposive and theoretical sampling was therefore, suitable for selecting participants for this GT study (Lacey 2010, Oktay 2012). The participants for this study included RNs (RGNs and RMNs) who had the experience of caring for people living with dementia at the end-of-life in nursing homes.

5.2.1: Purposive sampling

According to Rees (2011) purposive sampling is a process whereby a researcher selects participants based on their knowledge of characteristics they know the participants possess. At the outset of this study, a purposive sampling approach was used to recruit RNs from the first nursing home identified to participate. These participants were selected because of their rich nursing experiences of caring for people living with dementia at the end of life in nursing homes. These nurses were directly involved in the provision of end-of-life care for people living with dementia. The analysis of the first four interview data guided further sampling to recruit other participants that were not initially sampled, to find answers to questions that evolved from preliminary analysis which is referred to as theoretical sampling (Corbin and Strauss 2015).

5.2.2: Theoretical sampling

In this study, data collection and analysis were done simultaneously, and the process was repeated until each category was well developed in terms of density and variation which is in line with the Straussian GT methodology (Corbin and Strauss 2008; 2015). Procter et al. (2010) define theoretical sampling as “further sampling in response to data analysis” (p.149). Theoretical sampling is considered a key component of sampling in qualitative, and specifically GT studies (Lacey 2010, Corbin and Strauss 2015). However, a systematic review conducted by McCrae and Pursell (2016) which investigated the use of theoretical sampling in grounded theory studies in nursing journals revealed that the theoretical sampling approach was not always correctly conveyed in the GT studies reviewed. In their study, McCrae and Pursell (2016) found that a high proportion (86%) of the 134 articles reviewed described an iterative process of data collection and analysis. However, half of the studies reviewed did not demonstrate theoretical sampling, with many studies declaring or indicating a purposive sampling approach throughout. These findings highlighted the risk of GT becoming indistinct from other qualitative research approaches if the methodology is not appropriately applied.

Theoretical sampling aims to collect data from sources such as places, people, and events to assist in developing concepts and categories by identifying variations and relationships between the concepts (Corbin and Strauss 2015). However, Corbin and Strauss (2015) argue that theoretical sampling involves sampling concepts and not people. Furthermore, Corbin and Strauss (2008) suggest that the open and flexible approach involved in

theoretical sampling is what allows researchers to follow the leads of the concepts and redirect data collection to other participants, which aids the development of a theory.

During the theoretical sampling phase, participants are selected based on the new concepts being identified to develop the categories further (Polit and Beck 2021). Corbin and Strauss (2015) recommend that the researchers go to places, people or situations that can provide more information regarding the concepts they want to develop, which then directs the questions that need to be asked in the subsequent interviews, implying that data analysis leads to concepts and the concepts will then generate questions for subsequent interviews.

In this study, theoretical sampling was guided by the outcomes of the Straussian stages of coding: open, axial, and selective which are discussed further down this chapter. Following the data analysis of the initial four interviews from one nursing home, the study moved to the rest of the participants with a diverse range of demographic characteristics being recruited from the four nursing homes. Further theoretical sampling was directed by the analytical outcomes of the concepts that were developed during concurrent data collection and analysis, hence remaining consistent with the Straussian approach. At this point, the researcher identified concepts related to the end-of-life care that the nurses provided to the people living with dementia in nursing homes. As such, the researcher proceeded with a further theoretical sampling to clarify these concepts. This process continued until data saturation was attained. 'Saturation' is described as the point where no new concepts are arising from the data analysis (Rees 2011, Strauss and Corbin 1998, Corbin and Strauss 2015), and when all categories, their properties and dimensions, and links between the categories are well developed, marking the end of data collection (Procter et al. 2010, Corbin and Strauss 2015).

Constant comparison is key in facilitating theoretical sampling (Corbin and Strauss 2015). In this process data are compared with other data, and coded data are constantly confronted with new data for verification (Corbin and Strauss 2015). Furthermore, Bagnasco et al. (2014) elucidate that unlike conventional sampling, theoretical sampling is responsive to the data rather than being pre-established at the onset of a study, which enables sampling to be more specific. In this study the researcher compared the data obtained from each participant and noted any similarities or differences in the accounts. The researcher also constantly reviewed the codes developed to see if there were any similar or new ones identified. This process assisted the researcher to identify any gaps in the data or the concepts that required further clarification.

5.3: Sample

A sample is a section of a specific population in a study intended for data collection (Rees 2011) which is used to answer a research aim (Gentles et al. 2015). According to Polit and Beck (2021), the participants in a study collectively form a sample. Following purposive and theoretical sampling, the participants for this study were recruited. The details of this sample are presented below under the sections: participant characteristics and sample size.

5.3.1: Summary of participant characteristics

The key aspects of the participants characteristics that were collected during the study included name, nursing home they worked in, age, self-identified gender, professional registration, years of practice in nursing homes, current grade, cultural background, and religious background. The relevance of these characteristics is explained in table 10.

Characteristic	Relevance
<i>Pseudonym</i>	This information is needed to be able to identify the accounts from each participant while maintaining confidentiality.
<i>Nursing home</i>	This was the participants' place of work.
<i>Age</i>	May contribute to participants' level of experience regarding death and dying and end-of-life care. Older participants may have encountered more deaths compared to the younger ones hence more experience. In addition, different generations may have different beliefs and practices relating to death and dying.
<i>Self-identified gender</i>	Different genders may view death and dying differently.
<i>Professional registration</i>	May indicate specific area of training. Approach to care may be different in some cases between RGNs and RMNs.
<i>Years of experience in nursing homes</i>	May indicate level of experience in end-of-life care for people living in nursing homes. Approach to care may be different between acute and long-term care settings.
<i>Professional standing</i>	May indicate level of responsibility or leadership/decision-making role in the end-of-life care delivery system.
<i>Cultural background</i>	Death and dying are physical processes that have socio-cultural aspects. Therefore, the way death and dying are understood by people and what they do in relation to both things is influenced by socio-cultural factors.
<i>Religious background</i>	Religion, faith, and spirituality influence the way in which people experience, understand, make sense of, and cope with death and dying.

Table 10: Relevance of participant characteristics

The participants' ages ranged between 30 and 70 years, with most of them being between 40-50 years ($n = 7$) and 50-60 years ($n = 8$). Two participants were aged between 30-40 years, and one was above 60 years. This study sample comprised of participants who identified as female except for two participants who identified as male. Fifteen participants were registered general adult nurses (RGNs), and three participants were registered mental health nurses (RMNs). The participants' experiences of working in a nursing home ranged between 1-17 years with most participants having worked in nursing homes for a period of 5 to 10 years. Most participants were working as staff nurses in the nursing homes except for five participants from two of the nursing homes who were employed in management positions and were classified as senior nurses. The participants had diverse cultural backgrounds but predominantly identified as British. In their accounts, most participants said that they had religious beliefs arising from the two of the Abrahamic religions, that is, Islam and Christianity. One participant stated that they did not have any religious belief.

Pseudonyms have been used to replace the participants' real names to maintain anonymity. The study took place in four nursing homes all within the South Wales area. The names of these nursing homes have not been disclosed for confidentiality and anonymity purposes, instead tree-based pseudonyms are used to identify each care setting. The details of the sample characteristics are outlined in Table 11.

Pseudonym	Nursing Home	Age range (years)	Self-identified gender	Prof. reg.	Years of practice in nursing homes	Professional standing	Self-reported cultural background
Grace	Oak	40-50	F	RGN	10-15	Nurse	White British
Ivy	Oak	40-50	F	RGN	15-20	Nurse	White British
Lily	Oak	50-60	F	RGN	5-10	Senior Nurse	White British
Rose	Oak	40-50	F	RGN	5-10	Nurse	White British
April	Ash	40-50	F	RGN	1-5	Senior Nurse	White British
Ben	Cedar	50-60	M	RMN	20-25	Nurse	White British
Emily	Ash	50-60	F	RGN	10-15	Nurse	Afro-Caribbean
Florence	Ash	60-70	F	RGN	1-5	Senior Nurse	White British
Hannah	Ash	50-60	F	RMN	5-10	Senior Nurse	Afro-Caribbean
Jane	Ash	40-50	F	RGN	1-5	Nurse	White British
May	Ash	50-60	F	RGN	15-20	Nurse	White British
Norman	Ash	30-40	M	RMN	1-5	Nurse	Mixed British
Pam	Holly	40-50	F	RGN	5-10	Senior Nurse	White British
Summer	Cedar	30-40	F	RGN	1-5	Nurse	White British
Tina	Holly	40-50	F	RGN	10-15	Nurse	East Asian
Cara	Holly	50-60	F	RGN	10-15	Nurse	East Asian
Dawn	Cedar	50-60	F	RGN	1-5	Nurse	White British
Winifred	Cedar	50-60	Female	RGN	1-5	Nurse	Eastern European

Table 11: Sample characteristics

5.3.2: Sample size

Sample sizes in qualitative studies are generally small ranging from four to fifty participants (Holloway and Wheeler 2010). Creswell (2013) considers a smaller sample of five to twenty-five participants to be ideal in achieving detail in GT studies. Although larger sample sizes are recommended to ensure representation of the population (Polit and Beck 2021), Procter et al. (2010) suggest that what matters most in qualitative research is not the total number of participants but the identification of individuals, settings and events that provide a rich source of data through a well-planned and thoughtful sampling strategy.

This study involved a total of eighteen RNs. In the first phase of data collection, four interviews were conducted in the first nursing home (Oak) where participants were identified using purposive sampling. Further interviews were conducted using theoretical sampling - two from the second nursing home (Holly), a further two from the third nursing home (Cedar), and seven from the fourth nursing home (Ash). The final theoretical interviews were conducted from two nursing homes: two from Cedar, and one from Holly as the nurses from these homes were suitable to clarify the concepts.

Furthermore, according to Procter et al. (2010), a sampling strategy should be designed in a study to help in identifying a study population and determining how best to select a sample from it. In this study, an inclusion and exclusion criteria were used to assist in the sample selection process (see Table 12).

Inclusion criteria	Exclusion criteria
RNs (RGNs or RMNs) involved in caring for people living with dementia at the end of life	Other staff involved in caring for people living with dementia at the end of life
RNs (RGNs or RMNs) with experience of caring for people living with dementia at the end of life of at least a year and over (to demonstrate sufficient experience of end-of-life care for people living with dementia)	RNs (RGNs or RMNs) with experience of caring for people living with dementia at the end of life of less than a year
RNs (RGNs or RMNs) working in nursing homes	RNs (RGNs or RMNs) working in other care settings
RNs (RGNs or RMNs) who gave consent to participate in this study	RNs (RGNs or RMNs) who did not give consent to participate in this study

Table 12: Sampling inclusion and exclusion criteria

In GT studies, sample sizes are not explicitly predetermined at the onset of a study according to Strauss and Corbin (1998). Sim et al. (2018) further explain that having a priori sample size (a sample size calculated prior to commencement of a study before the design and planning stage) may be incompatible with notions that underpin qualitative research, hence they advise that further sampling and analysis should continue until theoretical saturation of each category is reached.

With the aim of obtaining rich and sufficient data, there was no rigid rule of a sample size in this study (Corbin and Strauss 2015). When this study commenced, the researcher and her supervisors discussed and envisaged that data saturation would occur at some point between 12-20 interviews based on similar Straussian GT studies on other topics. The sample was intended to include RNs (RGNs or RMNs) who were working in the nursing homes and who engaged in the provision of end-of-life care for people living with dementia.

5.4: Study setting

A setting is described as the physical location where research data is collected (Polit and Beck 2021) whereas a context widely covers the environment/location and the conditions in

which a study takes place, as well as the culture of the participants and location (Holloway and Galvin 2017). The context of a study is useful in explaining the actions and interactions going on within a research setting (Corbin and Strauss 2015).

The selection of a suitable study setting is crucial when conducting a qualitative study (Holloway and Galvin 2017) to ensure information richness (Polit and Beck 2021).

Researchers are expected to collect data in a setting where participants experience the issue under investigation to generate suitable data (Denzin and Lincoln 2005). It was suitable to recruit nurses working in nursing homes because this is one of the places where people living with dementia receive end-of-life care which was the focus of this study. Therefore, this study was conducted across four nursing homes in South Wales that were purposively selected.

During the conduct of this study, it was also important to ensure that the chosen setting would provide data relevant to answer the research question, as is suggested by Holloway and Galvin (2017). Each one of the selected nursing homes provided end-of-life care for people living with dementia, which was suitable to provide relevant data to answer the question for this study.

Furthermore, the choice of a study setting depends on the researcher's intimate knowledge of and their professional relationship with the area (Holloway and Galvin 2017). The nursing homes in this study were selected based on the good professional relationship that the researcher had with all the nursing home managers and staff in her role as a Nurse Assessor which eased approachability and access. The researcher's role as Nurse Assessor also increased her familiarity with the settings. Moreover, from her previous experience, the researcher had the knowledge that each one of the selected nursing homes provided end-of-life care for people living with dementia, which allowed the researcher to collect data that would assist in answering the study question. Out of the five nursing homes that were contacted, four agreed to take part in the study. One nursing home was unable to participate because of the timing of the study. The nursing homes were chosen because they were involved in the care of people living with dementia, but they also fell within the remit of the researcher's role, which eased accessibility.

However, the four nursing homes offered different perspectives in terms of care as they were owned by different organisations which presented variations in terms of staff behaviours and culture. Different ownership of the nursing homes could mean variations in the way that end-of-life care for people living with dementia was organised and delivered such as number of beds, type of patients, opportunities for staff training, staff-resident ratios,

staff skill mix, and leadership/management style. As such, collecting data from different homes could be helpful in providing different perspectives into the delivery of end-of-life care for residents with dementia. The differences between these homes will be discussed in the analysis section. The details of the four nursing homes involved in this study are outlined in Table 14.

5.5: Access and recruitment of participants

The success of a research study relies on the recruitment of participants who are accessible and willing to take part (Creswell 2013). In this study, negotiations to access the research participants and settings were made possible with the support of the managers of the nursing homes who functioned as gatekeepers. In qualitative research, a gatekeeper is described as the individual in a study setting with control over a researcher's access to the study setting or participants (Rees 2011). All four managers gave written permission/consent for access and the study to be conducted in their nursing homes (see letters in Appendix iii). After obtaining ethical approval from the School of Healthcare Sciences Research Ethics Committee (SREC) (details in Appendix ii) in December 2020, the researcher made appointments to meet with each manager of the four identified nursing homes. Nursing home managers have an overall responsibility for all nursing activities and staff within their nursing homes and that is why it was practical for them to function as gatekeepers for this study.

During these meetings, the researcher brought to the attention of the nursing home managers the ethical approval letter from the SREC, copies of which had been sent to each manager via email prior to the meetings. The purpose of the meeting was to discuss the details of the proposed study. Practical issues on the conduct of the study were discussed such as recruitment of participants, the convenient days, time, and venue for the interviews, and a schedule of the activities in the nursing homes. The participant' information sheet was also reviewed so that the areas that were not clear to the managers were clarified, and questions answered. Fortunately, all four managers were enthusiastic and confirmed support for the study. The role of the managers as gatekeepers in the recruitment process was also discussed and agreed. The tasks agreed for the managers to perform included allowing access into the nursing homes, displaying poster adverts in the designated places (Appendix iv), ensuring interview venues were ready on the dates agreed, acting as go-betweens between the researcher and the participants by facilitating smooth communication, and communicating any changes to the interview plans.

Furthermore, the researcher requested the managers to assist in the identification of potential study participants. With the managers' permission, the researcher introduced herself and the proposed study to RNs in the nursing homes and invited them to take part during staff meetings and handover meetings. Participant information packs were then sent via email to those who expressed interest. The information packs consisted of invitation letters, participant information sheets, study poster, and consent form (see Appendix v). The RNs were also given the researcher's contact details in case they needed any clarification about the study, or to confirm their agreement to take part in the study. The RNs were given a timeframe of three to five days to respond after distribution of the study information. A closing date for receiving participant responses was confirmed with all involved. In total 37 RNs across the nursing homes were contacted and all agreed to take part: Ash = 6; Cedar = 10; Holly = 12, and Oak = 9. The researcher then gave the RNs details about how interviews will be arranged and conducted. A summary of the recruitment timeline is illustrated in Figure 4.

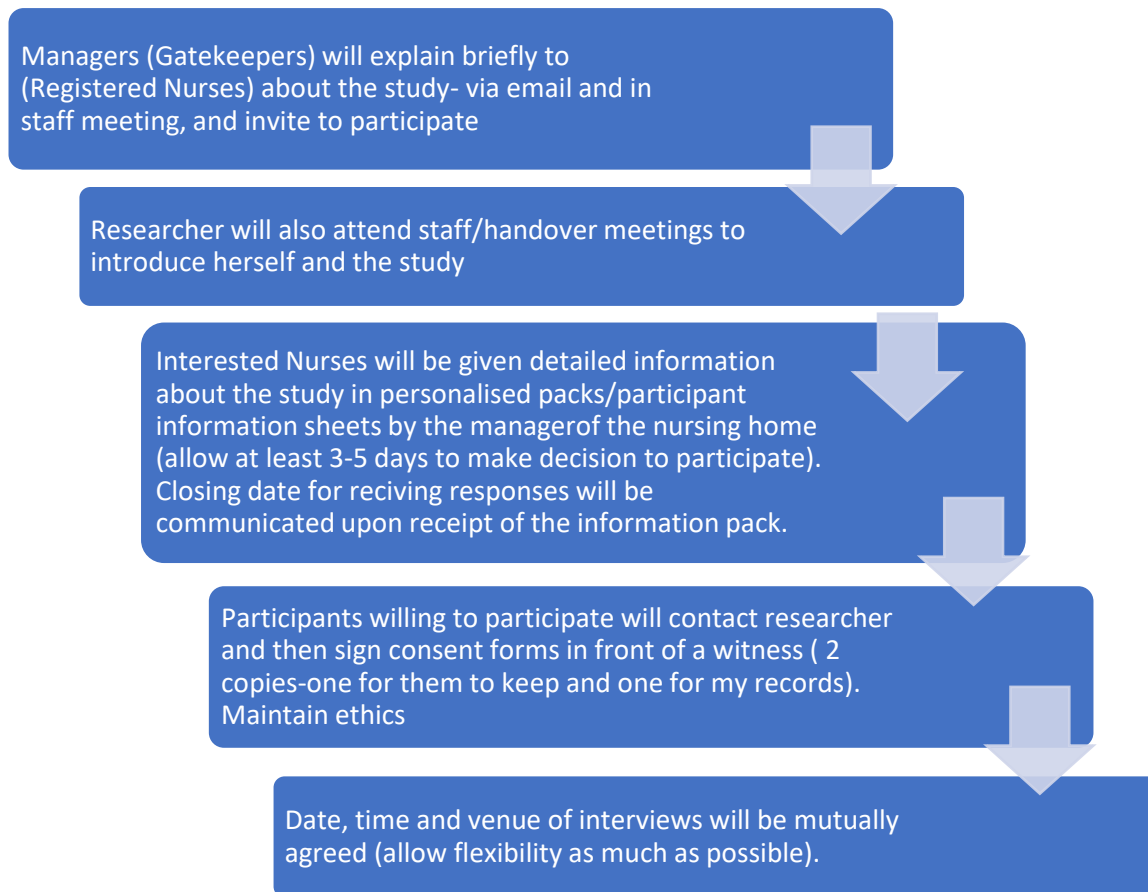


Figure 4: Timeline for recruitment of study participants

5.6: Data collection

Interviews are one of the sources for data collection in GT studies (Corbin and Strauss 2008, Rees 2011) alongside others such as observations, focus group discussions, historical documents, newspapers, videos, diaries, memoirs, and biographies (Corbin and Strauss 2008; 2015). A researcher may choose to use one or several of these methods in isolation or in combination depending on the topic under investigation (Corbin and Strauss 2015).

In this study, individual in-depth semi-structured face-to-face interviews with the RNs were conducted. Individual interviews were chosen to collect data because of the restrictions of the COVID-19 pandemic, and because the researcher wanted data with greater depth to explore the nurses' experiences. In addition, due to the pandemic, virtual interviews via skype or Zoom were offered as an alternative. However, all participants preferred face-to face interviews. The researcher was allowed access into the nursing homes despite the

COVID-19 restrictions due to her role as a Nurse Assessor. Nurse Assessors continued to visit nursing homes during this period for duties such as monitoring and to complete fast track assessments. The researcher, therefore, planned the interviews around these visits in liaison with the nurses. A detailed explanation of these data collection activities has been provided in the section below.

5.6.1: Semi-structured interviews

Corbin and Strauss (2015) recommend semi-structured interviews as one of the suitable approaches in collecting data in GT studies. Strauss and Corbin (2015) consider semi-structured interviews to be suitable for their methods because they allow the researcher to maintain consistency during each interview. Moreover, Rees (2011) considers the flexibility of semi-structured interviews to be helpful as it enables the researcher to probe key areas, developing the depth of data required for this research. It is also suggested that semi-structured interviews allow participants to be in control and hence feel more valued (Polit and Beck 2021). Individual face-to-face semi-structured interviews were therefore deemed suitable to explore the experiences of RNs of caring for people living with dementia at the end of life in nursing homes.

Additionally, the use of face-to-face interviews was ideal in maintaining rapport with participants which would enable them to feel more relaxed to express their thoughts and experiences (Rees 2011). The face-to-face interviews also allowed the researcher to read and respond to the participants' body language and emotional response in real-time (Tod 2010).

In this study, interview guides were used to direct the interviews and provide a broad structure which allowed the researcher to maintain consistency and remain focused during the interviews (Rees 2011, Corbin and Strauss 2015). The interview guides that were developed have been explained further in the following section.

5.6.2: The interview guide

Interview guides contain loosely formed questions, topics, or subjects around the area of study, which are used flexibly to direct the interview process (Rees 2011). Interview guides are useful in facilitating a consistent approach in data collection whilst allowing for flexibility to further explore other areas that require clarification or further probing that may have been omitted (Flick 2014). The interview guide for this study was developed from the results of the

scoping literature review that the researcher conducted and was approved by the ethics committee prior to commencement of data collection (see Appendix vi for details of the interview guide used in this study).

The interview guide consisted of open-ended questions, as recommended by Strauss and Corbin (1998), which allowed the participants a chance to tell their stories freely without restriction (Polit and Beck 2021, Corbin and Strauss 2015). The questions focussed on exploring the RNs' experiences of caring for people living with dementia within a nursing home setting. These experiences were in terms of the nurses' role in end-of-life care for people living with dementia, identification of care needs, challenges in care delivery, teams involved, associated training, and the impact of the COVID-19 pandemic on care delivery.

Pretesting a data collection tool using a small sample is recommended to estimate the time it will take to administer, identify questions that may be difficult to understand and areas that may need more probing, evaluate whether the tool yields sufficient data and variability, and identify any potentially sensitive questions (Polit and Beck 2021). As such, two pilot interviews were conducted involving two RNs in one nursing home in the area. The interview schedule worked well hence no amendments or modifications were required. The pilot interviews however, helped the researcher in estimating the duration of the interviews and, as a new researcher, learn how to probe further to allow a participant to expand their explanation fully.

5.6.3: Conduct of the interviews

The interviews were conducted within the participating nursing homes, which constituted the RNs' usual working environments. Conducting the interviews in familiar surroundings was intended to promote participant comfort and facilitate open discussion of their experiences (Corbin and Strauss 2015). To optimise privacy and minimise interruptions, interviews were undertaken in designated private rooms within the nursing homes (Rees 2011). All interviews were conducted in English, the formal language of communication within both the local area and the participating nursing homes. Data collection took place between February 2021 and December 2021, after the third and last national lockdown (see Figure 2: COVID-19 timeline in Wales: lockdowns, declarations, milestones and data collection, and Table 13: Sample chart with interview details).

The purpose of the interviews was to explore the experiences of RNs caring for people living with dementia at the end of life within nursing home settings. Interviews are considered most

effective when conducted at a location and time that are mutually convenient for both the participant and the researcher (Dempsey et al. 2016). Participants therefore elected to be interviewed during their own time, typically before or after their work shifts. In recognition of the demands placed upon nursing staff, particularly during this period, the researcher adopted a flexible approach to scheduling and accommodated changes necessitated by personal or professional commitments, including illness and staff absences.

Prior to each interview, participants were welcomed and thanked for their willingness to contribute to the study. The informed consent process was reviewed, and written consent was confirmed before data collection commenced. The researcher then explained the purpose of the study and the interview process in order to foster a relaxed and supportive environment in which participants felt comfortable sharing their experiences and perspectives. Participants were reminded that their involvement was entirely voluntary and that they retained the right to withdraw from the study at any stage without any consequence. They were also given the opportunity to seek clarification regarding any aspect of the participant information sheet. All participants indicated that they understood the aims of the study and were comfortable proceeding with the interview.

The rationale for audio-recording the interviews was explained prior to commencement. With participants' consent, all interviews were digitally audio-recorded using an encrypted recording device accessible only to the researcher, thereby ensuring data security and confidentiality. The recordings were subsequently transcribed verbatim for analysis. Audio recording of the interviews enabled the researcher to focus more on the interview questions, and participant responses, non-verbal language, and to maintain good rapport with the participants, rather than focusing more on taking detailed notes during the interview (Holloway and Galvin 2017).

The majority of interviews conducted for this study elicited emotional responses from both participants and the researcher-interviewer. As participants reflected on their experiences of providing end-of-life care for people living with dementia during the COVID-19 pandemic, a range of emotions emerged, including sadness, anger, frustration, and disgust. Participants' accounts also had a considerable emotional impact on the researcher. Following many of the interviews, the researcher spent time reflecting on the conversations and processing the emotions they had evoked. On one occasion, after completing an interview in a nursing home, the researcher remained in her car for some time before driving home, having become overwhelmed with emotion and tearful. This reaction was unexpected and highlighted the extent to which the emotional demands of conducting research on such a

sensitive topic had been underestimated. Upon returning home, the researcher engaged in a number of self-care activities, including taking a bath and going for a walk with her son, to help manage the emotional distress she was experiencing.

Recognising the potential implications of this experience, the researcher arranged a meeting with her supervisory team to reflect on the interview and seek guidance on managing similar situations in the future. This proved to be a valuable learning experience, reinforcing the importance of attending not only to participants' wellbeing but also to the emotional wellbeing of the researcher. Furthermore, it highlighted the need for appropriate mechanisms of emotional support, ongoing reflexive practice, and self-care when undertaking research involving sensitive and emotionally demanding topics.

The researcher completed reflective accounts following the interviews to capture her thoughts, feelings, decisions, and personal views which would be useful in analysing and interpreting the data, keeping an audit trail, and track researcher bias. In addition, detailed field notes were documented during and immediately following each interview to capture contextual information, non-verbal behaviours such as facial expressions, and the researcher's observations and reflections. These field notes formed an important component of the dataset and contributed to the richness and depth of the analysis (see an example of a field note and reflective account in Appendix vii and viii respectively).

At the conclusion of each interview, participants were thanked for their valuable contribution to the study. The researcher clarified that no further direct involvement would be required and explained how the study findings would be disseminated. Interview duration averaged approximately 35 minutes, although some interviews were longer or shorter depending on the depth and breadth of participants' responses. A summary of interview durations is presented in Table 13.

Pseudonym	Nursing Home	Interview duration	Interview date
Grace	Oak	22 minutes	26/02/2021
Ivy	Oak	28 minutes	23/02/2021
Lily	Oak	26 minutes	23/02/2021
Rose	Oak	31 minutes	26/02/2021
April	Ash	48 minutes	19/04/2021
Ben	Cedar	65 minutes	27/03/2021
Emily	Ash	28 minutes	21/04/2021
Florence	Ash	25 minutes	13/04/2021
Hannah	Ash	40 minutes	13/04/2021
Jane	Ash	29 minutes	13/04/2021
May	Ash	54 minutes	19/04/2021
Norman	Ash	18 minutes	13/04/2021
Pam	Holly	30 minutes	24/03/2021
Summer	Cedar	26 minutes	27/03/2021
Tina	Holly	25 minutes	24/03/2021
Cara	Holly	29 minutes	21/04/2021
Dawn	Cedar	56 minutes	21/04/2021
Winifred	Cedar	53 minutes	20/12/2021

Table 13: Sample chart with interview details

5.6.4: Transcribing interviews

Transcribing data involves converting audio data to written form in narrative form of analysis (Lathlean 2010). This process is considered pivotal in qualitative data analysis as it ensures that interview data are participants' actual verbatim responses (Kowal and O'Connell 2014, Polit and Beck 2021). Holloway and Galvin (2017) advise novice researchers to be actively involved in the transcription of their interviews as it helps them to immerse in the data and become sensitive to the issues of importance. Furthermore, careful reading and listening of the audio-recordings is advised as it enables researchers to focus on the participants' words, hence promoting accurate and in-depth analysis and interpretation (Holloway and Galvin 2017). Burns and Grove (2009) advise researchers to add non-verbal cues captured during interviews such as tone of voice and pauses which may indicate emotions or emphasis. In this study the researcher added the captured non-verbal cues noted on her field notes to the

transcriptions to add meaning and emphasis to the participants' accounts which was useful for the analysis.

The transcription process although often lengthy, taxing, and costly (Lathlean 2010, Holloway and Galvin 2017), is considered a crucial step in qualitative research (Loubere 2017). Being a novice researcher eight of the interviews for this study were transcribed manually by the researcher herself for experience. However, due to time constraints, the researcher sent the remaining ten interviews to a professional transcriber. Although using the professional transcription services saved the researcher time, the transcription fees incurred were quite costly. However, the researcher felt that the benefit of saving time outweighed the cost.

Stuckley (2014) in support advises researchers to produce full interview transcripts even if time is an issue because bias can occur if the researcher analyses the data without careful examination of the actual transcriptions. Carter (2004) adds that full transcription is essential because it facilitates the researcher's interaction with the data to clearly illuminate the meaning of participant's voices (Carter 2004). Being a novice researcher, completing some of the transcriptions independently was a valuable learning experience which enabled the researcher to interact with the data by going over the data for several times. The researcher was aware of the impact getting help with the transcription would have on the analysis of the data. As such she made sure that on receipt of the transcriptions from the professional transcriber, she read each one of them carefully to correct any errors or clarify any views of the participants that the transcribers could have misunderstood/mis-presented, to add notations, and to interact and familiarise herself with the data.

The researcher ensured that data protection was adhered to and reviewed the transcription company data protection policies, procedures, and certificates prior to sending off the interview transcripts. All transcripts were therefore password protected and anonymised ensuring that the participants' names were removed, as well as identifiable variables such as workplace, place of birth, profession, or any name used in the document (Stuckley 2014).

5.7: Data management

In this study the researcher made sure that research documents such as field notes, reflective journals, memos, audio-recordings, transcripts, and signed consent forms were stored securely. All paper research data, such as consent forms, were stored in a locked cabinet in the researcher's office at work, which was accessible to the researcher only, thus

complying with Cardiff University Data Protection policy and research governance guidance. In normal circumstances, the paper research documents would have been stored on Cardiff University premises, but due to the pandemic, access was restricted which made the researcher to seek an alternative safe storage space. All electronic versions of the research documents such as MP4 interview files, transcripts, memos, reflective journals, and field notes were kept in password protected files that were accessible by the researcher only.

Furthermore, pseudonyms were used on all the interview transcripts to protect the identity of the participants. Anonymised research data was shared with the researcher's supervisors only when necessary for supervision purposes. Participants were also reassured that only anonymised data would be analysed and disseminated in academic journals and conferences to protect their identity. Participants were informed that all the data would be destroyed after the completion of the study in line with the Cardiff University data retention policy/schedule.

5.8: Data analysis

Data analysis for this study was commenced immediately after completing the first interview, and thereafter following each subsequent batch of interviews, keeping in line with the GT methodology (Corbin and Strauss 2008; 2015). Data analysis involves a systematic organisation and synthesis of research data (Polit and Beck 2021). According to Holloway and Todres (2010), in GT studies the data analysis process is iterative (the researcher goes back and forth throughout the course of the research updating and revising concepts), and interactive (researchers are immersed in constant comparison. Corbin and Strauss (2015) explain that the process of data analysis goes on until the researcher reaches theoretical saturation where new concepts can no longer be found from the data. The researcher in this study conducted the data analysis in line with the tenets of Straussian GT with constant comparison under the supervision and guidance of her supervisors with due reflexivity to generate a theory.

In this study, data was collected from the four nursing homes to help in providing different perspectives into the delivery of end-of-life care for the residents with dementia. Key similarities and differences among these nursing homes were identified which will be discussed in the cross-case analysis that follows below.

5.8.1: Cross-case analysis

5.8.1.1: Introduction

This cross-case analysis examines the four nursing homes that were included in this study; Ash, Cedar, Holly, and Oak (see table 14). The comparison considers key organisational characteristics, including ownership, organisational context, leadership and management, staffing, specialist education, communication, and organisational culture. Examining these characteristics across the four nursing homes provides a broader understanding of the contextual factors that facilitated or constrained dementia end-of-life care.

	Nursing home			
	Ash	Cedar	Holly	Oak
Management model	Supportive leadership	Coaching style leadership	Strategic and supervisory roles	Strategic and supervisory roles
Ownership	Private	Private	Private	Private
Beds	76	73	78	45
Home age	11 years	22 years	9 years	4 years
Location	Urban	Urban	Urban	Urban
Residents admitted from	Local area and surrounding counties	Local area and surrounding counties	Local area and surrounding counties	Local area and surrounding counties
Residents' age	65+	65+	65+	65+
Service	Residential care	Residential care	Residential care	Residential care
Type of care	General nursing and dementia	General nursing and general residential including dementia	General nursing and dementia	General nursing and dementia
Dedicated end of life beds	None	None	None	None
Dedicated dementia beds	57	None	16	None
Carers (NAs and HCAs)	93	48	56	42
Qualified nurses	6	10	12	9
Staff turnover	Low	High	High	Low
Deaths/year	22 (17%)	25 (34%)	19 (24%)	22.2 (49%)
Deaths in 2020	32	38	18	17
Deaths in 2021	18	35	20	23
Bespoke end of life care training	No (in-house training)	No (in-house training)	Training by the local hospice and in-house training	Formal post-graduate education and in-house training
GSF status (Does the home use this training?)	No	No	No	No

Table 14: Details of the nursing homes involved in this study

5.8.1.2: Key findings

This section presents the key findings of this cross-case analysis under the following sub-headings: context, ownership and location, management style, capacity, longevity, and mortality rates, staffing levels and turnover, and specialist care and training.

Context

Ash, open for eleven years, provided 76 beds encompassing general nursing and dementia care, of which 57 were dedicated dementia beds, the largest specialist dementia provision among the four homes. It employed 93 carers alongside six registered nurses, reported low staff turnover, and delivered end-of-life education exclusively through in-house training.

Cedar was the most established home at the time of data collection, having operated for 22 years, with 73 beds offering general nursing and general residential care, including dementia care, but without dedicated dementia beds. It employed 48 carers and ten registered nurses, reported a coaching model of management and a high staff turnover (29%), and relied solely on in-house end-of-life training.

Holly, open for nine years, was the largest home at 78 beds, sixteen of which were dedicated dementia beds; it employed 56 carers and twelve registered nurses, the largest nursing complement of the four settings, reported high staff turnover, and supplemented its in-house end-of-life training with education provided by the local hospice. Oak was both the newest (four years) and the smallest (45 beds) of the homes, integrating dementia care within its general nursing beds. This home employed 42 carers and nine registered nurses, reported low staff turnover, and combined in-house training with formal education; one registered nurse having completed a standalone end-of-life care module. None of the four nursing homes had dedicated end-of-life care beds, and none held Gold Standards Framework in Care Homes (GSFCH) accreditation. The GSFH as a structured quality improvement programme helps care homes to deliver better end of life and palliative care by improving care planning, communication, symptom management, and reducing unnecessary hospital admissions for residents (Hockley and Kinley 2017).

Ownership and location

All four homes were privately owned, independently operated, and located within the same urban area, admitting residents from the local area and surrounding counties. This shared geography suggests overlapping catchment areas and potential competition for staff and residents. Drawing on similar populations could, however, mean consistency in terms of the

specialist teams involved. Nonetheless, these nursing homes differed in management style, staffing levels, specialist care, and end-of-life care training.

Management style

Comparative analysis demonstrated that leadership was enacted differently across the four settings, reflecting variations in organisational context, managerial visibility, mentoring practices, and levels of clinical involvement. Cedar adopted a coaching-oriented leadership model in which managers functioned as mentors, placing a strong emphasis on staff development, guidance, and collaborative learning. Participants' accounts from these three settings showed that Ash exhibited a supportive leadership approach characterised by accessible senior staff and shared decision-making, which fostered multidisciplinary collaboration and encouraged staff to seek support when managing complex clinical situations. Contrastingly, Oak and Holly reported leadership models in which senior nurses had largely transitioned from direct clinical practice to strategic and supervisory roles, while remaining accessible for professional guidance and support.

Across all four settings, supportive leadership emerged as a key organisational characteristic influencing staff confidence, communication, and decision-making. This indicates that effective leadership extends beyond operational oversight and plays a crucial role in creating environments in which nurses feel empowered, supported, and confident to deliver high-quality dementia end-of-life care.

Capacity, longevity and mortality rates

The four nursing homes differed in organisational size, length of operation, and mortality rates, providing important contextual information for interpreting the cross-case findings. Ash, Cedar, and Holly each accommodated between 70 and 80 residents, whereas Oak was considerably smaller, with capacity for 45 residents. Cedar was the longest-established nursing home, having operated for 22 years, while Oak was the newest, having been established four years before data collection. Ash and Holly represented organisations of intermediate age, having operated for 11 and 9 years, respectively.

Comparison of mortality rates demonstrated considerable variation across the four nursing homes. Oak reported the highest mortality rate (49%), followed by Cedar (34%), Holly (24%), and Ash (17%). However, these differences should be interpreted cautiously, as data collection took place during the COVID-19 pandemic, when mortality was substantially

influenced by factors beyond organisational characteristics, including infection outbreaks, resident frailty, and case complexity.

Across the four cases, neither organisational size nor longevity demonstrated a consistent relationship with mortality outcomes. The larger or more established nursing homes did not necessarily experience lower mortality than the smaller or newer organisations. This suggests that organisational characteristics provide important contextual information but are insufficient, in isolation, to explain differences in end-of-life outcomes. Instead, mortality appeared to reflect the interaction of multiple organisational and clinical factors, including resident complexity and the unprecedented impact of the pandemic.

Staffing levels and turnover

Staffing arrangements varied considerably across the four nursing homes in terms of registered nurse availability, care staff numbers, and workforce stability. Calculated registered nurse-to-resident ratios ranged from 1:12 in Ash to 1:5 in Oak, with Cedar and Holly each reporting ratios of approximately 1:7 (Table 15). Similarly, the balance between registered nurses and care staff differed across the organisations, reflecting variation in workforce composition and models of care delivery.

Comparison across the cases demonstrated that staffing levels alone did not consistently explain differences in resident outcomes. Although Oak reported the most favourable registered nurse-to-resident ratio, it also experienced the highest mortality rate, whereas Ash achieved the lowest mortality despite having the least favourable nurse-to-resident ratio. These findings indicate that staffing numbers should not be interpreted in isolation but considered alongside resident acuity, organisational context, and the exceptional pressures associated with the COVID-19 pandemic.

Differences in workforce composition also highlighted contrasting approaches to care delivery. Ash relied proportionately more on healthcare assistants and nursing assistants than the other nursing homes, suggesting greater emphasis on direct personal care supported by a smaller registered nursing workforce. Cedar, Holly, and Oak maintained comparatively higher proportions of registered nurses, potentially increasing access to clinical expertise for complex decision-making and end-of-life care. Nevertheless, across all four nursing homes, effective dementia end-of-life care depended upon collaborative working between registered nurses and care staff rather than the contribution of any single professional group.

Staff turnover also varied between the nursing homes but did not demonstrate a consistent relationship with mortality or organisational performance. While Ash experienced relatively low staff turnover alongside the lowest mortality, Oak reported low turnover despite the highest mortality, and Cedar experienced comparatively high turnover with moderate mortality. Collectively, these findings suggest that workforce stability alone was insufficient to explain variation in outcomes. Instead, staffing effectiveness appeared to be shaped by the interaction of workforce composition, organisational leadership, resident complexity, and wider contextual pressures during the pandemic.

	Ash	Cedar	Holly	Oak
Bed capacity	76	73	78	45
RGN: resident ratio	1:12	1:7	1:7	1:5
RGN: HCA ratio	6:93	10:48	12:56	9:42

Table 15: Staffing levels

Specialist care and training

Residents in all four nursing homes were aged 65 years and over and had nursing needs. Ash and Holly operated dedicated dementia-specific units, while Cedar and Oak integrated dementia care within their general beds. No home had a dedicated end-of-life care unit; dying residents were cared for within the general nursing and dementia beds, and no differences in staff confidence were noted according to care specialisation.

Approaches to specialist education differed across the four organisations. Holly supplemented in-house training through the local hospice, while Oak combined in-house training with formal postgraduate education. Ash and Cedar relied exclusively on internal training. These differences appeared to influence the level of clinical autonomy demonstrated across the four homes and informed an important contextual feature for understanding subsequent cross-case patterns.

In summary, this analysis has shown that although the four nursing homes served similar populations and operated in comparable contexts, they differed in leadership approaches, staffing structures, specialist dementia care provision, end-of-life care training, and autonomy in clinical practice. These differences shape staff competence, confidence, interprofessional collaboration, and care outcomes. Notably, training alone was insufficient to ensure high-quality end-of-life practice; experience, supportive leadership, and a strong

organisational culture were found to be crucial to the organisation and delivery of end-of-life care. Mortality and turnover patterns were inconsistent across the nursing homes, underscoring the need for further investigation into resident complexity, organisational processes, and pandemic-related effects on outcomes.

5.8.2: Development of the grounded theory for this study

The grounded theory for this study was integrated using the six-step analytic processes in accordance with the Straussian grounded theory. These procedures included coding processes, constant comparison, reviewing and sorting out memos, theoretical sensitivity, and theory integration which will be explained in this section.

5.8.2.1: *Coding processes*

Coding is a fundamental analytical process which involves integrating data into categories (Corbin and Strauss 1990). Strauss and Corbin (1998) describe the six steps to grounded theory coding which include: 1. Simultaneous data collection and analysis, 2. Three-step coding process using a coding paradigm (open, axial, selective), 3. Comparative methods, 4. Memo writing to aid conceptual analysis construction, 5. Sampling to refine the emergent theoretical ideas, and 6. Integration of the theoretical framework.

The researcher in this study used the NVIVO 12 Plus (QSR) computer software to assist her in analysing the data collected. NVIVO is one of the software used in analysing qualitative data which enables the researcher to organise the data into codes, examine relationships between concepts, and develop categories (Polit and Beck 2021). These functions are especially important in a Straussian GT.

Open coding was performed first. By thoroughly reading and rereading the interview transcripts line by line, the researcher identified concepts and their properties from the data. The researcher identified the main lines of inquiry and identified a total of 48 open codes. The identified concepts were labelled with an abstract name which represented the participants actual words or behaviours. Examples of these concepts included moral beliefs, peer support, family involvement, relationship with family, management and leadership, end-of-life care training, goals of care, challenges, standing in place of family, COVID-19 pandemic, confidence, knowledge and skill, experience, teamwork, appreciation, decisions, debrief, emotions, emotional attachment, expectations, and anticipation.

This stage of analysis helped the researcher to identify gaps in the data which informed theoretical sampling to collect further information and clarify some of the identified concepts. During supervision, the researcher discussed the open codes with her supervisors to confirm her thoughts and seek advice. A memo was then completed after each supervision to document the researcher's analytical thought processes and decisions in this phase. The codebook for some of the open codes developed is included in Appendix x(A).

Next, axial coding was performed. During this phase, the researcher synthesised the open codes together in terms of their similar patterns, properties, or dimensions into axial codes. The axial codes were further synthesised into sub-categories. The researcher considered questions that guided and prompted her thinking such as 'what does this data/incident mean or indicate?' 'What possible theories is this data leading to?' 'What category would these concepts fit in?' These questions assisted the researcher in the selection of relevant open codes which were condensed into groups of similar properties and dimensions to form the axial codes(sub-categories). The sub-categories developed were then compared with each other to clarify their theoretical variations and properties. A total of seven axial codes (sub-categories) were developed which included person-centred care, off-loading, dementia and the trajectory of death, advance care plan, expertise of carers, package of care, and facilitators of a good death (Appendix x(B)).

Like the open coding phase, the researcher discussed the identified axial codes with her supervisors and completed a memo documenting the analytical processes and decisions in this stage. Areas for further theoretical sampling were again identified this time.

Next, selective coding was performed. This stage involved the development of main categories which are also referred to as theoretical codes. Theoretical codes are informed by a combination of literature and the researcher's clinical knowledge or experience (Munhall and Oiler 1986). The sub-categories developed during the axial coding phase were further synthesised into main categories in terms of their patterns or properties, dimensions, and their theoretical relationship to the other main categories and the core category. Questions such as 'what is going on in the data?' 'What does the behaviour of the nurses indicate?' 'What is the explanation of the way the nurses are providing end-of-life care?' 'What are these data in study of?' 'How do these categories link together?' These questions prompted the researcher to think in theoretical terms. The researcher returned to the data repeatedly to find explanation of the data. Reviewing relevant literature relating to the sensitizing concepts also assisted the researcher to understand and interpret what was going on in the data to support the development of the theory. In the end, the researcher, in consultation with her

supervisors, integrated four categories explaining the data which included ‘end-of-life care wishes and preferences,’ ‘end-of-life care organisation and delivery,’ ‘moral distress,’ and ‘interpersonal relationships’ (Appendix x(C) and Table 16).

During the coding process, the researcher identified gaps which directed further theoretical sampling to clarify the identified concepts. Memo writing (discussed in the next section) was an essential step in this process which assisted the researcher to keep track of her analytical process, keeping in line with Corbin and Strauss (1990). In addition, making comparisons of the interview accounts and concepts was useful for the researcher to challenge the concepts with fresh data, hence guarding against bias which could have arisen from her preconceptions. The following section outlines the process that was involved in generating the codes, main categories, and grounded theory of this study.

To develop the first main category of ‘end-of-life care wishes and preferences’, several open and axial codes were reviewed. These included the axial code of ‘navigating individual care needs’, and the open codes: end-of-life care needs, ACP and last wishes, conversations, decisions, cultural influence, family involvement, and impaired communication (Figure 5). This main category, therefore, revealed participants’ accounts of their experiences of navigating wishes and preferences for end-of-life care for the residents with dementia in the nursing homes

Field notes were reviewed and a memo was completed to document this analytical stage and results. A reflective diary was also completed which explored the researcher’s own cultural and religious beliefs/values in relation to end-of-life care and discussions. The researcher ensured that these did not influence the way that she interpreted the data. Direct quotes were used to ensure that the participants’ voices were accurately and fully presented.



Figure 5: Illustration of the development of the main category of ‘end-of-life care wishes and preferences’

To develop the second main category of ‘end-of-life care organisation and delivery’, several open and axial codes were reviewed. These included the axial codes of ‘dementia and the disease trajectory’ (open codes- diagnosing end-of-life ‘end-of-life, disease progression), ‘end-of-life care’ (open codes- goals of end-of-life care, holistic approach, navigating individual care needs, person-centred care), and ‘package of care’ (open codes- access to services, teams, involvement of care, expectations, GP consultations, learning from mistakes, outside support, standards of care) (Figure 6). This main category revealed participants’ accounts of their experiences of the organisation and delivery of end-of-life-care for people with dementia who resided in the nursing homes.

Field notes were again reviewed, and a memo was completed to document this analytical stage and results. A reflective diary was also completed which explored the researcher’s own personal and professional experiences of end-of-care provision. The researcher also made sure that these did not influence the way that she interpreted the data. Direct quotes were used to ensure that the participants’ voices were accurately and fully presented.

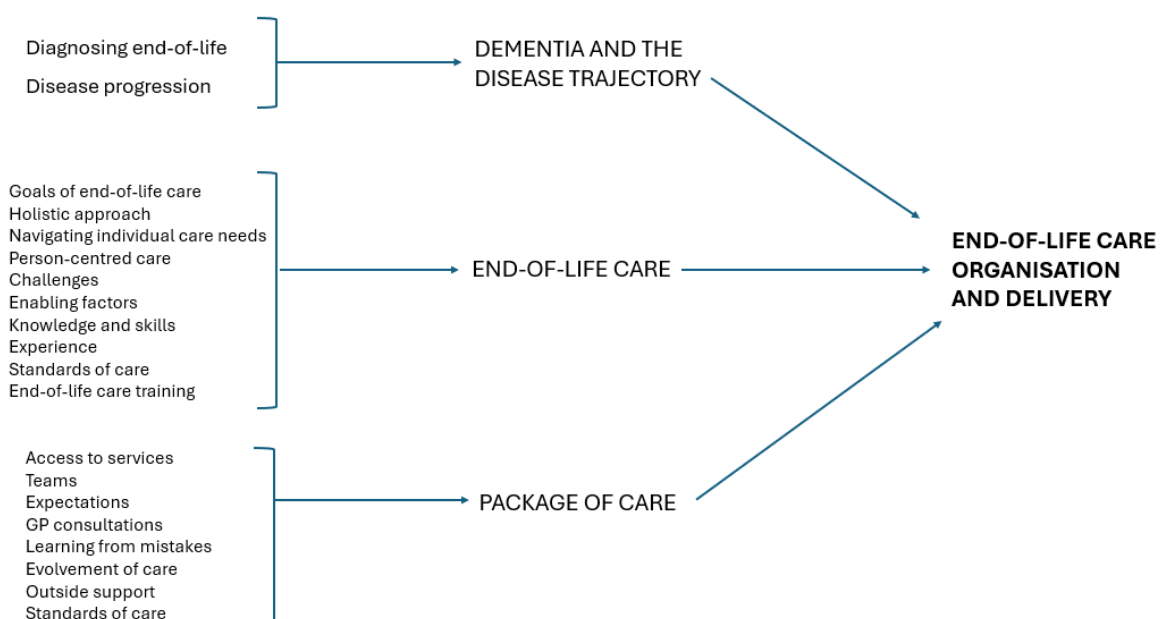


Figure 6: Illustration of the development of the main category of ‘end-of-life care organisation and delivery’

The third main category of ‘moral distress’ included several open and axial codes: the axial codes of ‘challenges of end-of-life care delivery’ (open codes- Impact of COVID-19 pandemic, expectations), ‘Expertise’ (open codes- Carer experience, competence and confidence, empowerment, personal experience, management and leadership, peer support, professionalism, responsibility), ‘enabling factors’ (open codes- Cultural Influence, passion and motivation, personal experience, relationships), and ‘off-loading’ (open codes- appreciation, de-brief, staff pastoral care, emotions, emotional attachment)(Figure 7). This main category revealed participants’ accounts describing the psychological anguish that they experienced as a result of being constrained from providing ethically correct end-of-life care for people with dementia during the COVID-19 pandemic.

Field notes were reviewed and a memo was also completed to document this analytical stage and results. A reflective diary was also completed which explored the researcher’s own personal and professional experiences in relation to end-of-care during the pandemic. The researcher also made sure that these did not influence the way that she interpreted the data. Direct quotes were used to ensure that the participants’ voices were accurately and fully presented.

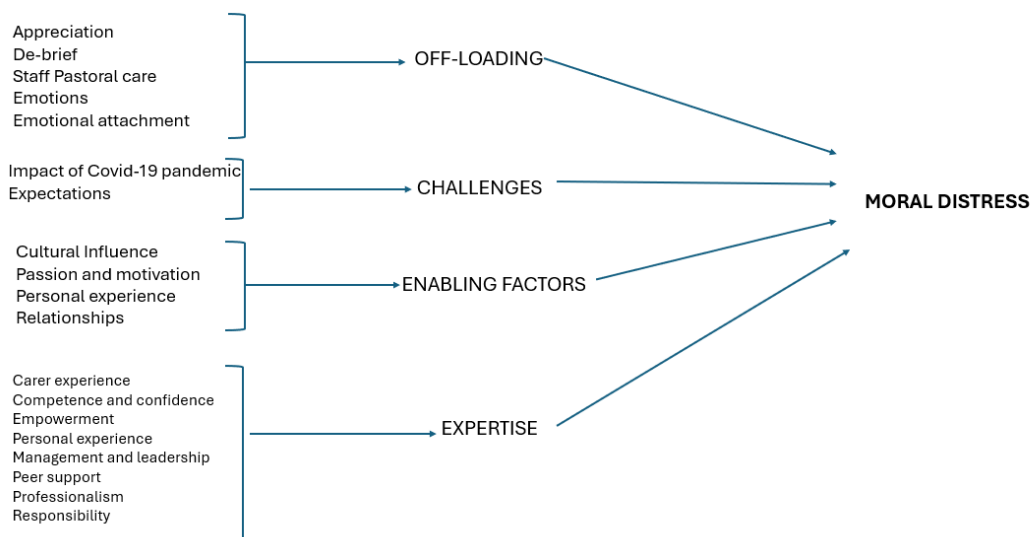


Figure 7: Illustration of the development of the main category of ‘moral distress’

To develop the core category of ‘interpersonal relationships’, several open and axial codes were also reviewed. These included the axial codes of ‘relationships with residents’ (open codes-passion and motivation, emotional attachment, advocate, standing in place of family, responsibility, relationship, impact of COVID-19), ‘relationships with family carers’ (open codes- relationship, emotional support, emotions, family involvement, collaboration, communication, impact of COVID-19), and ‘relationships with team members’ (open codes-peer support, de-brief, emotional support, teamwork, outside support) (Figure 8). This core category, therefore, revealed participants’ accounts describing the nature and quality of relationships that they formed when providing end-of-life care for people with dementia in nursing homes.

Field notes were reviewed and a memo was again completed to document this analytical stage and results. A reflective diary was also completed which explored the researcher’s own beliefs and experiences during the pandemic. The researcher ensured that these did not influence the way that she interpreted the data. Direct quotes were used to ensure that the participants’ voices were accurately and adequately and represented.

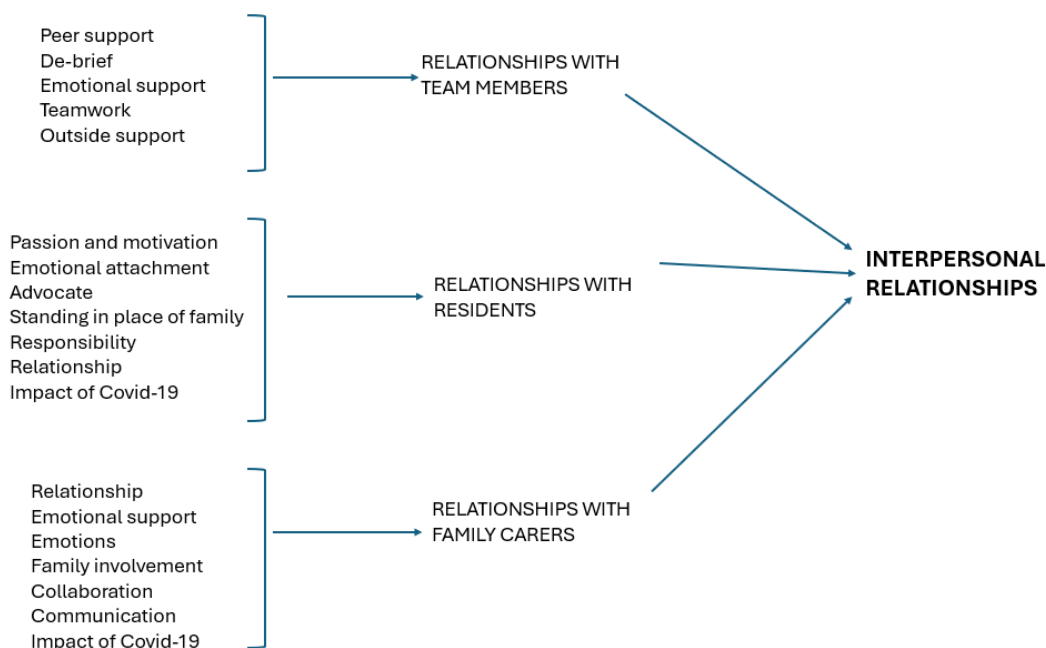


Figure 8: Illustration of the development of the core category of ‘interpersonal relationships’

5.8.2.2: *Constant comparison*

As the researcher went through the coding of the data, the concepts identified were constantly compared against each other in terms of their properties, dimensions and patterns, and the coded data was contrasted with new data for verification. Finding patterns or regularities helps to give order to the data which is useful with integration (Corbin and Strauss 1990). The data from the interviews were also compared against each other to develop new concepts and categories. For example, following the completion of the first batch of interviews from the first nursing home, the researcher proceeded with the first phase of theoretical sampling and went to the other three nursing homes. The researcher proceeded to collect data from participants with a diverse range of demographic characteristics from the other nursing homes.

The first four interviews were compared to the next set of eight interviews in terms of their similarities and variations. New concepts were identified, and similar concepts were grouped together into sub-categories. Following this analysis, the researcher proceeded to another phase of theoretical sampling and conducted another set of three interviews. The data collected was compared with that from the earlier interviews and to clarify the concepts that had already been developed. New concepts were developed and then grouped with those containing similar properties to integrate axial codes and the core category. This process was repeated until data saturation was attained after the last three interviews which marked the completion of data collection. Data saturation was achieved when no new codes and axial codes were being developed from the interviews, and the researcher confirmed that the categories were fully developed. Corbin and Strauss (2015) and Varpio et al. (2017) describe theoretical saturation as the point at which there is sufficient data to integrate a theory that accounts for key issues relating to the topic under investigation when a theory is complete.

The categories developed were also compared with each other to make sure that they were independent of each other in terms of their theoretical variations, properties, and dimensions which contributed substantially to the richness of the theory. The researcher made sure that all discussions with her supervisors and decisions made in this phase were recorded in memos. Memo writing proved especially useful for the researcher during the analysis phase as they prompted her to have an internal dialogue that increased her understanding of the data. In addition, the researcher maintained reflexivity to remain mindful of her own subjective view(s) and their impact on the analysis and interpretation of data in this study. Reflexivity played a key role in avoiding forcing her ideas but rather avoiding preconceptions and ensuring that her interpretations were grounded solely in the data.

5.8.2.3: Reviewing and classifying memos and field notes

In GT studies, data collection, coding, memo writing and writing of field notes occur simultaneously (Corbin and Strauss 2015). Memos are described as written notes completed after every analytical session (Corbin and Strauss 2008; 2015) which collate the researcher's thoughts, interpretations, and direct where to collect further data (Strauss and Corbin 1998), and identifying conceptual relationships that exist between distinct categories (Corbin and Strauss 2008).

The researcher used memos in this study as reflections on the patterns of the data collected, and on the relationships between the concepts and the categories developed. Memoing is considered a key part of generating a Straussian grounded theory because it aids conceptual analysis construction (Corbin and Strauss 2008). The researcher made sure that the memos were written as soon as an idea emerged to avoid forgetting (Corbin and Strauss 1990). Keeping a pen and paper always handy enabled the researcher to jot down any ideas that came to mind at any time.

Memos may vary in content, length, and style (Corbin and Strauss 2015, Polit and Beck 2021) depending on the stage of research and their reason for writing (Corbin and Strauss 2015). As such, Glaser (1978) advised researchers to adopt a flexible approach when writing memos. Furthermore, Corbin and Strauss (2015) suggest that what matters is researchers completing memos other than focussing on the actual style. The memos completed in this study helped the researcher to keep track of her analysis hence providing an audit trail of the data analysis process. These memos became useful in informing the next stage of theoretical sampling and directed the generation of the grounded theory for this study, as recommended by Corbin and Strauss (2015). An example of a memo written by the researcher in this study has been included in Appendix ix.

Field notes on the other hand, are detailed descriptions of the setting, events or participant's behaviours that are recorded during data collection (Holloway and Galvin 2017). A field note may include for example, a participant making an ironic statement, or saying something as a joke, seeming anxious, unsettled, or upset during an interview. These observations may not be expressed clearly in an interview transcript but are vital when analysing data to ensure accurate interpretation of participants' accounts (Polit and Beck 2021, Corbin and Strauss 2008; 2015).

To keep track of the progress of the analysis, all memos and field notes were dated (Strauss and Corbin 1998). An example of the field notes completed in this study has been included in Appendix vii. The memos that the researcher wrote throughout the analysis helped to keep a

record of all the ideas that were generated since the study began. The memos also helped the researcher to remember all the ideas even those that were constructed right at the beginning of the analysis which some time prior to the point of integration. Regularly revisiting the memos, enabled the researcher to refresh her memory of the whole analysis, create a coherent theory and arrive at the final integration.

The memos that were written at the beginning of the analysis were much shorter involving the identification of single concepts derived from the open codes. These initial memos helped to direct theoretical sampling to develop concepts further. The memos then progressed to more detailed and complex records exploring relationships between two or more concepts. The more complex memos were written around the time when sub-categories and categories were being developed as the researcher sought to identify links and variations between these categories. The researcher delved in deeper into the data by revisiting the memos and the raw data to find meanings and explanations in relation to the nurses' behaviours.

Re-reading the initial memos and raw data helped the researcher to direct her line of inquiry towards developing further theoretical concepts. Main ideas were identified by sorting the memos into category headings which were around the way the nurses identified end-of-life care needs, organised, and delivered care, the impact of the COVID-19 pandemic, and what influenced the nurses to deliver care or behave the way that they did. This led to the development of the three main categories of end-of-life care wishes and preferences; end-of-life care organisation and delivery; and moral distress.

The main question on the researcher's mind at this point was 'why do the nurses behave the way they do, or why do they do what they say they do?' The researcher focussed her thoughts on this question and reviewed the memos and data around the team work and impact of COVID-19 sub-categories. A link was then identified to the pandemic restrictions during the COVID-19 pandemic which explained the nurses' relationships within the team of nurses, and with the residents with dementia and their families around this period. The researcher identified a recurring concept whereby the nurses' accounts described their 'relationship' with their colleagues, people residing in the nursing homes, and the relatives of those that resided in the nursing homes as 'family.' These family-like relationships are what were seen to enhance the bonds that existed among the nurses, residents and family carers, which led to the development of the core category of 'interpersonal relationships.'

With the aid of the memos and literature, the researcher identified several potentially sensitising concepts which guided her thoughts towards theory integration. These sensitising

concepts included moral beliefs, moral distress, COVID-19 pandemic restrictions and impact, and interpersonal relationships. Following the development of the core category, the researcher revisited the data and memos to better understand the nature of the links between the core category and the other categories in this study. Arranging the memos based on the categories and the sensitising concepts enabled the researcher to integrate a grounded theory for this study.

5.8.2.4: Theoretical sensitivity

Theoretical sensitivity refers to the ability of a researcher to bring data analysis to a theoretical level where they become more aware of vital data that may be useful to developing a theory (Corbin and Strauss 2015, Tie et al. 2019). Birks and Mills (2015) allude that the researcher's level of theoretical sensitivity to analytic possibilities increases by immersing deeply in the data. Furthermore, reviewing literature during data collection and analysis, plus the researcher's relevant knowledge and experience is said to increase the researcher's understanding of the concepts identified and stimulate questions that direct further theoretical sampling (Corbin and Strauss 1990; 2008).

In this study the researcher maintained theoretical sensitivity by remaining aware of the relevant and significant elements of the data (Holloway and Galvin 2017). As advised by Strauss and Corbin (1998), the researcher interacted with the data for this study by thoroughly reading the interview transcripts, memos, field notes, and reflective diaries to identify emerging ideas, ask further questions until all concepts were confirmed by the data. Consequently, interview schedules were reviewed when new lines of inquiry were open to direct further data collection for further exploration and clarification of the identified concepts, and the emerging theory, and to identify potential new concepts.

In addition, the researcher conducted literature reviews before and after data collection/analysis, which was used as baseline information to understand and compare data, create theoretical sensitivity, and explain results, keeping in line with the Straussian GT (Strauss and Corbin 1998). The literature helped the researcher to identify potentially useful sensitizing concepts for developing a theory. Sensitizing concepts are background ideas that provide a framework for understanding social phenomena and the first step of the analytic process towards the development of a grounded theory (Bowen 2019). Bowen (2019) explains that sensitizing concepts used as interpretive devices, are helpful in suggesting possible lines of inquiry during the development of categories from research data, by stimulating relevant prompts and questions. Furthermore, sensitising concepts can be

selected from existing research, literature, or theories (Bowen 2019, Strauss and Corbin 1998).

Through constant comparison of the data and reviewing memos, field notes, relevant literature, the researcher developed theoretical sensitivity by identifying several potential sensitising concepts to aid in the development of the theory for this study. These concepts originating from the literature and existing theories were identified during the analysis of the data which served as guiding principles in the integration of the grounded theory for this study. These included interpersonal relationships, teamwork, impact of COVID-19, and moral distress. Moreover, relevant paradox theories assisted in identifying these sensitizing concepts related to end-of-life care for residents with dementia in nursing homes which helped to integrate the core category and grounded theory for this study. This grounded theory is presented in chapter nine of this thesis.

Furthermore, the researcher's positionality shaped the analysis and interpretation of the findings. The researcher's clinical experience included eight years of caring for older persons in nursing homes including those with dementia at the end of life. The researcher also had seven years of service at a local health board as a Nurse Assessor, which involved nursing home governance and monitoring of the standards of care provided to people that resided in the nursing homes. The researcher's clinical experience as a registered nurse in the nursing home, and a care home monitoring role as a Nurse Assessor provided additional contextual insights that were useful in analysing and interpreting the data in this study. This clinical experience equipped the researcher with the context specific knowledge about the needs of people with dementia at the end-of-life in nursing home settings, as well as the current practices in caring for this group of people. For example, the researcher prior experience meant that she had an awareness of the gaps in dementia care services compared to other life-limiting conditions such as cancer, which led to her interest to conduct this research and explore this area of care further.

5.8.2.5: Theory Integration

Integration is the final step of analysis in research aiming to develop theory which involves linking the main categories around the core category and refining and trimming the theory (Corbin and Strauss 2015). Corbin and Strauss (2015) consider this stage as the most challenging aspect of data analysis even for the experienced researchers as it involves a lot of thinking and sorting out the memos to look for clues of how the categories fit together. As such, the researcher in this study sought a lot of support and advice from her supervisors to

ensure that the theory integrated was grounded solely in the data collected and not her own understanding or preconceptions.

During this stage, the researcher often went for long walks to have some thinking time trying to better understand the data. At times, this process was quite frustrating as nothing seemed to make sense, or things could get confusing. Regular meetings with the supervisors provided some reassurance and encouragement. The researcher recalls the supervisors advising her not to force data into codes and categories saying, “one day it will just come to you; maybe when you are watching your son’s rugby game.” However, it was frustrating as that the ‘aha!’ moment never seemed to arrive. What eventually helped was the supervisors’ questions that teased and prompted the researcher’s thinking and to read more around the relevant concepts.

Furthermore, the researcher followed several steps to integrate the theory for this study which included reviewing and sorting through memos, discussion with supervisors, refining of the theory, and validation of the theory.

The researcher discussed several theoretical insights based on the sensitising concepts with her supervisors with the aim of testing which one fit best with the data. These discussions proved invaluable in the development of the theory for this study. Following several debates the researcher successfully integrated an original grounded theory of ‘interpersonal relationships’. It was agreed that the data evidenced that interpersonal relationships that were formed among nurses, residents and residents’ relatives shaped end-of-life care for people with dementia in the nursing homes during the COVID-19 pandemic. The researcher then completed a concluding memo to describe the development of this proposed theory and continued to work on this summary by cross-checking with the data until she felt that the theory was adequately grounded in the data.

The researcher was unsure about the direction her research would take at the beginning of the study. As such she let the data and the concepts derived from the analysis rather guide her thinking which was key to the development of the theory. Following the development of the theory, the researcher went over the data and theory over and over to ensure that any gaps in the logic were filled. The concepts that were developed fitted in well with the data.

The researcher examined the quotes from the participants’ accounts to make sure that they adequately supported the core category around all the three stakeholders involved (residents, relatives, and staff), and how these relationships influenced end-of-life care provision for the people with dementia in the nursing homes. The memos written during the analysis were also revisited to better understand how the concepts and categories were

related to each other and to the core category in terms of the nurses' behaviour in caring for the people living with dementia at the end of life.

During this stage, the researcher was able to establish how the data linked interpersonal relationships to the ways in which nurses delivered care during the COVID-19 pandemic. Analysis revealed a relational paradox within the nursing home setting: interpersonal relationships functioned simultaneously as the primary facilitators of high-quality end-of-life care and as the principal sources of moral distress when nurses were unable to provide the care they perceived as necessary due to external constraints.

This final stage of theory integration involved the researcher validating the theory that had been developed for this study. The memos that informed theory development were re-read to sense check negative cases and outliers in the data. The researcher was satisfied at this point that there was adequate data to support the proposed theory that added new insights into end-of-life care for the people with dementia who resided in the nursing homes.

The researcher also held a final discussion with her supervisors to make sure that they all agreed that the proposed theory in this study was consistent with the data. The researcher supervisors agreed and confirmed that the theory integrated was grounded in the data collected in this study.

5.9: Evaluating the study's methodological rigour

The rigour in the conduct of this study was assessed based on the concept of 'trustworthiness.' Rees (2011) describes trustworthiness in qualitative studies as the quality, authenticity, and truthfulness of findings which relates to the extent to which readers can trust and have confidence in the findings of a study. Lincoln and Guba's framework for establishing trustworthiness of qualitative research involves the following criteria: credibility, confirmability, dependability and transferability, the details of which are provided in the next section (Lincoln and Guba 1985).

5.9.1: Credibility

Lincoln and Guba (1985) and Corbin and Strauss (2015) describe credibility as the ability for research findings to be believable and plausible. Corbin and Strauss (2015) suggest that for a research study to be believable and plausible, the findings of the study should have the

ability to be readily used because they provide insight, understanding, and work with diverse populations and situations to bring about the desired change.

Corbin and Strauss (2015) explain that for a study to achieve credibility, the researcher must conduct the study meticulously and provide sufficient detail of the conduct of the whole study which enables the reader to judge for themselves and assess how the researcher came to the conclusions of their findings. The researcher in this study ensured that she followed the techniques for conducting a Straussian GT study in relation to ethics approval, participant recruitment, and data collection and analysis, for example, adhering to the step-by-step guidance, conducting data collection alternate with analysis, memoing, constant comparison, and quoting the participants exact words to support the analysis and interpretation of the data.

Furthermore, the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist (Tong et al. 2007), was completed to report important aspects of the study including the research team, study methods context, findings analysis, and interpretations (Appendix xi), to evaluate the trustworthiness, transparency, and methodological quality of this study. Although the checklist is advocated for most research journal manuscript submissions, and enhancing qualitative research credibility, it has been criticised that its use is not generic and universally applicable which could result in methodological reporting incongruency in qualitative reporting (Braun and Clarke 2024). Braun and Clarke (2024) therefore, recommend that the tool should be extensively revised to ensure that it accommodates more transparent and complete reporting especially when used by less experienced researchers and evaluators.

In addition, to produce credible findings, Rees (2011) advocates on member checking (also referred to as participant validation) which involves participants checking the interview transcripts for accuracy to reduce the potential for researcher bias. Although there may be justifiable reasons for conducting member checks in qualitative research, the practice is not recommended in GT studies because the stories the participants recount can acquire different meanings or significance over time resulting in the participants viewing their stories in a different manner (Corbin and Strauss 1990, Birt et al. 2016). Birt et al. (2016) explain that participant validation is also plagued by difficulties in ascertaining when to start checking, the failure of participants to recall what they said, an unwillingness to contradict the researcher by the participants, and a lack of clarity about the level of verification that is acceptable. To ensure that she had captured accurate information, the researcher in this

study made sure that she went over the key points that were discussed at the end of each interview to confirm with the participants her understanding of their perspective.

5.9.2: Confirmability

Confirmability refers to the researcher demonstrating that the ideas in their study are based on the findings of the study other than their own preconceptions (Lincoln and Guba 1985, Rees 2011) or imagination (Polit and Beck 2021). Topping (2010) explains that to achieve confirmability, there should be evidence of a clear link between data, findings, and researcher interpretation. In addition, a researcher can demonstrate confirmability by ensuring that the data in their study represents the participants' voice (Polit and Beck 2021).

In this study, the researcher made sure that the interviews were transcribed verbatim to capture the participants' voices fully (Polit and Beck 2021). The researcher was also consciously aware of her professional background and experience and ensured that her interpretation of the findings was based on the participants' voices by reviewing the quotes in the transcripts. The researcher carefully listened to the audio recordings and re-read the transcribed text to get close and be familiar with the data hence increasing her confidence in the interpretation of the findings. Furthermore, discussions with the supervisors helped the researcher to develop explanations and interpretations of the data.

5.9.3: Dependability

The researcher's ability to demonstrate their decision trail in the development of categories from the analysis of their interview data is known as dependability (Lincoln and Guba 1985, Rees 2011). Dependability, existing alongside credibility, is related to the transparency of the research (Polit and Beck 2021) which assists readers to judge the decisions made in developing the main categories (Topping 2010). Researchers are expected to provide an outline of an audit trail that explicitly discusses the decisions taken about the theoretical, methodological, and analytical approaches throughout the research process (Lincoln and Guba 1985, Rees 2011). In this study, the researcher presented detailed information regarding: the theoretical underpinnings of this study; the conduct of the interviews and observations; all the coding processes and how the codes and categories were developed. The writing of memos also assisted in demonstrating how the researcher progressed in the analysis of the data and formulation of the main categories as described in the section on memos.

5.9.4: Transferability

Transferability refers to extent to which a study's findings could be applied to other settings, contexts, or groups of people (Lincoln and Guba 1985, Polit and Beck 2021, Noble and Smith 2015). Clear and transparent reporting of key aspects of the design and conduct of the study are said to enhance the transferability of the study and findings (Lincoln and Guba 1985). However, Rees (2011) points out that transferability is not always possible in qualitative research due to the highly subjective nature of the findings relying on the researcher's analysis and interpretation, but however, still suggests that some insights or interpretation of this type of research could still be useful in other settings. The researcher has included detail to aid the reader in their judgement of whether this study could be replicated or whether the findings or interpretation could be applied to other settings.

A robust Straussian grounded theory is comprehensive and has broad conceptual interpretations, which provide it with sufficient abstraction to be applicable to a range of different contexts related to the phenomenon of interest (Strauss and Corbin 1998). On the other hand, there is also an argument that Straussian grounded theory is highly transferable to situations that exactly match the conditions in which the study was undertaken, but the reality of life is that there is a low probability of finding other situations that are identical to those in which the study was undertaken (Gasson 2003). So, the decision about the extent of transferability is down to the discernment of the reader and relies on the quality and clarity of the description of key aspects of the design, conduct and reporting of a Straussian grounded theory study (Corbin and Strauss 2015).

5.10: Reflexivity

In qualitative research reflexivity, a component part of establishing rigour, is described as a researcher's critical self-reflection of their own biases, preferences, and preconceptions (Polit and Beck 2021), and their relationship with participants which may have an influence on the research process, data collection or the interpretation of findings (Lathlean 2010, Rees 2011, Corbin and Strauss 2015). Strauss and Corbin (1998) accept that this at times may be inevitable but acknowledge the impact this can have on the information provided by the participants or the way the researcher asks questions. In this study for instance, the researcher was aware of how being in the same professional group as the participants, and her previous relationship with them as a Nurse Assessor could affect the participants' responses resulting in them providing socially desirable answers, saying what they thought

the researcher wanted to hear, and/or their answers being influenced by the way she framed her questions. As such, the researcher was always mindful of her privileged position and ensured that her role as a researcher was clarified before each interview by reassuring the participants of her role in this study which was separate from how they related to her previously and therefore encouraged them to freely talk about their views, perspectives, and experiences in their accounts.

The researcher also remained focused on her role as a researcher and did not manage any issues related to her job as a Nurse Assessor during the interviews. During recruitment and data collection, the researcher sought to distinguish her role as a researcher from her job as a Nurse Assessor by wearing the university's student identification badge. Moreover, the Participant Information Sheets, and Consent Forms also included information that specified that the researcher was a PhD student at the local university.

Furthermore, to mitigate the potential for personal biases, assumptions, and perspectives to affect the rigour of a grounded theory, Corbin and Strauss (2015) advise researchers to implement measures, such as reflexivity, which enable them to be mindful of them and their potential impact. Therefore, the researcher was conscious of how her knowledge and experience of caring for people living with dementia at the end of life in nursing homes could influence her analysis and interpretation of data. In addition, the researcher took steps to maintain a reflexive approach by keeping a reflective journal, regularly discussing her analysis and interpretation of the data with her supervisors to help in clarifying the extent to which the analysis and interpretation was based on the data or subject to other factors such as her own perspective (see an example of one of the reflective journals completed in appendix viii). The researcher's supervisors also regularly reviewed her coding framework and codes to ensure that they were grounded in the data.

5.11: Summary of chapter

This chapter has outlined the methodological approach used in a Straussian Grounded Theory (GT) study examining RNs' experiences of providing end-of-life care to people living with dementia in nursing homes. It has detailed the sampling strategy, study setting, data collection, analysis procedures, and approaches to ensuring rigour and reflexivity. The study used purposive sampling initially to recruit experienced nurses, followed by theoretical sampling driven by emerging concepts until data saturation was achieved. In total, 18

RNs from four nursing homes in South Wales participated, representing varied demographics and professional backgrounds.

Data were collected through semi-structured, face-to-face interviews, supported by field notes and conducted between February and December 2021 despite COVID-19 restrictions. All interviews were audio-recorded, transcribed verbatim, anonymised, and securely stored. Data analysis followed GT procedures, including open, axial, and selective coding, constant comparison, memoing, and iterative movement between data and emerging theory. Cross-case analysis highlighted differences in management style, staffing, training, and organisational culture across the four homes, which shaped nurses' confidence and care practices.

The resulting grounded theory identified interpersonal relationships, between nurses, residents, and families, as the core category influencing end-of-life care, particularly under pandemic constraints, enhancing both care quality and fuelling moral distress in the nurses. Rigour for this study was maintained through adherence to GT methods, audit trails, verbatim transcription, and reflexive practices, ensuring credibility, confirmability, dependability, and transferability of the findings.

The next chapter presents the ethical considerations that were applied in the conduct of this study.

Chapter 6: Research ethics

6.1: Introduction

This chapter presents a discussion of the ethical issues which underpinned the conduct of this study. A detailed description of how the ethical principles were applied in this study has also been included.

Research ethics refer to moral values that guide research procedures in a study (Parahoo 2014, Polit and Beck 2021) starting from the commencement until the completion of a study, including the dissemination of findings (Rees 2011). According to Rees (2011), research ethics are a part of research governance which are designed to protect the dignity, rights and welfare of those taking part in a study.

6.2: Research ethics

To adhere to ethics standards, the researcher made sure that a number of ethical principles were considered in this study. These included ethical approval, informed consent, voluntary participation, autonomy, confidentiality/anonymity, data protection, beneficence, non-maleficence, lone working, and justice (Johnson and Long 2010, Rees 2011, Parahoo 2014, Polit and Beck 2021), which have been discussed in detail in the following sections.

6.3: Gaining ethical approval

All studies involving human participants including their organs, tissue or data require approval by the relevant ethics committees prior to commencement to ensure that they meet the required ethical standards (Gelling 2010, Rees 2011). Ethical clearance was therefore obtained by the researcher for this study. At the outset of the study, a research protocol was written by the researcher, which was used to apply for the ethical approval. The protocol contained the background of the study and full details of how the study would be conducted including access to research participants, informed consent, data generation and storage, data analysis and dissemination.

The protocol was presented to the School of Healthcare Sciences Research Ethics Committee (SREC) for ethical review and consideration. Following this initial review, recommendations were made for some action to be amended and clarified. With guidance from the supervisors, the researcher responded to the queries raised and made the clarifications and amendments as proposed by the committee following which a full approval to conduct the study was granted in December 2020 (see approval letter in Appendix ii).

6.4: Informed consent

Informed consent is a key ethical consideration in qualitative research involving both staff and health care service users (Rees 2011). Informed consent is obtained after assimilation of important information pertaining to a proposed study, which include the research activities involved, potential risks and benefits of taking part and support services available, confidentiality and anonymity option to withdraw at any time, dissemination of findings and data management (Creswell 2013). Gaining consent from research participants is said to respect the individuals' rights to decide whether taking part in the study would be compatible with their interests (Drazen et al. 2017). Moreover, the Nuremberg Code (1986) highlights important elements of informed consent in research studies which include voluntary participation and capacity to make the decision to take part.

The researcher in this study ensured that each participant voluntarily gave informed consent to take part. Researchers are advised to provide clear and comprehensive details of the study, written in plain language which is easy to understand (Johnson and Long 2010, Holland and Rees 2010, Rees 2011) through verbal explanations and in writing using the participant information sheet (Polit and Beck 2021). As such, all information packs for this study were written clearly in English, which was the official language of communication within the nursing homes. The researcher was conscious that this study was undertaken in South Wales where the Welsh language is also prevalent. As such, she was prepared to offer translated documents to those who preferred communication in Welsh. However, all participants preferred to communicate in English, so this was not an issue.

Furthermore, the participants were allowed time (at least 3-5 days) to read and consider the information given before making the decision to take part. This is consistent with Holloway and Galvin (2017) and Polit and Beck (2021) who advise that participants must be given time to decide to take part in a study freely without feeling coerced.

In addition, participants must also be informed of their right to withdraw their consent at any point without needing to provide a reason (Johnson and Long 2010, Polit and Beck 2021). This right was made clear in the participant information sheet (see Appendix v: B) and the participants were also reminded of their right to withdraw during the consent stage and before commencing each interview. Moreover, the participants were made aware that it would be impossible to withdraw their data after being anonymised or analysed as it would be difficult to identify and remove their information. As such, they were given at least a week after being interviewed to withdraw should they wish to.

Potential participants must have the capacity to consent to take part in research whether verbally or in writing (Glasper and Rees 2017). The participants in this study were RNs who had the capacity and the level of literacy to comprehend the information that was given and the implications on which they based their decisions. The participants, however, were still given the opportunity to ask questions or seek clarification where they were not clear. Following their agreement to take part, the participants were asked to complete and sign two consent forms which were enclosed in the participant information packs, one copy for the researcher's and the other for the participant's records.

6.5: Respect for autonomy

Patients/service users and their relatives/representatives must be involved where possible in all stages of the research including the design of the study, data collection, analysis, and reporting of findings for a researcher in order to respect their autonomy (Rees 2011). According to Rees (2011), autonomy can be achieved through informed consent.

In this study, the participants were given the chance to make their own individual choices whether to participate in the study or not. In addition to the information provided to gain consent, the participants were also reassured that there would be no repercussions for non-participation. The participants were involved throughout the study and were kept up to date with the progress of the study. They were also given information on how to access the findings of the study.

6.6: Maintaining confidentiality and anonymity/data protection

Data collected from patients must be protected, hence requiring researchers to be vigilant and ensure that secure systems are put in place to protect confidential information (Glasper and Rees 2017). In this study participants were assured of confidentiality and details of how this was going to be achieved throughout the study were provided based on the recommendations by Glasper and Rees (2017). For example, participants were assured of anonymity where pseudonyms were going to be used to protect their personal and nursing home identity.

To store research data safely and securely, the researcher ensured that paper consent forms were kept in a locked cabinet and separated from the data gathered. Electronic documents were encrypted and stored securely in password protected files which were accessible to the researcher only. The data collected were accessible to the researcher and her supervisors only.

Holland and Rees (2010) suggest that participants should also be given information regarding the period that the research data would be retained after the completion of the study. The researcher in this study was guided by the Cardiff University data retention schedule in retaining her data.

Furthermore, confidentiality does not only involve protecting participants' identifying information but also collecting information only relevant to the study and using the information collected for the intended purposes only (Johnson and Long 2010, Parahoo 2014, Polit and Beck 2021). As such, only data relevant to answer the research question was collected in this study and was used for the purposes of this study only. In addition, the participants were informed that only aggregate data would be used when disseminating research findings in presentations or conferences.

It is important for researchers to note that confidentiality cannot be absolute in certain cases (Johnson and Long 2010). A researcher may need to report any information that poses a safety risk related to dangerous activity or unsafe practice and participants must be made fully aware of this before they agree to take part in the study (Johnson and Long 2010). Participants were clearly reminded of the researcher's duty to disclose any essential information to an appropriate authority or professional that would suggest any potential for

harm to themselves or third parties before agreeing to take part in this study and prior to each interview.

6.7: Protection of participants and researchers

Research studies that involve interacting with people, may involve ethical issues that could cause problems and lead to undesirable effects on the part of research participants (Hammersley 2016). As such, researchers need to ensure that risks and harm to participants are avoided or minimised as much as possible, and where inevitable there should be a balance between the risks involved and the potential benefits (Rees 2011). Rees (2011) recommends a number of ways that can be followed to protect participants from harm which include balancing risk and benefit, maintaining confidentiality/anonymity, minimising pain, discomfort or distress, and provision of debriefing/referral to appropriate services where necessary.

6.7.1: Beneficence/non-maleficence

The principle of beneficence demonstrates the researcher's obligation in ensuring that the research being undertaken benefits the participants, society and carers, whereas non-maleficence means the researcher avoiding harm (physical or psychological) being caused to those involved in a study (Glasper and Rees 2017).

This study posed both emotional distress, and physical risk to the participants and researcher. Parahoo (2014) comments that although qualitative research seems harmless, those involved could still end up with emotional harm as it is believed that any type of research has potential to cause distress by bringing back painful, sad, or traumatic memories. As discussed in the methods chapter, the sensitive nature of the topic area in this study exposed both the participants and the researcher to some level of emotional distress. Talking about death and dying is known to induce emotions (Felber et al. 2023) which could result in some level of emotional harm to the participants and the researcher (Parahoo 2014). As such, the researcher addressed this risk by completing a risk assessment. In addition, the researcher ensured that information on available support services was shared with the participants, which was also included in the participant information sheet. The researcher was also prepared to support the participants who would be distressed during the

interviews and make appropriate referrals. The researcher maintained a compassionate attitude towards distressed participants and always made sure that there was a box of tissues available for the participants to use if needed. On several occasions, participants broke down and cried when telling their stories. In these instances, the researcher would pause the interviews and offer the participants support. An opportunity to cancel, postpone or rearrange the interviews would then be given to the participants. In all cases, the participants chose to continue with the interviews after taking a short break.

Furthermore, the managers also arranged debriefing sessions with the participants following interviews as advised by Polit and Beck (2021). During these debriefing sessions participants had a chance to discuss any issues, air complaints, express their feelings, ask questions and seek peer support. Each nursing home also confirmed that they held their own local policies and procedures for managing emotional distress which were accessible to all employees.

The researcher was also aware that conducting research around sensitive topics can be taxing and can affect researchers emotionally, especially when listening to participants' stories which could affect their ability to think critically (Corbin and Strauss 2015). As such, the researcher made sure that she took short breaks in data collection to care for herself when she felt overwhelmed. The researcher was also aware of the available support services that she could access. Speaking with the supervisors also helped the researcher in dealing with her emotional distress resulting from conducting the research. Keeping a reflective diary also helped the researcher to critically analyse her feelings, also to release some of the stress caused by the research, as advised by Corbin and Strauss (2015).

The physical risk that this study posed was risk of COVID-19 infection transmission to both the researcher as well as the participants. Data collection for this study was conducted during the COVID-19 pandemic. All participants in this study opted for face-to-face interviews, which increased the risk of transferring the infection. As such, the researcher had to adhere to the infection control procedures when visiting each nursing home by completing a risk assessment to address these risks.

To maintain the safety and well-being of the public, participants, staff, residents, and students during the pandemic, face-to-face contact was restricted especially in those individuals who had recently experienced COVID-19 symptoms or had recently been exposed to someone with symptoms or diagnosed with the infection. A COVID-19 participant self-declaration questionnaire was therefore completed by each participant and the

researcher on the day of the interview before the visit was made which helped to assess any risk of the virus.

Moreover, the participants and researcher were only allowed into the nursing homes if they had a negative result for the COVID-19 lateral flow test on the day of the visit. Also, infection control measures such as correct use of personal protective equipment (PPE), hand sanitation, and physical distancing were adhered to during the visits. The nursing home managers also arranged research interviews to be conducted away from resident areas to protect the vulnerable residents. The researcher also arranged to conduct a number of interviews per time where possible to minimise the number of visits to the nursing homes. In cases of high risk of transmission, virtual interviews would be an alternative. Fortunately, there was no need to conduct any interviews online throughout the whole period which met the participants' preferences for face-to-face contact.

6.7.2: Lone working

Lone workers are described as individuals who operate out of sight or sound of others (Swallow et al. 2015) or those who work by themselves without close or direct supervision, or who are physically isolated from colleagues and without access to immediate assistance (Health Service Executive (HSE) 2020). In research, lone working poses various risks for the researcher, which include physical threat, psychological harm, and accusations of improper behaviour (HSE 2020). The SRA Code of practice (2021) helps to guide researchers in the UK on how to ensure the safety of those taking part in or conducting research.

This study involved the researcher travelling to reach participants in the nursing homes to conduct interviews. The specific risks that the researcher was exposed to included road traffic accidents, adverse weather, assault- physical or verbal, and sudden illness/medical emergency. The researcher hence completed a risk assessment to address these risks which was submitted as part of the ethical approval application.

In addition, the researcher, keeping in line with the HSE (2020) lone working guidelines, developed a buddy system with a colleague on the same programme who was available during the period that the researcher was collecting data. The buddy and supervisors had the researcher's phone number and emergency contact details. The buddy was informed of the place where data were to be collected and specific times. The researcher would send a text to the buddy: 'Start' indicating that the interview had started and 'End,' signifying that the

interview was over, and 'Home' when the researcher got home. This was done to alert the buddy that the researcher was safe. It was agreed that the buddy would alert the postgraduate research office and supervisors if she did not receive any communication at the agreed times. The researcher made sure that her mobile phone was in good working order and with enough battery power so that she was able to make contact or be contacted at any time as required. However, there were no incidents during the entire data collection period to cause any concern. All other risks identified in relation to this study were included in the risk assessment.

6.8: Justice

Justice, one of the key ethical principles, ensures that all participants in a study are treated fairly and equally without any preference or prejudice (Polit and Beck 2021) which ensures equal distribution of benefits and burden (Rees 2011). Parahoo (2014) adds that justice also makes sure that the researcher's power is fairly used to the researcher's advantage over the study participants. Rees (2011) therefore advises that researchers select study samples fairly by ensuring that all eligible subjects are included without any preference (Rees 2011).

In this study, all RNs in the nursing homes involved were given equal opportunity to take part in the study. Uniform information on the study was given to all RNs, and those who expressed interest to participate were selected. Furthermore, transparency was maintained by ensuring that the inclusion and exclusion criteria were specified on the poster adverts available to all RNs to provide information which was used to select the eligible subjects. A study sample should, therefore, not be selected based on the sample's easy availability, compromised position, or manipulability only (Burns and Grove 2009) but should represent the diversity of a society (Johnson and Long 2010). The RNs that were willing to take part in this study did not receive any favours or special treatment for choosing to participate. Similarly, there were no repercussions for those who did not wish to be involved in this study.

The researcher was also conscious of the power imbalance that could have resulted between herself and the RNs due to her supervisory and monitoring role as a Nurse Assessor in nursing homes. As such, the researcher made sure that her two roles were kept separate. During her visits to the nursing homes to conduct the research interviews, the researcher identified herself as a research student and wore her university identification

badge which assisted in creating a relaxed atmosphere hence encouraging the RNs to take part in the study voluntarily and share their experiences freely.

6.9: Summary of chapter

This chapter has provided a comprehensive overview of the ethical principles and safeguards that guided the design and implementation of the study. The chapter has demonstrated how the researcher upheld professional, legal, and institutional ethical standards to protect participants, ensure integrity, and maintain research rigor.

The chapter begins by outlining the foundational role of research ethics, defining them as the moral values and governance structures that ensure the dignity, rights, and welfare of research participants throughout the study lifecycle. Key ethical principles underpinning the research included ethical approval, informed consent, voluntary participation, autonomy, confidentiality, anonymity, data protection, beneficence, non-maleficence, lone working, and justice.

The researcher obtained formal ethical approval from the School of Healthcare Sciences Research Ethics Committee after developing a full research protocol and responding to committee recommendations. Approval was granted in December 2020, allowing the study to proceed. Informed consent and voluntary participation were upheld through clear, accessible participant information, adequate decision-making time (3–5 days), and assurance of the right to withdraw. Participants were fully informed of risks, benefits, confidentiality measures, and data handling procedures, and provided written consent. Capacity to consent was ensured, and participants received opportunities for questions and clarification.

Moreover, respect for autonomy was demonstrated through participant choice, absence of coercion, ongoing communication, and access to study findings. Participants were reassured that non-participation carried no repercussions and were kept informed throughout the research process. To maintain confidentiality, anonymity, and data protection, the researcher used pseudonyms, secure physical storage for consent forms, encrypted electronic files, and strict access controls. Only essential data were collected, retained according to Cardiff University policies, and disseminated in aggregate form. Participants were also informed about limits to confidentiality in cases involving safety risks.

This chapter also highlights measures to protect both participants and the researcher. Emotional and physical risks, particularly related to the sensitive topic of death and dying and the COVID-19 pandemic, were mitigated through risk assessments, availability of support services, debriefing sessions, protective equipment, and infection control protocols. The researcher also monitored her own emotional well-being through reflective practice and supervisory support. Given the need for interviews in multiple nursing homes, lone working risks were addressed using a structured buddy system, communication protocols, and adherence to national lone-working guidelines. Travel and safety risks were assessed and managed throughout data collection.

Finally, the principle of justice was upheld through fair participant recruitment, equal access to information, transparent inclusion and exclusion criteria, and equitable treatment of all registered nurses. The researcher also took steps to minimise power imbalances arising from her professional role by identifying herself solely as a research student during interviews. Overall, the chapter concludes that robust ethical standards were embedded throughout the study, ensuring the protection, respect, and fair treatment of participants while maintaining the researcher's own safety and well-being.

The next two chapters present the findings of this study including the main categories in chapter seven, and the core category in chapter eight.

Chapter 7: Research findings-main categories

7.1: Introduction

This chapter presents the findings of this study which include three main categories that were integrated from the analysis of the data collected: end-of-life care wishes and preferences, end-of-life care organisation and delivery, moral distress, and the core category: interpersonal relationships (Table 16). As the data for this study was collected during the pandemic, the participants' narratives also included how the provision of end-of-life care for people with dementia in nursing homes had been affected during this period.

The categories are supported by a selection of direct quotes which best illustrate the views expressed by the participants. Differing views or divergent opinions expressed by the participants are also included. The selected quotes are accompanied by additional information from field notes, memos, and diary notes, where applicable, so that they can be read and understood with due contextualisation.

Categories	Description	Sub-categories
End-of-life care wishes and preferences (main category)	This category incorporates participants' accounts of their experiences of navigating wishes and preferences for end-of-life care for people with dementia who resided in nursing homes	-Goals of end-of-life care -Navigating end-of-life care wishes and preferences
End-of-life care organisation and delivery (main category)	This category incorporates participants' experiences of the organisation and delivery of end-of-life-care for people with dementia who resided in nursing homes	-Addressing end-of-life care needs -Teamwork -Intra-professional working -Interprofessional working -Collaboration with family members, relatives, loved ones or friends
Moral distress (main category)	This category incorporates participants' accounts describing the psychological anguish that they experienced as a result of being constrained from providing ethically correct end-of-life care for people with dementia during the COVID-19 pandemic	-Dealing with death and dying -Moral distress due to the COVID-19 pandemic: -Social restrictions during the COVID-19 pandemic -Staffing issues and moral distress -End-of-life care decisions
Interpersonal relationships (core category)	This category incorporates the participants' accounts describing the relationships that they formed when providing end-of-life care for people with dementia in nursing homes.	-Relationships with residents -Relationships with residents' Relatives -Relationships with team members

Table 16: Findings by category

7.2: End-of-life care wishes and preferences

This category incorporates participants' narratives about their experiences of navigating the wishes and preferences for end-of-life care for people living with dementia residing in nursing homes. The narratives in relation to this category are presented under the subcategories: goals of care and navigating end-of-life care wishes and preferences.

7.2.1: Goals of end-of-life care

The participants provided their understanding of the objectives of end-of-life care for individuals with dementia in nursing homes. A wide range of what they considered as the main goals of care in their practice were discussed. Their accounts revealed areas of end-of-life care that were prioritised by the participants. Summer's account, for example, highlights the physical comfort side of care aimed at controlling symptoms such as pain and agitation.

"The main thing that we have to look into is to make sure they are comfortable, they are not in pain, they are not agitated"
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Rose and Lily, on the other hand, highlight the ethical-relational dimensions of dignity and respect, making end-of-life care a fundamentally moral concept rather than a clinical one. Furthermore, Lily's comment stating that dignity applies 'whether they have got dementia or any other diagnosis' is particularly important as it challenges the potential stigma around dementia, hence maintaining the dying individual's right to respect regardless of their health status.

"Our responsibility is to maintain their privacy, respect, and dignity at the end"
(Rose, Staff Nurse, RGN, Oak Nursing Home).

"The most important thing is that their lives end with dignity whether they have got dementia or any other diagnosis"

(Lily, Senior Nurse, RGN, Oak Nursing Home).

Tina's account emphasises on the significance of place, familiarity, and relational continuity. Her emphasis on 'home' as a place of death to describe the nursing home environment suggests that for long-term residents, the institution becomes their home, and that dying within this familiar environment constitutes a good death.

"In the end that person died here back home, under familiar place, with familiar carers that she knows, she died as peaceful as we could make for her"

(Tina, Staff Nurse, RGN, Holly Nursing Home).

It is worth noting that the references of a good death provided in this section are merely based on the participants experiences, and as such, cannot accurately represent the dying person's own views of what constitutes a 'good death.' The goals of end-of-life care being defined by professional carers, therefore, raise questions about whose views ought to be considered in shaping the end-of-life care for individuals with dementia in the nursing homes.

Furthermore, the nurses' accounts revealed that a good death would be achieved if an individual's wishes were respected. The participants described a range of wishes that people living with dementia expressed regarding their end-of-life care. These wishes broadly incorporated physical, emotional, and spiritual needs. Specific examples included refusing treatment, funeral arrangement plans, having their favourite pet present, people they wished to be or not to be with them at the time of death, clothes they wanted to wear, music to be played or hymns to be sung, scripture from the bible to be read to them, dying comfortably or without pain, place of death, and having their privacy and dignity respected. Having loved ones around at the time of death was one of the most commonly described wishes.

Across these accounts, a shared goal to achieve a 'good death' was apparent. There was a noticeable convergence in terms of the way the participants interpreted the concept. Words such as 'nice', 'beautiful', 'peaceful', or 'dignified' were used to describe a 'good death' by different participants. The consistency of this language shows a shared understanding of what a good death meant amongst the nurses. However, the use of the various terms by the nurses renders the concept to a subjective interpretation between individuals which may be

based on a number of factors such as background, personal experiences, nature of relationships, values, and beliefs.

"A 'nice death' is someone that passes with their family, or if they have not got family then with someone with them, holding their hand...."

(Hannah, Senior Nurse, RMN, Ash Nursing Home).

"...and at the end of his life, his daughter was lying in bed with him.... he was very peaceful at the end of his life, and his family were there..."

(Dawn, Staff Nurse, RGN, Cedar Nursing Home).

"And she was going into the sort of last few hours of her life. And her family were with her.... the lady was in the room with them, sharing the most wonderful experience"

(Lily, Senior Nurse, RGN, Oak Nursing Home).

These three accounts construct a powerful narrative of relational dying in which the quality of death is measured not solely by the absence of suffering, but by the presence of meaningful human connection. Hannah's account demonstrates that an ideal situation is family presence, but failing that, 'someone', even a carer, holding the dying person's hand. This reveals the nurses' strong objection to their residents dying in solitary, and their willingness to stand in when the residents' biological family are unavailable.

Dawn's account of a daughter lying in bed with her dying father describes an intimate and physical closeness that goes beyond professional boundaries within care. This highlights that in long-term care settings domestic intimacy can coexist alongside professional care. Moreover, Lily's description of a death she experienced as 'the most wonderful experience' highlights the nurses' important role of facilitating and enabling such moments which provide a great sense of satisfaction in their professional role. However, the emphasis on family presence as constituting a 'good death' raises debate for those residents without family or those whose family are not able to be present at the time of death due to reasons such as distance, work, and family commitments.

In addition to close family and friends, some dying individuals were said to also want their favourite pets with them at the time of their passing. Ben explained that in most nursing homes pets would be allowed in but with some restrictions or caution. In challenging situations, staff would endeavour to find the safest ways to ensure that a dying individual's wishes were still respected.

"...she said she had a little pony...and she would love to see the pony.... we had rearranged the bed to get the horse into the room.... and she saw the horse.... and she just kept on saying, "I cannot believe it! I cannot believe you have done this!" and it was a beautiful thing.... she was over the moon and happy"

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

Ben's account of facilitating a dying resident's wish to see her pony is an illustration of creative and unconventional person-centred care. The logistical effort involved by rearranging the bed to accommodate a horse in a nursing home room signifies a willingness to break institutional norms or policies to provide meaningful opportunities to meet a dying resident's wish. The resident's expression of disbelief shows that such action and consideration exceeded her expectations of what could be achieved within a nursing home setting. This suggests that some residents may not express their wishes fearing that they may not be achievable in such care institutions. Ben's description of this as 'a beautiful thing' reveals how such extraordinary acts can be professionally and emotionally significant for nurses, reinforcing their sense of purpose.

The participants' accounts showed that during the COVID-19 pandemic residents' wishes were not always respected. The visiting restrictions imposed on care homes, social isolation, and shielding practices put in place as infection control measures meant that relatives could not visit the nursing homes to spend time with their loved ones who were dying. This created a significant disconnect between the participants' beliefs of a 'good death' and the constrained reality of pandemic care delivery.

"It is important to make sure that their wishes and needs are understood.....Covid took a lot of that away"

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

"I do recall having four people of end-of-life care on one shift due to Covid and phoning the relatives up and they were not allowed to visit. It was awful." [tearful]

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

Ben's previous account revealed the extraordinary lengths to which staff went to honour a resident's wish to see her pony. However, in his latter statement he narrates how the most basic wish of having family present at the time of death could not be met in the same context due to organisational constraints. The phrase 'Covid took a lot of that away' demonstrated how the pandemic stripped residents, their relatives, and nurses of the relational practices that would help to facilitate meaningful end-of-life care. Ben's recollection of managing four simultaneous deaths on a single shift and making phone calls to their families who were not allowed to visit flags how morally challenging the situation could have been for him, which he labels as 'awful'.

Furthermore, the prolonged periods of separation due to the visiting restrictions were said to result in distress in both the dying residents and their relatives, which the participants felt was detrimental to their well-being. This reveals how the pandemic did not impact on the care delivery alone, but also the residents and their families.

"There's a big impact to the family and the resident. Because when they are dying, they want their family, they are calling, where is my daughter, when is she coming? We explain, but because of the dementia, they cannot understand....so it is hard. And of course, the family also want to be with them during the last days but are not able to because of this lockdown." [tearful]

(Cara, RGN, Staff Nurse, Holly Nursing Home).

"I am sure the people dying also were aggrieved in that they did not understand what was going on, they did not have any family members attending at that time, so it must have been difficult for them I am sure when they did not realise what was going on due to their dementia"

(Emily, RGN, Staff Nurse, Ash Nursing Home).

Cara's account displays a very touching picture of the impact of the pandemic restrictions on dementia care in the nursing homes. The situation where a dying resident is described to repeatedly call for her daughter, yet not understanding the reasons given for her absence due to her cognitive impairment presents a good example of an emotionally challenging scenario created by the pandemic. This situation was difficult for nurses to manage as their explanation could not be effective in consoling the distressed resident. Emily using the phrase 'I am sure', reveals the difficulty nurses face in the attempt to interpret the subjective experience of residents with cognitive impairment, hence raising important questions about how the experiences of people with advanced dementia are represented in qualitative research.

7.2.2: Navigating end-of-life care wishes and preferences

The participants highlighted the importance of Advance Care Plans (ACPs) in understanding the end-of-life care wishes of people living with dementia in nursing homes. The participants explained that ACPs assisted them to understand the needs of the individuals that they cared for. The ACPs were also said to guide the care that the participants provided, especially during times when nursing home residents were being looked after by people who were not familiar to them, such as out-of-hours doctors or temporary workers.

The participants further narrated that choosing the way they were cared for at the end of their lives meant that the people living with dementia were provided more autonomy to make decisions and take control of their own ending. This was particularly important in the context of dementia as the ACPs would ensure that the residents' wishes were known and respected even at such a time when they are unable to communicate their needs.

"You can be in control of your own death"

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

"The best thing is to have everything in place like a good end of life care plan...if you have a good care plan in place and everything that you need to know, it is quite easy to look after them."

(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Summer's pragmatic approach ensuring 'everything is in place' positions the ACP primarily as an enabler of effective end-of-life care for residents with dementia. The assertion that good care planning makes it 'quite easy to look after them' underscores the importance of ACPs.

Furthermore, ACPs were found to be useful in directing care given by those professionals who were not familiar with the dying individuals. Having the residents' wishes written down was said to give healthcare professionals support and confidence in making decisions about care and treatment for the dying individuals.

"ACPs really support the out of hours doctors, gives them that confidence"
(April, Senior Nurse, RGN, Ash Nursing Home).

April's observation highlights the importance of ACPs in supporting the decision-making confidence of unfamiliar practitioners. This is particularly significant in the nursing home context, where out-of-hours care is frequently provided by doctors who do not know the residents. The documented ACP, therefore, helps to relay the information about residents' care decisions to others in the absence of familiar or regular staff. It could, however, be argued that the rich information that nursing home staff possess about a resident through daily contact cannot all be captured in a written document.

To fully understand a resident's end-of-life care wishes and preferences, the participants explained that they would normally obtain information from the resident themselves, but if not possible, from their relatives upon admission into the nursing home. The participants would then become more familiar with what matters to the residents over time as they settled into the nursing home.

"With advanced dementia if there isn't anything in place, we'll have a discussion with the family..."
(Hannah, Senior Nurse, RMN, Ash Nursing Home).

The nurses further explained that at times they had to deal with residents with advanced dementia who did not have any relatives or representatives. In such cases, they stated that they had to find ways to learn the individuals' needs slowly as they went along caring for them. This scenario represents arguably an ethically complex situation within end-of-life care

for people with dementia and raises questions as to how wishes of a person who can no longer express themselves be honoured when someone is speaking on their behalf. The nurses highlighted another option which would require them to learn such residents as they went along caring for them.

"Unfortunately, if someone does not speak and we have not got anyone to ask we just have to consider how we learn about this person along the way really."

(April, Senior Nurse, RGN, Ash Nursing Home).

April's use of 'unfortunately' however, suggests that this approach is only an improvisation where the preferred pathways of direct communication or family consultation are unavailable. Also, the phrase 'along the way' suggests a process of getting to know a person through routine care interactions, for example, noticing preferences, responses to stimuli, sources of comfort or distress. However, the reliance on staff interpretation of non-verbal cues in the absence of any documented or family-reported preferences could carry a risk of staff basing their assessment on their own values, beliefs or experiences, rather than the resident's.

The participants' accounts showed that information about a new resident's wishes and preferences was best collected upon admission into the nursing home as in Tina's explanation. She explained that the information that they collected would then help them to design care plans that would direct the individual's care.

".... An ACP is a must once the person comes to the home... it will help the family and the nurses on how they are going to deal with everybody if they know what the person's needs or wishes are"

(Tina, Staff Nurse, RGN, Holly Nursing Home).

Tina's use of the word 'Must' highlights a mandatory requirement for ACPs to be completed for residents upon admission into the nursing homes, making the process central to care planning and beneficial to both families and nurses. This suggests the ACP dual function of providing families with reassurance that their relative's wishes will be respected, and simultaneously equipping staff with the information needed to deliver appropriate care.

During the pandemic, the participants explained that they faced challenges in completing comprehensive assessments and obtaining full histories from residents with dementia on admission. This was said to be due to the staff shortages during this period, which prevented the nurses from finding enough time before the resident died to speak to the new residents and/or their relatives to establish their wishes and preferences as part of a normal admission procedure.

".... we did not have enough time to communicate with the family and to get end-of life care plan— what they like and what they do not like ..."

(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Summer's account reveals a fundamental contradiction within this period. It is noted that ACP were most urgently needed during this period when residents were deteriorating rapidly and often cared for by unfamiliar staff, yet it is highlighted as precisely the period in which it was least achievable. The time pressure Summer describes created an ethical crisis as residents were dying without individualised care plans which the participants had consistently identified as foundational to dignified end-of-life care for the residents with dementia.

7.2.3: Summary of category

The participants' accounts in this category have revealed a shared commitment to achieving a 'good death' for residents with dementia, defined through interrelated principles of comfort, dignity, autonomy, and relational presence. ACPs were regarded as essential instruments for preserving residents' wishes and guiding care delivery, particularly when unfamiliar staff were involved. However, the data has also exposed significant tensions. Although residents' autonomy was highly advocated, the cognitive realities of advanced dementia posed practical challenges in its achievement. Also, the aspiration toward person-centred care planning depended heavily on family involvement and adequate staffing, both of which were severely compromised during the COVID-19 pandemic. The visiting restrictions and staff shortages during this period prevented family contact/involvement, and meaningful interactions and care planning at the point of greatest need. In addition, residents with dementia were left unable to comprehend the enforced absence of their loved ones which

was detrimental to their well-being. The pandemic thus created a mismatch between what the nurses believed end-of-life care should be and what they were able to deliver.

7.3: End-of-life care organisation and delivery

This category incorporates participants' experiences of the organisation and delivery of end-of-life care for people living with dementia in the nursing homes. The section is presented under the sub-categories: end-of-life care needs and teamwork.

7.3.1: Addressing end-of-life care needs

The participants described a range of end-of-life care needs for people living with dementia which included physical comfort, emotional and psychological, social, and spiritual needs. The participants consistently emphasised a holistic approach when discussing these needs, though the degree to which this holism was realised in practice, particularly during the pandemic, was not clear from the data.

"It is a total holistic approach to looking after somebody...."
(Ben, Staff Nurse, RMN, Cedar Nursing Home).

Ben's reference of 'total holistic approach' asserts a model of care that encompasses the entirety of the person. However, the subsequent data reveals a notable inconsistency in the depth with which different domains of need are discussed. Physical care needs received the most detailed and clinically specific attention from participants, while emotional, social, and spiritual needs, though acknowledged as important, were often described in more general terms. This pattern shows that physical symptom management is more clearly categorised and therefore more readily articulated within nursing practice.

The participants' accounts highlighted the challenges faced when assessing end-of-life care needs for people with dementia. Communication was identified as the main barrier caused by poor cognition. Consequently, the nurses stated that they had to rely on non-verbal cues to read and interpret the communication, a practice requiring advanced assessment and interpretation skills.

"It is difficult with dementia clients because they cannot always tell you if they do not feel well; you have got to go a lot with body language, particularly if they are coming to the end of their life"
(May, Staff Nurse, RGN, Ash Nursing Home).

May's account highlights the cognitive and emotional effort required to decipher and understand communication with people living with dementia. The phrase 'you've got to go a lot with body language' underscores a clinical practice that requires the nurse to be aware of subtle physiological and behavioural signals such as facial expressions (grimacing, smile), restlessness, or shouting; and to interpret these within the context of what they know about the individual. This form of clinical/tacit knowledge is not easily transferable to unfamiliar staff, which has significant implications for the continuity of care during periods of high staff turnover such as the pandemic.

To manage the challenges encountered in communicating with the individuals with dementia, the nurses explained that they would consult people who knew the individuals with dementia better, such as family members and close friends, to provide or clarify information about the individuals' needs to assist in care planning. However, the visiting restrictions during the pandemic significantly hindered family involvement in this process.

*"... and they might have one friend who you could involve... a close friend....
It is dealing with whoever knows the resident best..... about what they would
want and what they would not want"
(May, Staff Nurse, RGN, Ash Nursing Home).*

*"So, they are already on the moderate to severe spectrum of dementia. And
the only way you will know their wishes is to speak to the family"
(Tina, Staff Nurse, RGN, Holly Nursing Home).*

Tina's claim that 'the only way you will know their wishes is to speak to the family' positions the family not merely as a helpful supplementary source of information, but as the only channel through which the wishes of a person with advanced dementia can be known. This dependency would impact on end-of-life care systems in situations where family access and involvement are disrupted such as the COVID-19 pandemic visiting restrictions. May's broadening of the network to include 'one friend' or 'whoever knows the resident best' reveals a more flexible approach which accommodated not only family members but significant others.

Amongst the categories of end-of-life care needs that participants presented, physical care needs were those that were widely described across all four nursing homes. These included symptom relief, personal hygiene, nutrition and hydration, and pressure area care. The priority of care in addressing these physical needs was stated as promoting comfort for the dying residents which could be achieved by managing symptoms such as pain, constipation, excess secretions, laboured breathing, agitation, and nausea. The progression across these quotes reveals a range of comfort measures with a central focus on pharmacological approach to symptom management. Dawn's systematic listing of medications and their indications demonstrate a high level of pharmacological knowledge which is required in nursing practice.

"We give Morphine for pain, Hyoscine for secretions, Midazolam for agitation and often Cyclizine for nausea"

(Dawn, Staff Nurse, RGN, Cedar Nursing Home).

April and Emily present a much broader focus on maintaining comfort,

"I think comfort is the main thing"

(April, Senior Nurse, RGN, Ash Nursing Home).

"Pain relief is paramount to make sure they are comfortable"

(Emily, Staff Nurse, RGN, Ash Nursing Home).

while Ben introduces bowel management, an aspect of care that is not always prioritised in end-of-life care but central to routine nursing care.

"Again, you are making sure that they have had their bowels opened.... you do not want somebody to be in agony with constipation during the end of life"

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

Moreover, Jane's description of 'rattles and gurgles', underscores the priority of care by maintaining comfort through airway management with mucolytic medication. Similarly, May noted that *Oramorph works well* for breathlessness.

"... He also had the rattles and the gurgles.... we gave Hyoscine I just wanted him to be comfortable..."

(Jane, Staff Nurse, RGN, Ash Nursing Home).

"If someone has got breathing problems, Oramorph works well for that"

(May, Staff Nurse, RGN, Ash Nursing Home).

Taken together, these accounts highlight how highly knowledgeable nursing home nurses are in pharmacological management of end-of-life symptoms, which is often under-recognised compared to specialist palliative care teams who are more prominently valued.

Good personal hygiene was another measure for maintaining comfort for dying residents. The participants discussed aspects of personal hygiene provided to dying residents which included oral care, general body cleansing, and continence care. These nursing interventions were intended to keep the dying individuals clean and fresh, hence ensuring comfort.

"We make sure that their continence needs are met...."

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

April's emphasis on oral care and her clarification that cleanliness extends beyond routine 'personal care' by including management of clamminess and sweat. Her phrase 'that must feel horribly uncomfortable' acknowledges the need to address that aspect of personal hygiene. These accounts collectively demonstrate that the physical care of dying residents extends beyond routine tasks of personal care.

"...oral care especially is a big thing that we try and encourage as much as possible because often people are gasping for breath, and their mouth is open and dry all the time...."

(April, Senior Nurse, RGN, Ash Nursing Home).

"And making sure people are clean as well. I am not just talking about personal care... some of them get quite clammy and sweaty, and that must feel horribly uncomfortable"

(April, Senior Nurse, RGN, Ash Nursing Home).

Maintaining a conducive environment was also discussed as a measure applied in maintaining comfort for the dying residents. Participants explained that they would ensure that the dying resident's room and body temperature were kept within normal ranges, adjusting ventilation, bedding, and using tepid sponging as needed.

"You are making sure that their temperature is controlled.... you can have fans on. You can put towels over the top of heads to cool people down. You can always ask them if they would like their feet out at the bottom of the blanket..."

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

"Making sure they have got the correct amount of beddings on, are they cold or are they hot...so making sure that they are comfortable..."

(April, Senior Nurse, RGN, Ash Nursing Home).

Ben's elaboration of the environmental interventions such as fans, cool towels, adjusting blankets at the feet, shows that even such small but thoughtful actions can be beneficial in promoting end-of-life comfort. Notably, Ben also refers to 'asking the resident about their preference', suggesting that communication with the dying person, however limited and autonomy, remains a valued practice even in the final stages.

Furthermore, nutrition and hydration were identified as care needs aimed to promote a dying resident's comfort. A number of participants explained that some dying residents continued to eat and drink until the end, but this would require modifying their diets and fluids and ensuring ample feeding time would be provided where needed.

"If they are eating and drinking then obviously you need to maintain their nutrition and hydration for as long as you can"

(May, Staff Nurse, RGN, Ash Nursing Home).

"Towards the end of dementia as the disease progresses very often people's diet will alter. They will go on a softer or a pureed diet and fluids get thicker"

(April, Senior Nurse, RGN, Ash Nursing Home).

"If they are still able to eat, they definitely need more time to feed"

(Ivy, Staff Nurse, RGN, Oak Nursing Home).

The participants' accounts of nutrition and hydration reveal an adjusted approach that balances continuation of oral intake with risk management while recognising the dying resident's physiological decline. May's use of 'for as long as you can' acknowledges the temporal limits of nutritional intervention in dying, while April's description of dietary modifications maps the progressive adaptation of care to the trajectory of the disease. Ivy's emphasis on allowing more time for feeding is practically significant, as it highlights the resource implications of person-centred care; feeding a person with advanced dementia can be time-intensive which may have implications on staffing levels, a factor that was severely compromised during the pandemic.

Furthermore, maintaining skin integrity was another fundamental aspect of end-of-life care described by the participants. According to their accounts, as residents became frailer and their mobility declined placing them at increased risk of pressure damage. Regular repositioning and pressure-relieving equipment were identified as interventions implemented to mitigate this risk.

"For somebody who lives in bed, you must make sure that they do not get any pressure sores.... Often, they are not eating, which puts the skin integrity at a remarkably high risk of breaking down, so we make sure they have appropriate mattresses and beds...."

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

".... we plan the care of course, and if somebody needs to be turned every two hours then we need to be putting that in place"

(April, Senior Nurse, RGN, Ash Nursing Home).

Ben's account demonstrates an understanding of the interaction of care needs- the relationship between nutritional decline and skin integrity. April's reference to the two-hourly turning schedule introduces the regimented dimension of pressure care, which, while

clinically necessary, contradicts the efforts to maintain comfort. In the terminal phase, the potential discomfort from frequent repositioning must be weighed against the potential risk of pressure damage.

Notably, participants' accounts did not indicate particular challenges in addressing physical care needs during the pandemic in the nursing homes. While the pandemic profoundly disrupted the relational, emotional, and spiritual dimensions of end-of-life care, the fundamental physical nursing care appears to have continued with relative consistency, suggesting that this domain of practice was more resilient to the external shocks of the pandemic.

Although the physical care needs were widely discussed across all the four nursing homes, the participants' accounts revealed how spiritual needs often dominated an individual's end-of-life in the nursing homes. The usual practice to address dying residents' spiritual needs, was to invite faith leaders into the nursing homes to conduct prayer services or perform rituals such as last rites.

"Spiritual beliefs are so very important and often dominate somebody's wishes for end of life over their physical ones"
(Dawn, Staff Nurse, RGN, Cedar Nursing Home).

"Before she passed away, she did see her minister, and they already planned about what they are going to do on her funeral"
(Tina, Staff Nurse, RGN, Holly Nursing Home).

Dawn asserting that spiritual needs 'often dominate' physical ones positions spiritual needs as foundational rather than supplementary to end-of life care. The Simultaneity of Pam's account: 'the resident died 'in a minute or two' after the vicar's prayers' evidences the nurse's satisfaction and relief that the resident's spiritual needs were fulfilled at the time of death.

"I had to organise a vicar to come to see her before she went...in the end I was so pleased the vicar came, he did his prayers and, in a minute, or two after, she went"
(Pam, Senior Nurse, RGN, Holly Nursing Home).

Moreover, May's description of an activities worker reading the bible and singing hymns illustrates how spiritual care was sometimes delivered not by ordained ministers but by nursing home staff who stepped into this role, demonstrating the flexibility and adaptability of the care team particularly during the pandemic. May's account stating 'that was probably the best passing that she could have had' indicate that the spiritual care provided aligned with the resident's wishes, hence acting as a measure of success.

"...and our activities lady sat with her, sang hymns with her, and read the bible to her...that was probably the best passing that she could have had.... It was tailored very much to the resident's wishes, which was good"
(May, Staff Nurse, RGN, Ash Nursing Home).

However, the COVID-19 pandemic visiting restrictions hindered the provision of spiritual care for the dying residents. The participants' accounts revealed that faith leaders were not permitted to visit the nursing homes during this period, and group religious services were also suspended.

"Prior to Covid we used to have regular religious services from various denominations... a couple of months ago we could not invite them in because we were completely locked down which is sad."
(May, RGN, Staff Nurse, Ash Nursing Home).

"....and I thought about this lady, I'm sure she would have liked to have had someone give her the last rites."
(Emily, RGN, Staff Nurse, Ash Nursing Home).

Emily's reflective statement 'I'm sure she would have liked' reveals an assumption about the spiritual wishes of a person who can no longer confirm them. The inability to provide last rites during the pandemic represents not only an unmet preference, but also a significant spiritual deprivation for the dying residents and their families.

The participants' accounts further highlighted another dimension of end-of-life care which involved emotional support for the dying residents. The emotional care they provided aimed to allay anxiety and minimise stress caused by the dying process, as they recognised how frightening death and dying could be.

"People can be scared by death, knowing they are going to die...."
(Jane, Staff Nurse, RGN, Ash Nursing Home).

*"We do not like people dying on their own, and we had promised her sister,
that we would not leave her alone"*
(April, Senior Nurse, RGN, Ash Nursing Home).

April's account introduces the notion of a promise, a commitment that carries moral weight beyond clinical obligation. The use of 'we do not like' speaks to a collective professional value system within the nursing home that positions solitary death as a failure of care. However, this commitment to ensure that no resident died alone was, as subsequent data reveals, profoundly compromised by the pandemic.

The participants' narratives showed how the provision of emotional care to dying residents was negatively affected during the pandemic. For instance, personal protective equipment (PPE), while essential for infection control, acted as a barrier to the relational and embodied aspects of emotional care.

*"He was obviously barrier-nursed, and with all the PPE you just felt you
could not do what you wanted to do"*
(Florence, RGN, Senior Nurse, Ash Nursing Home).

Florence's use of the term 'barrier-nursed' presents two opposing sides to care particularly during the pandemic: the role the practice played in infection control, but also the barrier the practice created between carer and dying resident. The phrase 'you could not do what you wanted to do' reveals the gap between the care the nurse aspired to provide and the care that pandemic conditions permitted. This disconnect between intention and action is a recurring feature of the pandemic narratives and constitutes a key source of the moral distress explored within the findings of this study.

The pandemic social isolation measures were seen, from the participants' accounts, to further compound these challenges. The participants narrated that during the pandemic all residents were required to stay in their own rooms to control the spread of the virus which resulted in some residents dying alone, mostly against their wishes.

"So, obviously we were isolating people and barrier nursing these people that were affected by the Covid.... and there were so many people on their own in their rooms that were passing away" [tearful]
(April, RGN, Senior Nurse, Ash Nursing Home).

April's account of 'so many people on their own in their rooms' illustrates the mass solitary dying that characterised the pandemic in care homes. The phrase 'so many' shows the intensity of the issue, hence challenges the proportionality and ethics of infection control measures over the relational needs of dying residents.

Moreover, social distancing rules imposed during the pandemic were said to impact on the provision of end-of-life care. The participants explained that they were required to observe a two-metre physical distance rule whereby no physical contact was allowed except when providing direct care. This prevented the provision of emotional care through touch, which participants considered particularly important for individuals with dementia.

"It has been hard with the Covid with the touch because obviously we have got to come away from so much touching. But I just find it soothing especially as their family are not here. obviously when they do not understand what is happening to them, they get irate. So, it is just to calm them down and spending time with them really and you start explaining what you are doing, like a gentle approach and more of a touch"
(Grace, RGN, Staff Nurse, Oak Nursing Home).

"We cannot give them hugs because of Covid."
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Grace's account provides a richly detailed description of the therapeutic function of touch in dementia end-of-life care. For residents who 'do not understand what is happening to them', touch serves as a communicative channel that bypasses the cognitive pathways disrupted by dementia, offering reassurance through non-verbal medium. The restriction of touch during the pandemic thus impacted negatively on the people with dementia, who relied on this sensory modality for connection and comfort. In addition, Summer's narrative 'We

cannot give them hugs because of Covid' illustrates how the well-intended infection control measures resulted in the loss of embrace at the point of greatest need.

Social needs were also highlighted in the participants' accounts as an important aspect of end-of-life care for the people with dementia in the nursing homes. The participants explained how they encouraged dying residents to maintain meaningful activities until the end, with the belief that quality of life could still be maintained regardless of the residents' terminal diagnoses.

"It depends on what stage of dementia.... we also look after other aspects of well-being like interests, hobbies which they still like to do such as watching birds outside or listening to their favourite music, reading their favourite books that will make this transition as smooth as possible."

(Pam, Senior Nurse, RGN, Holly Nursing Home).

"The same care plans as normal.... just because somebody is end of life, it does not mean that everything stops.... We still try and make things as normal as possible. We have had people at end of life who still attended activities like singing because that is what they used to do before, it should not change... "

(Florence, Senior Nurse, RGN, Ash Nursing Home).

Florence's insistence that 'it should not change' asserts continuity which means that the onset of the dying phase should not disrupt a person's established patterns of activity and engagement. This helps to maintain a dying person's existing identity hence promoting a quality life beyond their diagnosis. Pam's reference to making 'this transition as smooth as possible' underscores the importance of the progressive management of the dying process.

Enabling these social needs yet presented a significant challenge during the pandemic due to the social isolation rules which forced residents to remain in their private rooms, hence preventing them from attending and participating in the social activities of their choice.

"So, obviously we were isolating people in their own rooms...."

(April, RGN, Senior Nurse, Ash Nursing Home).

Moreover, the COVID-19 pandemic accounted for increased sickness and absences amongst the nursing home staff which severely impacted on the delivery of end-of-life care for people with dementia. Due to the understaffing participants were left to look after large numbers of residents, most of whom were very unwell and approaching their end-of-life.

"We have three nurses, two were off sick with Covid and one was on annual leave. So, that was it, me on my own for seven days all through Covid. The most heart-breaking thing I have ever done in my entire nursing career.... we lost a lot of people. So, that was a real struggle for me because I could not separate myself between 70 plus people that we had here.... I was in pieces.... So, that was difficult, and I just had to work like a machine and work my way through all these people suddenly deteriorating and we were literally one out, and one out, and one out. It was just heart breaking"
[tearful]

(April, RGN, Senior Nurse, Ash Nursing Home).

April's account offers a powerful insight in this dataset. Her description of being the sole nurse for seventy residents over seven consecutive days during a period of mass mortality is an account of professional endurance under conditions that, by any reasonable standard, were unsafe. The metaphor of working 'like a machine' reveals the self-protective emotional mode that was necessary to function under such conditions by dehumanising herself. The reference of 'one out, and one out, and one out' describing the sequential deaths in her nursing home at this time, conveys both the relentless pace of the residents' deaths and the magnitude of the experience. Furthermore, her statement 'I was in pieces' shows that she was simultaneously broken emotionally though physically functional; a paradox that brings to light the profound psychological cost of the pandemic on delivery of care in the nursing homes. This account raises serious concerns about the duty of care owed to the nurses themselves, and the adequacy of the support systems that were available to them during this most taxing period.

Furthermore, the high levels of staff absences were reported in this study to lead to an increased usage of agency staff to cover for the shortages. However, these agency workers were in most cases not familiar with the residents' needs. The participants explained that situation resulted in increased confusion and distress, particularly in residents with dementia.

"If they are with the people they know I think it can relax them more before they die."

(Pam, Senior Nurse, RGN, Holly Nursing Home).

"When I first started going in nursing homes but that was on an agency, so I didn't really get to know the residents very well, and it was more me going into a home for a night and then going to another home, and going to another home..."

(April, RGN, Senior Nurse, Ash Nursing Home).

Dawn's analysis identifies a compounding effect of the pandemic; the loss of family contact was simultaneous with the loss of familiar staff, creating a double disruption of the relational environment upon which residents with dementia depended for their sense of security and identity. Her statement that 'any change is detrimental' reflects an understanding of dementia that positions environmental and relational stability as crucial and, conversely, instability as essentially detrimental to the individuals' well-being.

"In environments where staffing may be changed because of Covid, they may be short-staffed, regular staff may be off work because of Covid. So, residents are seeing lots of strange faces and that constant in their lives they love, their family, is suddenly gone.... it's detrimental and has a profound effect. When you start having this turnover of staff, the loss of that regularity impacts on somebody with dementia. Any change is detrimental because they do not understand what is going on and they become frightened and anxious"

(Dawn, RGN, Staff Nurse, Cedar Nursing Home).

The pandemic thus impacted on the very foundations of dementia care: the familiar faces, routines, and relationships that supports an individual's diminishing world. April's reflection on her own earlier agency work raises awareness that the constraints in care she highlights existed well before the pandemic in nursing homes, and the pandemic simply exacerbated the issues.

7.3.2: Teamwork

The participants' accounts illustrated key multidisciplinary and multi-agency collaboration in the provision of end-of-life care for people with dementia in the nursing homes. This teamwork was formed between intra-professional, inter-professional, specialist service teams, professionals from other sectors, and relatives or significant others. The following sections examine each dimension of this teamwork, revealing both its strengths and the ways in which the pandemic disrupted established collaborative practices.

7.3.2.1: Intra-professional working

The majority of the participants described how they worked collaboratively within the nursing homes to provide end-of-life care for people with dementia. The core nursing home team included qualified nurses and nursing assistants and/or health care assistants. The participants recognised and respected the contribution that each team member made, demonstrating teamwork that was notably equitable.

"We all need to be working together ... we all respect each other's views, from somebody coming in from the kitchen to take their order in the morning to the manager downstairs, we do work together"
(Florence, Senior Nurse, RGN, Ash Nursing Home).

Florence's account illustrates an inclusive team extending from the kitchen worker to the manager. This picture of nursing home care flattened hierarchy may be a distinctive feature of nursing home care where the intimacy of daily residential life creates conditions for a more collaborative culture. Florence's narration 'we all need to be involved' positions end-of-life care as a collective responsibility shared across the entire nursing home community.

"I think it's the teamwork.... we normally have multidisciplinary teams coming in.... we all need to be involved [in end-of-life care]."
(Florence, Senior Nurse, RGN, Ash Nursing Home).

Team spirit became heightened within the nursing homes during the pandemic. Due to the critical staff shortages, staff were seen to 'muck in' wherever they could, sometimes performing duties outside their job description and qualification.

"Before Covid, the families were allowed in. During this Covid period we've had residents who have passed away. And obviously, because family can't come in, I've always made sure a carer, or our activities girls would sit with them so they're not by themselves."

(Jane, Staff Nurse, RGN, Ash Nursing Home).

"The processes that we put in [during the pandemic] was that she always had a female carer, a member of staff, whether it would be somebody from the kitchen who knew her, or whether it be somebody who cleaned the local floors, or a housekeeper or somebody who knew her to sit with her"

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

These accounts reveal an adaptive response to the crisis in which the boundary between 'clinical' and 'non-clinical' staff was deliberately dissolved. Some staff were said to take on roles that were profoundly intimate and emotionally demanding, but outside their formal job description or training. For example, the activities worker read the bible and sang hymns to a dying resident, and the kitchen worker and housekeeper sat with a dying resident.

Furthermore, shifting the companionship role from family members to any available staff member who 'knew her' demonstrates both a creative adaptation to crisis, and an affirmation that, in the absence of family, the key requirement was not clinical expertise but relational familiarity. Ben's specification that the staff member should be someone 'who knew her' highlights that meaningful presence at the end of life requires not just physical proximity, but a pre-existing relationship.

The participants further explained that the nursing home teams at times required expert support from specialist practitioners. For example, they would require assistance from District Nurses for complex nursing procedures such as syringe driver management.

"With the syringe drivers, ...we do not do it here, ... the District Nurses will come in to set the syringe driver and regulate the medication dosages.... we

only monitor the patient and the syringe driver and contact the District Nurses if we need to"
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Summer's account reveals an important scope-of-practice boundary; syringe driver management was considered beyond the competence of nursing home staff and required District Nurse involvement. This dependency on external specialist input highlights a gap in the provision of end-of-life care in the nursing homes, which the pandemic's disruption of routine community nursing services may have exposed.

7.3.2.2: Interprofessional working

The participants' accounts also described teamwork involving healthcare professionals outside the nursing home. These included General Practitioners (GPs) and Out of Hours doctors who were responsible for the provision of routine and end-of-life medical care for the residents. The participants' narratives revealed a complex and, at times, deeply problematic relationship with medical practitioners that was significantly fuelled by the pandemic.

"... the GP will say, "they are deteriorating, they are elderly, they have dementia. Let us put them on end-of-life [commence end-of-life pathway]"
(Florence, Senior Nurse, RGN, Ash Nursing Home).

"You can see there is a decline in their intake, in their mobility, in their overall health, deterioration, then you know to contact the doctor.... then a decision must be made about end-of-life"
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Summer's account highlights distinct roles by positioning the nursing home nurses as primary assessors of residents' decline, and the doctor as the main decision maker in end-of-life care. This reflects a care model in which clinical authority for prognostic decisions remains vested in medical practitioners, despite the nurses' superior knowledge of the individual resident. Similarly, Ivy's phrase below 'we do take our guide from the GPs' supports the doctors' authoritative decision-maker stand in end-of-life care for the nursing home residents. It was noted across from across all four nursing homes that the term

'pathway' was still being used loosely, such as in Florence's narrative to describe end-of-life care plans. This is quite common across different care settings in Wales where 'pathways' are still embedded with care practices. Perhaps this area requires further exploration and training in the whole UK to ensure a consistent approach to end-of-life care, particularly in terms of terminology used and planned course of care.

"The GPs are the ones who would come in and say obviously there is a deterioration in their condition and that they are coming to the stage now where end of life medications need to be put in place.... we do take our guide from the GPs"

(Ivy, Staff Nurse, RGN, Oak Nursing Home).

The participants' accounts further indicated that during the pandemic, routine doctors' visits became infrequent, with most face-to-face consultations replaced by virtual interactions. Most critically, participants reported that diagnoses and end-of-life prognoses were being made remotely, without adequate clinical assessment.

"One GP does a video call at least once a month where we go around with the video and she speaks to them."

(April, Senior Nurse, RGN, Ash Nursing Home).

"The doctors would not come into the home. I'd had a week off in March on holiday and when I came back every single person in the home had a prescription for end-of-life medication. They just assumed everybody had Covid. So, of course when people started getting poorly, they didn't want to come in because you've got everything you need in place."

(April, Senior Nurse, RGN, Ash Nursing Home).

April's account presents profoundly disturbing implications of the pandemic. The blanket prescription of end-of-life medication for every resident in the home, based on an assumption of COVID-19 infection rather than individual clinical assessment, demonstrates lack of individualised care. The phrase 'they just assumed everybody had Covid' describes a form of collective prognostic categorisation that reduced each resident to a demographic risk profile; elderly, in a care home, with dementia, therefore presumed to be dying. April's subsequent

statement 'you've got everything you need in place' shows that the pre-emptive prescribing was intended to minimise the doctors' visits into the nursing homes, a decision that prioritised the doctors' safety over individualised clinical care. This account questions how ethical the standards of medical care provided to nursing home residents during the pandemic were, and whether the treatment of this resident population constituted a form of structural discrimination based on age, setting of care, and diagnostic category.

"They don't come out to test that person and say, okay it's not Covid, we'll treat them. As soon as you mentioned a cough or a cold, or anything like that, then straightaway the GP would say, we think it's Covid, they're this age, they've got underlying conditions, then they go down the line of end-of-life medication. I think it's completely wrong and disgusting the way they've been treated through this pandemic. I just think it's quite unbelievable where nearly, well probably half, if not more, residents were written up for end-of-life medication."

(Hannah, Senior Nurse, RMN, Ash Nursing Home).

Hannah's remark 'completely wrong and disgusting' and 'quite unbelievable' reflects not merely disagreement with a clinical decision, but a moral judgement about the treatment of a vulnerable population.

Moreover, Florence's comment 'they're deteriorating, they're elderly, they've got dementia', followed by 'that's not always the answer' challenges the doctors' clinical reasoning and asserts the nurse's right to question such decisions.

"I think we need to have the right medication at the right time, especially with Covid. I think it's very much like the GP's say, oh they're deteriorating, they're elderly, they've got dementia, let's put them on end-of-life. That's not always the answer."

(Florence, Senior Nurse, RGN, Ash Nursing Home).

Collectively, these accounts show how the pandemic exposed and exacerbated a pre-existing power imbalance between nursing home staff and medical practitioners. Furthermore, the participants explained that they faced challenges in getting doctors to

certify residents' deaths during the pandemic. Consequently, the nurses had to take up this additional role.

"And lately we have challenges with Out of Hours for example to come and certify death, and that's we should be doing it in the home which am working on it now to train staff, we've got to have the processes to certify death"
(Pam, Senior Nurse, RGN, Holly Nursing Home).

"The UHB sent out a thing about end-of-life verification.... So, most of the nurses here verify as well, so that's been a massive step for us."
(April, Senior Nurse, RGN, Ash Nursing Home).

The devolution of death verification to nursing home nurses represents a significant expansion of their professional role, driven by necessity rather than planned development. April's framing of this as 'a massive step for us' reveals how this change is simultaneously an empowering extension of professional competence but at the same time, an additional burden resulting from the disruption of medical services in the nursing homes.

"The most anxious part that I find when the resident does pass away, is checking for signs of life, and just obviously feeling anxious in myself then. I'm there looking for a pulse, and I can sometimes feel my own pulse, and that's quite a nervous experience... it is all on me, and that is quite hard, especially on nights....but I still have to make that decision"
(Norman, Staff Nurse, RMN, Ash Nursing Home).

The phrase from Norman's account 'it is all on me' conveys an example of situations where the nurses felt isolated, particularly during night shifts where there was only one qualified nurse on duty and no colleagues immediately available for support or confirmation. This account illustrates how the pandemic not only expanded nurses' clinical responsibilities, but also their exposure to psychologically demanding situations for which they may have received only minimal preparation.

The specialist palliative services also formed part of the end-of-life care team for the people with dementia in the nursing homes according to the participants' accounts. The nurses

explained that they found this group of specialists useful for expert advice in complex situations such as uncontrolled pain.

"The palliative to be frankly, are the main ones They are the ones which are the most helpful.... She was having horrible pain; she was always seen by the palliative team...I had to get a lot of support from the palliative nurses"
(Pam, Senior Nurse, RGN, Holly Nursing Home).

"The experience is so different when the Palliative Care team are involved... It is so much easier, everything is seamless"
(Ivy, Staff Nurse, RGN, Oak Nursing Home).

Ivy's account stating: the experience is 'so different' and 'so much easier' with palliative care involvement reveals the value of specialist care input. The word 'seamless' further demonstrates how the involvement of the specialist palliative care services transformed care through expert management.

Ivy's claim that 'all the focus is on cancer and not dementia' asserts that palliative care support is predominantly available for people with conditions such as cancer but not for people dying with dementia, revealing inequity and systemic bias within the healthcare system.

"Other people do not tend to have palliative input for somebody with dementia without a specific illness like cancer, brain tumour, and Motor Neurone Disease.... But it is like all the focus is on cancer and not dementia...."
(Ivy, Staff Nurse, RGN, Oak Nursing Home).

However, it can be argued though that dementia being a terminal condition with a complex symptom burden is a condition that would require specialist palliative attention as much as, even more than, other terminal diagnoses.

7.3.2.3: Collaboration with family members, relatives, loved ones, or friends

Also forming part of the end-of-life care team were family members and significant others. The role that family members played in the delivery of end-of-life care for people with

dementia was widely discussed by the participants. Family members and significant others were said to be crucial in providing emotional support and making decisions on behalf of dying residents who lacked capacity. This, therefore, highlights how the disruption of family access during the pandemic not only caused social loss, but as also removed a key component of the care team.

"For me the family are a massive part of end-of-life care"
(April, Senior Nurse, RGN, Ash Nursing Home).

"The best thing is for them to have their family, if that's possible of course, this has a big impact. Sometimes the medication don't always help, sometimes you need emotional support, like someone there from your family to hold your hand even to talk, if you talk, they can still hear you, even if they don't say anything back, they will hear you, even if they have dementia am sure they still recognise your voice."
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Summer's account asserts that family presence can achieve what medication cannot. Her belief that people with dementia 'still recognise your voice' shows that relational recognition operates at a level deeper than conscious awareness. Understanding the importance of meaningful relationships in advanced dementia could, therefore, help to challenge the association of cognitive decline with the loss of relational capacity.

The participants' accounts demonstrated that before the pandemic, visits into the nursing homes were unlimited. Families were allowed to spend time with and be involved in the care of their loved ones as much as they wished was beneficial for the emotional well-being of both the dying residents and the families.

"So, the family was involved, the family was here every single day for hours and hours so that they could spend more time with their mom. So, this is very important.... You need the family to be there for the last moment or for the last period. Some of the family cannot accept. So, we need to reassure them all the time. So, we need to involve them. We need to give them the opportunity to see the patient before the death. The touch is important yeah."

Even sometimes you can't give anything, even the strong painkillers, they are not so strong like the family touch, the family feelings, you know."
(Rose, Staff Nurse, RGN, Oak Nursing Home).

"And because they [family members] are super anxious, you know, in normal times that in these times they're even more anxious because they know that they're only going to get that one visit when things are really close to the end. So, it's important that they feel supported."
(Ivy, Staff Nurse, RGN, Oak Nursing Home).

Rose's assertion that 'the family touch' is more powerful than 'the strong painkillers' elevates relational presence above pharmacological intervention in the hierarchy of comfort measures. Yet, despite this knowledge, Ivy observed that family members of dying residents were not being given adequate time to visit and say farewell to their dying relatives in the nursing homes during the pandemic. The pandemic visiting restrictions severed the relational thread that participants had consistently identified as central to quality end-of-life care.

"About a year ago when everything was normal, we had someone who had reached the end of life and we had family around. And unfortunately, because of the pandemic, the family are unable to come."
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

"Before Covid, the families were allowed in. During this Covid period obviously, family can't come in..."
(Jane, Staff Nurse, RGN, Ash Nursing Home).

April provides a striking narrative about the two sisters who had shared a bed throughout their lives the shared double bed. The frequency of her visits and being 'very lost' without her sibling demonstrate a lifelong interdependence that was brutally severed by the pandemic visiting restrictions.

"One lady who recently who passed away. Never been married. Lived with her sister to the extent that they were so close they used to sleep in the same double bed and so when she came into the home her sister was very

lost without her so she'd come and see her very frequently and during lockdown obviously she couldn't"
(April, Senior Nurse, RGN, Ash Nursing Home).

A number of participants reported going out of their way to maintain contact between the families and their loved ones in the nursing homes. Some nurses, like Ben, even reached the extent of using their own devices to facilitate telephone or video calls during this period as presented in chapter 8, section 8.3.

"So, we keep in touch, we call the family...we are able now because of the problem with covid, we are able to have a video call.... Most of the residents they have the opportunity to see their family on video call.... I don't know when they will open the house regarding this to visit their family, they can't visit at the moment."
(Rose, Staff Nurse, RGN, Oak Nursing Home).

However, the participants felt that these efforts could not replace physical contact and were of the opinion that families deserved to be allowed to visit their loved ones in the nursing homes, particularly those who were dying.

"I think if someone is passing it is an exceptional circumstance, and they should be allowed in— it's not the same as seeing somebody over Skype or whatever."
(May, RGN, Staff Nurse, Ash Nursing Home).

"I think even with Covid it's a very good idea to allow them to come if they want to."
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

May's considering a person's passing as 'an exceptional circumstance' that should override standard infection control restrictions presents a moral argument about the limits of public health measures when they conflict with the fundamental relational needs of dying people and their families. Her dismissal of video calls as an inadequate substitute, 'it's not the same', reinforces the physical nature of the comfort that family presence provides. In

addition, Summer's views about family visiting, even during the pandemic, highlights the imbalance between infection control and relational care, hence carries policy implications in terms of prioritising relational dying over institutional risk management.

7.3.3: Summary of category

In summary, the findings in this section have shown that organisation and delivery of end-of-life care for residents with dementia relied upon a holistic approach addressing physical, spiritual, emotional, and social needs, underpinned by tiered teamwork covering intra-professional collaboration, inter-professional partnerships with GPs and specialist palliative care, and the integral involvement of family members.

Moreover, physical symptom management proved relatively resilient to pandemic disruption, yet the relational, spiritual, and emotional dimensions of care were profoundly compromised: PPE and social distancing measures obstructed therapeutic touch, whereas isolation rules enforced solitary dying, and staff shortages forced nurses into unsustainable working conditions. The withdrawal of GP visits led to blanket end-of-life prescribing that participants regarded as ethically wrong, and nurses assuming additional responsibilities despite their own staffing issues.

The pandemic also exposed pre-existing systemic gaps in care provision, including the inequitable access to specialist palliative care for people with dementia compared to those with cancer, and the power imbalance between nursing home staff and medical practitioners. While the pandemic crisis triggered adaptive responses such as non-clinical staff assuming companionship roles and nurses undertaking death verification, these adaptations resulted in significant emotional and professional costs.

7.4: Moral distress

This category incorporates participants' accounts describing the psychological anguish that they experienced as a result of being constrained from providing ethically correct end-of-life care for people with dementia during the COVID-19 pandemic. Understood through the lens of Jameton's (1984) foundational concept, moral distress arises when an individual knows the ethically appropriate course of action but is prevented from carrying it out by institutional, structural, or situational constraints. The participants' narratives throughout this section

illustrate how nurses who possessed a well-developed understanding of what constituted good end-of-life care for people with dementia found themselves systematically prevented from delivering it by forces beyond their control such as government-mandated social restrictions, critical staff shortages, and medical decisions made without adequate clinical assessment. This section presents the consequences of the constraints experienced by the participants, organised under the heading of moral distress due to the COVID-19 pandemic, with sub-headings of social restrictions, staffing issues, and end-of-life care decisions.

7.4.1: Dealing with death and dying

It was evident from a number of participants' accounts that nursing home nurses often struggled with their residents' deaths. Before examining the moral distress generated specifically by pandemic conditions, it is important to establish the emotional baseline against which the pandemic's impact must be understood. The data reveal that nursing home nurses carry a persistent and cumulative emotional burden associated with the deaths of residents, even under normal circumstances. This pre-existing emotional weight demonstrates that the moral distress of the pandemic is not a new concept but an exacerbation of an already demanding emotional situation.

"It's really sad when we lose our residents."

(Jane, Staff Nurse, RGN, Ash Nursing Home).

"It is normally hard for nursing home nurses to deal with a death of a resident..... when somebody dies it is quite a taxing experience"

(Emily, Staff Nurse, RGN, Ash Nursing Home).

The phrase that Jane uses 'our residents' reveals a caring relationship that extends beyond professional obligation into personal attachment. Moreover, Emily describing death as 'taxing' positions death not as her individual experience but as a generalised feature of nursing home nursing ('it is normally hard for nursing home nurses') hence, recognising this emotional burden as a systemic feature of the role rather than an individual failing.

Emily further explained that she found deaths of her residents 'draining' because they were physically as well as emotionally demanding. Supporting dying residents over prolonged periods was what was said to cause the strain.

"It was really touching and at the same time I had to physically and emotionally support this lady over a whole night shift pretty much..... and that has stayed with me ever since.... Two days after that I was physically drained because we were sitting, and I was physically holding her."
(Emily, Staff Nurse, RGN, Ash Nursing Home).

This account represents the embodied nature of end-of-life care. The phrase 'physically holding her' over an entire night shift describes a form of caring work that is simultaneously physical and relational. Emily's acknowledgement that the experience 'has stayed with me ever since' points to what Jameton (1993) later termed 'moral residue' which means the lingering psychological aftermath that accumulates from repeated morally distressing experiences. Even in this pre-pandemic account, the traits of cumulative moral distress are evident whereby each death leaves an emotional residue that does not fully dispel before the next one arrives.

Narratives from two other participants further showed that the nurses formed close emotional attachments with the residents under their care. These participants stated that they regarded the residents as their own families. This bond was seen to make it difficult for the nurses when their resident was dying.

"In this environment they become your family and I think that is why we are so emotional. I think we are very much family, we become very close to these people."
(April, Senior Nurse, RGN, Ash Nursing Home).

"They are like my family, it is very emotional because you care about them like your father, like your mother. It is like you are part of the family. You do everything to make sure they are happy. And when the end is coming [they are dying], it is a bit difficult."
(Rose, Staff Nurse, RGN, Oak Nursing Home).

April and Rose's accounts reveal the nurse-resident relationship that forms a basis for understanding moral distress. If residents are regarded as family members, then the constraints that prevent nurses from delivering appropriate care are experienced not only as professional frustrations but as failures toward people they love. The distress is simultaneously moral (I know what is right and cannot do it) and personal (I am failing someone I care about as family). Rose's use of specific kinship terms 'your father,' 'your mother' represents an intimate relationship that make it more acute, painful, and frustrating for the nurses when faced with care constraints.

Furthermore, Rose adds that this situation becomes even more challenging when a nurse is expected to remain professional when caring for a dying resident who they are close with, which is also the case in Pam's account.

"I need to maintain to make sure I am a professional and do not express how hard it is for me."

(Rose, Staff Nurse, RGN, Oak Nursing Home).

"Sometimes when you let your feelings get in a situation it's hard for you as a nurse even as a healthcare professional when you are attached to the person, it's hard for you to accept."

(Pam, Senior Nurse, RGN, Holly Nursing Home).

These accounts reveal an additional dimension of moral distress. For example, Rose's statement 'I need to maintain to make sure I am a professional' describes a form of emotional labour whereby nurses are expected to suppress their grief to maintain a degree of professionalism that is incompatible with visible distress. This suppression constitutes a constraint on its own as the nurse knows that her emotional response is natural yet feels compelled to conceal it. In Pam's account, the same attachment she identifies as problematic is what she identifies as precisely what enables the person-centred, relational care that the participants in this study mark as good practice. This is a fundamental contradiction as the emotional closeness that makes care meaningful also makes loss devastating, and the professional norms that demand composure prevent nurses from processing their grief in healthy ways.

Even though death was a common occurrence in the nursing homes, the participants still struggled with their emotions when one of their residents died, as shown in Ben's account.

"We see death and we see a lot of deaths, and I suppose we are certainly not immune to it, but it is something that you see often. It does not mean that it does not kill you inside and it does not make you upset and cry, it does."

(Ben, Staff Nurse, RMN, Cedar Nursing Home).

Ben's statement challenges any assumption that repeated exposure to death produces emotional desensitisation. The metaphor he uses 'kill you inside' illustrates how each resident's death bruises the nurses emotionally. Moreover, the phrase 'we are certainly not immune' resists the cultural expectation that healthcare professionals should develop emotional resilience through exposure. Ben's account, therefore, reveals the cumulative effects of the exposure to these deaths, which if continue to 'kill the nurses inside,' potentially moral residue can occur over time resulting in a reservoir of unprocessed grief.

Deaths of nursing home residents during the COVID-19 pandemic, however, compounded the emotional stress in the nursing home nurses. The participants described residents' deaths during this period as qualitatively different.

"Obviously, the Covid deaths were a bit more traumatic than the normal deaths."

(Jane, Staff Nurse, RGN, Ash Nursing Home).

The phrase 'normal deaths' in Jane's account reveals that within the nursing home context, death is an expected, routine part of the care environment. However, the description 'a bit more traumatic,' while understated, shows that residents' deaths during the pandemic exceeded this established norm. This distinction is therefore consistent with Jameton's conceptualisation of moral distress which showing how 'normal' deaths enabled the nurses to generally deliver the care they believed to be right and how the pandemic removed that possibility, transforming routine moral strain into acute moral distress through the imposition of external constraints.

In addition, the increased number of nursing home residents' deaths during this period also contributed to the physical and emotional stress experienced by the nurses.

"Especially in this time of Covid where there has been a lot of people dying which is also another issue... So many people dying around you is just physically and emotionally draining." [tearful]
(Emily, Staff Nurse, RGN, Ash Nursing Home).

"We were literally one out, and one out, and one out [deaths]. It was just heart breaking." [tearful]
(April, Senior Nurse, RGN, Ash Nursing Home).

Emily's account positions the pandemic deaths as additional strain to an already burdensome emotional load ('another issue'), supporting Ben's account confirming the cumulative nature of moral distress. April's rhythmic repetition, 'one out, and one out, and one out' shows how the fast pace of the Covid deaths stripped away the individuality of each death. This deindividuation of death directly contradicts the participants' expressed values of person-centred, relational end-of-life care, and it is this contradiction between what death should mean and what it was reduced to that caused moral distress in the nurses during the pandemic.

Also, the way that some residents infected with the virus died during this period was described as quite traumatic, leaving some nurses struggling emotionally over prolonged periods.

"It was the most traumatic death I had seen in a long time purely because of the way he died, and whatever it was that was pouring out of him, and he was obviously clearly distressed. So, that was a horrible experience for me, it really was... I have never managed to talk to anyone yet about the Covid thing.... I know what we went through and I know that I am still struggling with that, and I know that I still need help for that." [tearful]
(April, Senior Nurse, RGN, Ash Nursing Home).

April's graphic description of the death 'whatever it was that was pouring out of him', conveys a distressing and horrifying death, exceeding the nurse's established frameworks for understanding and managing death. Her subsequent disclosure 'I have never managed to talk to anyone yet about the Covid thing' reveals a profound failure of organisational support. The use of 'yet' shows that she recognises the need to process the experience but has found no method for doing so. Her confession 'I know that I am still struggling,' 'I know that I still need help' conveys her self-awareness of her psychological injury and the need to access support even though she has not found a remedy yet. Epstein and Hamric (2009) warns how repeated morally distressing experiences without adequate resolution can lead to moral lasting effects referred to as moral injury. The lack of accessible support systems constitutes a form of institutional moral failure that compounds the original distress in the nurses.

On a different note, the participant expressed an additional frustration over the fact that, despite trying their best to care for their residents in isolation during the pandemic, their efforts were not recognised by people outside the nursing homes.

"I just feel these residents they just become a little bubble, and we care for them and the outside do not see what we are doing inside... it just sucks, it just sucks the energy out of you to be honest. In a way it is draining"
(Grace, RGN, Staff Nurse, Oak Nursing Home).

Grace's metaphor of the 'little bubble' describes how the residents were isolated from the outside world, and the staff who cared for them were equally invisible during the pandemic. Grace's account reveals that moral distress can be amplified when one's suffering, sacrifice, and efforts go unwitnessed or unacknowledged. Her repeated phrase 'it just sucks' represents an energy depletion stemming not just from the work itself, but also from the demoralising lack of recognition.

7.4.2: Moral distress due to the COVID-19 pandemic

The participants' narratives presented in this section demonstrate that the nurses experienced moral distress when caring for people living with dementia during the COVID-19 pandemic. Based on these accounts, the sources of moral distress stemmed from three interrelated categories of constraint: social restrictions, staffing issues, and end-of-life care decisions, as illustrated in Figure 9. Crucially, these three sources did not operate in isolation

but interacted jointly, creating a compound form of moral distress in which each constraint amplified the impact of the others.

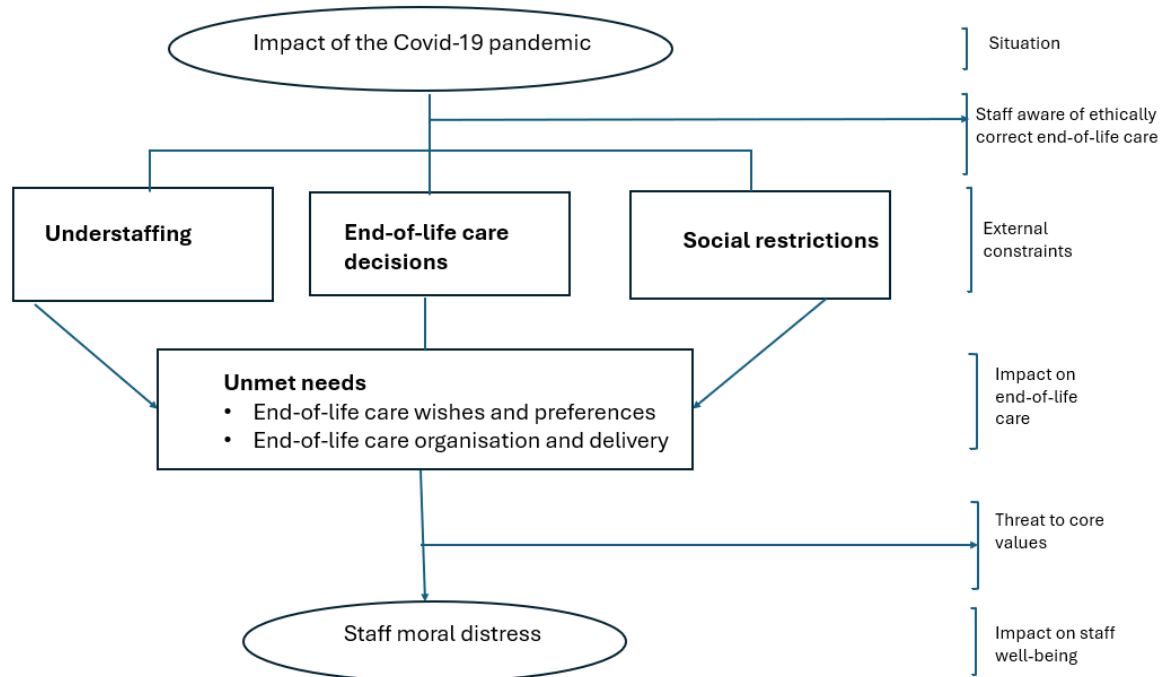


Figure 9: Moral distress and the COVID-19 pandemic

7.4.2.1: Social restrictions during the COVID-19 pandemic

The social restrictions imposed by the UK government on nursing homes as a measure to control the spread of the virus had a profound impact on end-of-life care for people living with dementia. The participants' accounts showed that visiting restrictions, social isolation, and social distancing resulted in a number of unmet care needs. These unmet needs triggered psychological unease in the nursing home nurses, as the externally imposed restrictions forced them to act against their core values, ethical beliefs, and professional integrity. Government policy prohibited the very actions that nurses knew to be ethically correct. The moral distress was therefore not a product of ethical uncertainty as the nurses were clear about what should be done but lacked the authority to override the restrictions that they judged to be causing harm.

"It is important to make sure that their wishes and needs are understood.....Covid took a lot of that away [tearful]"
(Ben, Staff Nurse, RMN, Cedar Nursing Home).

Ben's tearfulness during this account is an example of a behaviour that transforms a narrative into lived anguish. This account details how the pandemic 'took away' the nurses' capacity to fulfil their most fundamental professional obligation of understanding and honouring residents' wishes. This led to feelings of powerlessness and, consequently, moral distress.

The visiting restrictions during this period meant that dying residents were not able to spend their last moments with their loved ones, which was against their end-of-life care wishes.

"I do recall having four people of end-of-life care on one shift due to Covid and phoning the relatives up and they were not allowed to visit. It was awful."
(Ben, Staff Nurse, RMN, Cedar Nursing Home).

Ben's recollection of simultaneously managing four dying residents while telephoning relatives who were prohibited from visiting illustrates how this situation, described as 'awful,' placed him in an impossible position of being both the bearer of devastating news and the enforcer of the restriction that caused its devastation. The moral conflict here is threefold:

Ben knows that family presence is central to a good death, he is structurally prohibited from facilitating it, and he is then required to personally communicate the prohibition to distressed families. This situation was particularly challenging especially for residents with dementia who were not able understand why their relatives were not present at this most crucial time.

“Because when they are dying, they want their family, they are calling, where is my daughter, when is she coming? We explain, but because of the dementia, they cannot understand....so it is hard. And of course, the family also want to be with them during the last days but are not able to because of this lockdown.” [tearful]

(Cara, RGN, Staff Nurse, Holly Nursing Home).

Cara’s account reveals a dimension of moral distress that is specific to dementia care and that extends Jameton’s framework. The resident’s repeated calling for her daughter represents a form of suffering that cannot be comprehended, because the cognitive impairment makes rational consolation impossible. The nurse is, hence, trapped in a situation where she witnesses an incomprehensible distress that she cannot alleviate; she cannot bring the daughter, and she cannot make the resident understand why. In this account, the nurse is powerlessly stuck between the resident and family who are both in anguish.

Furthermore, the participants explained that residents infected with the virus happened to deteriorate quite rapidly resulting in unexpected deaths. The participants stated that they struggled in such cases as they had to give the relatives the sad news of the sudden deaths of their loved ones, and particularly over the phone.

“She died unfortunately unexpectedly and I found it extremely difficult to tell the family.”

(Pam, Senior Nurse, RGN, Holly Nursing Home).

“That was a very difficult experience for me.... I was having to ring people and tell them your parent, or your mother has deteriorated, and then the next phone call they’re really bad now, I’m really sorry you can’t come in.... that was absolutely destroying....” [tearful]

(April, RGN, Senior Nurse, Ash Nursing Home).

April's account describes making series of quick phone calls, each delivering progressively worse news, at the same time enforcing the visiting restrictions. The word 'destroying' describes how she had to deliver news that she knew would cause suffering, while enforcing a restriction she believed was ethically wrong, but at the same time not being able to offer the comfort to the family members in person. Pam's statement 'I found it extremely difficult' indicates similar anguish.

Unmet spiritual needs were also identified as a cause of moral distress in the nurses during the pandemic. One participant explained how they were saddened when a dying residents' spiritual needs could not be met due to the visiting restrictions. Restricting religious leaders' visits against a dying resident's wishes conflicted with her core values.

"Prior to Covid we used to have regular religious services from various denominations... a couple of months ago we could not invite them in because we were completely locked down which is sad... I felt sad for those who wanted the priest at the end of their life to.... hopefully, it will not be that long before we can have priests back in."
(May, RGN, Staff Nurse, Ash Nursing Home).

May's account was one of empathy; 'I felt sad for those who wanted the priest,' from her awareness of the resident's unmet spiritual needs. This structural limitation prevented her from inviting faith leaders regardless of dying resident's wishes, representing a violation of the resident's spiritual autonomy. The clause in May account 'hopefully, it will not be that long' in itself represents powerlessness as there was nothing, she could do to change this situation but wait and hope for the best.

Furthermore, the participants' accounts also exposed instances of unmet emotional needs. These were said to originate from the social distancing rules that were imposed during the pandemic which restricted physical contact. This, as a result, prevented the nurses from providing comfort to the dying residents through therapeutic, which was against the nurses' professional and moral values.

"We cannot give them hugs because of Covid."
(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Summer's statement summarises the moral distress of the pandemic in only nine words. Summer knows that physical comfort is what the dying resident needs; she possesses the capacity to provide it; yet she is prohibited by the pandemic regulations. The prohibition of hugging, an instinctive gesture of human comfort, shows how the COVID-19 infection control measures overruled the most basic expression of compassion, forcing nurses to suppress their natural caring impulses.

"It has been hard with the Covid with the touch because obviously we have got to come away from so much touching. But I just find it soothing especially as their family are not here. Obviously when they do not understand what is happening to them, they get irate. So, it is just to calm them down...."

(Grace, RGN, Staff Nurse, Oak Nursing Home).

Grace's account further elaborates the moral distress of touch restriction with specific reference to dementia. She identifies therapeutic touch as an intervention deployed 'especially as their family are not here' in the attempt to compensate the relational deficit created by the visiting restrictions. The removal of touch thus compounded the loss of family contact, creating a double deprivation in which both primary and compensatory sources of comfort were simultaneously withdrawn. For residents with dementia who 'do not understand what is happening to them,' touch represented perhaps the last remaining communicative channel through which reassurance could be conveyed. Its restriction constituted a particularly cruel structural limitation for this population, and the moral distress stemmed from Grace's clear understanding of this cruelty coupled with her absolute inability to override the policy.

7.4.2.2: Staffing issues and moral distress during the pandemic

Understaffing was another source of moral distress described by the participants in this study. The participants' accounts throughout this study demonstrated that every resident deserved individualised, attentive, and compassionate care. However, depleted staffing levels rendered this impossible.

"We have three nurses, two were off sick with Covid and one was on annual leave. So, that was it, me on my own for seven days all through Covid. The most heart-breaking thing I have ever done in my entire nursing career.... we

lost a lot of people. So, that was a real struggle for me because I could not separate myself between seventy plus people that we had here.... I was in pieces.... So, that was difficult, and I just had to work like a machine and work my way through all these people suddenly deteriorating ...It was just heart breaking” [tearful]
(April, RGN, Senior Nurse, Ash Nursing Home).

April's account illustrates an extreme example of moral distress in this dataset. Looking after seventy-plus residents, many of whom are dying on her own prevented her from providing ethically correct, individualised, compassionate, and present care for each dying person. Although she desires to be with each one of the dying residents, ('I could not separate myself'), the structural limitation became a great challenge. Her metaphor of working 'like a machine' describes the psychological defence of suppressing the very emotional engagement that defined her professional identity. The phrase 'I was in pieces' contradicts the machine metaphor. This shows how April was broken emotionally but had to remain physically functional as a worker. Moreover, her tearfulness during the interview, long after the described events, evidences the moral residue (Jameton 1993) that persists when distressing experiences remain unresolved.

This situation proved particularly distressing for April, who held a deep belief that residents should not die alone. Despite this, many residents were dying unaccompanied because there were not enough staff.

“We do not like people dying on their own.....So, obviously we were isolating people and barrier nursing these people that were affected by the Covid.... and there were so many people on their own in their rooms that were passing away.” [tearful]
(April, RGN, Senior Nurse, Ash Nursing Home).

April's statement 'we do not like people dying on their own' conflicts with the reality of mass solitary dying in the nursing homes during this time. This became more challenging for nurses who had made promises to families that their loved ones would not be left alone, commitments that became impossible to honour due to the staff shortages.

“So, I’d had her on the phone absolutely distraught because she hadn’t seen him, begging me to look after him, and saying to me “please don’t leave him” and I had people begging me down the phone please can I come and see them, no, and then please just promise me, promise me that you won’t leave them alone [tearful].... and we had promised her sister, that we would not leave her alone... So, that was very, very hard.” [tearful]
(April, RGN, Senior Nurse, Ash Nursing Home).

“I’m with him, I will give him my complete attention....”
(Dawn, RGN, Staff Nurse, Cedar Nursing Home).

April’s account presents the devastating dimension of broken promises. The families’ pleas ‘begging,’ ‘promise me, promise me’ describe a transfer of moral responsibility from family to nurse that the nurse commits to willingly but is not always possible to practically fulfil due to the staffing constraints. This consequently translates to broken promises, and betrayal of a grieving family member. Similarly, Dawn’s statement ‘I will give him my complete attention’ although aspirational and ethically correct, was not practically achievable in the pandemic end-of-life care.

The staff shortages resulted to an increased usage of agency staff. Consequently, this resulted in moral distress as the frequent changes in staff were seen as detrimental to residents with dementia.

“When you start having this turnover of staff, the loss of that regularity impacts on somebody with dementia. Any change is detrimental because they do not understand what is going on and they become frightened and anxious”
(Dawn, RGN, Staff Nurse, Cedar Nursing Home).

Dawn’s account reveals a form of moral distress stemming from her belief that staff turnover is damaging for the residents with dementia but has no power to prevent it, leading to experiences of fear and anxiety. In addition, Dawn’s assertion that ‘any change is detrimental’ reflects the absolute need for stability for residents with dementia. The

pandemic's disruption of this stability constituted a form of unintended harm which the nurses had no power to prevent.

Furthermore, the participants' accounts also revealed how the staff shortages prevented comprehensive assessment of residents' needs, particularly end-of-life care wishes for people with advanced dementia.

"We didn't have enough time to communicate with the family and to get like a plan for them like what they like and what they don't like because the ones with dementia they not always be able to express you know their wishes for the future....and sometimes we just had to communicate over the phone, which wasn't a very good way to do it..... but then it was sad if we just had someone like who came to us when they were poorly, it was a bit hard to get to know them...."

(Summer, Staff Nurse, RGN, Cedar Nursing Home).

Summer's account reveals how the staffing constraints led to failures of person-centred care. The inability to communicate with families and develop care plans meant that residents were dying without their wishes being known. This was a direct violation of the principle of autonomy that the participants had identified as central to facilitating a good death. Summer's account exposed a form of moral distress brought about by abandoned essential care processes; she recognised that telephone communication was an inadequate substitute ('wasn't a very good way to do it') but was constrained to use it regardless. Her description of new residents who arrived 'when they were poorly' and died before staff could 'get to know them' describes the most ethically troubling scenario; a resident dying among strangers who do not know their history, their wishes, preferences, or their fears. The sadness that Summer expressed stemmed from the moral violation she could identify clearly but could not prevent.

7.4.2.3: End-of-life care decisions

Decisions made in caring for people with dementia at the end of life constituted a third source of moral distress during the pandemic. Where social restrictions and staffing shortages represented constraints imposed by policy and resource limitation respectively, end-of-life care decisions introduced moral distress rooted in clinical authority and professional hierarchy. These decisions concerned end-of-life medication prescriptions and death verification which exposed the nurses' subordinate position within the healthcare

power structure, a position that forced them to witness, and at times comply with, decisions they believed to be ethically wrong.

‘Doing the right thing’ was a phrase from one of the participants’ accounts indicating that nurses sometimes struggled with the moral weight of their own decisions. For example, April was not confident in her decision to discontinue a dying resident’s oral intake without a doctor’s order.

“She was just there, unconscious, dying, so that I found really, really difficult, and then of course as a nurse, you’re fighting with your conscience, are we doing the right thing?”

(April, RGN, Senior Nurse, Ash Nursing Home).

April’s phrase ‘fighting with your conscience’ describes a moral conflict between the duty to sustain life through nutrition versus the recognition that continued oral intake may cause suffering in an unconscious, dying person. The absence of a doctor to authorise the decision leaves the nurse bearing sole moral responsibility for an action with irreversible consequences.

Moreover, the pandemic profoundly impacted how end-of-life medication was prescribed. Two participants explained that doctors were prescribing end-of-life medication without proper examination, based on assumptions rather than individual clinical assessment.

“They do not come out to test that person and say, okay it is not Covid, we will treat them. As soon as you mentioned a cough or a cold, or anything like that, then straightaway the GP would say, we think it’s Covid, they’re this age, they’ve got underlying conditions, then they go down the line of end-of-life medication. It is completely wrong and disgusting the way they have been treated through this pandemic. I just think it is quite unbelievable where nearly, well probably half, if not more, residents were written up for end-of-life medication.”

(Hannah, Senior Nurse, RMN, Ash Nursing Home).

“We need to have the right medication at the right time, especially with Covid. I think it is very much like the GP’s say, oh they are deteriorating,

they are elderly, they have dementia, let us put them on end-of-life. That is not always the answer.”

(Florence, Senior Nurse, RGN, Ash Nursing Home).

Hannah and Florence’s accounts expose another most ethically grave source of moral distress in the dataset: the perception that medical practitioners were making life-and-death decisions based on categorical assumptions rather than individual assessment. Hannah’s language ‘completely wrong and disgusting,’ ‘quite unbelievable’ represents a strong moral outrage condemning the violation of the nurse’s ethical values. In this account, it is apparent that the nurses possessed superior knowledge of individual residents yet lacked the authority to override medical decisions they judged to be harmful.

On the other hand, Florence’s more measured critique ‘that is not always the answer’ asserts the nurse’s clinical judgement against the medical formula of ‘elderly plus dementia plus deterioration equals end-of-life pathway.’ The blanket prescribing of end-of-life medication for residents who may not have been terminally ill represents not only poor clinical practice but a potential violation of residents’ right to appropriate treatment.

Furthermore, the participants described facing challenges in getting doctors to visit the nursing homes to certify deaths of their residents during the pandemic which led to the extension of death verification responsibilities to the registered nurses in the nursing homes.

“And lately we have challenges with Out of Hours for example to come and certify death, and that’s we should be doing it in the home which am working on it now to train staff, we’ve got to have the processes to certify death.”

(Pam, Senior Nurse, RGN, Holly Nursing Home).

“The UHB sent out a thing about end-of-life verification.... So, most of the nurses here verify as well, so that has been a massive step for us.”

(April, Senior Nurse, RGN, Ash Nursing Home).

The devolution of death verification to nursing home nurses represents a significant shift in professional responsibility. Pam’s pragmatic framing suggests acceptance born of necessity, while April’s description of it as ‘a massive step’ conveys the magnitude of the change. The

moral distress associated with this shift was not primarily about objecting to the task, but about the inadequacy of preparation for its emotional weight and the isolation in which it was performed.

Although some training was provided, participants felt it did not adequately prepare them. One participant described the anxiety of being the sole decision-maker, particularly during night shifts.

“Most anxious part that I find is like when the resident does pass away, it is like checking for signs of life, and just obviously feeling anxious in myself then. I am there looking for a pulse, and I can sometimes feel my own pulse, and stuff like that. And that is quite a nervous experience... it is all on me, and that is quite hard, especially on nights.... but like I still have to make that decision.”

(Norman, Staff Nurse, RMN, Ash Nursing Home).

Norman’s phrase ‘it is all on me’ captures the essence of structural isolation: a task that should ideally be supported by medical expertise and collegial reassurance is instead performed alone, at night, with minimal training. The final clause ‘but like I still have to make that decision’ conveys a resigned acceptance of a burden that is both admirable in its professionalism and deeply concerning in its implications for staff welfare. This represents a form of moral distress arising not from being prevented from doing the right thing, but from being compelled to bear a moral and clinical responsibility for which one feels inadequately equipped, without the structural support that such responsibility demands.

7.4.3: Summary of category

In summary, the participants’ accounts provide compelling evidence of moral distress, understood through Jameton’s (1984) framework, arising from three interconnected sources of external constraint during the COVID-19 pandemic: government-imposed social restrictions that severed the relational foundations of good end-of-life care; critical staffing shortages that rendered individualised, compassionate care physically impossible; and medical decision-making practices that nurses perceived as ethically indefensible yet lacked the hierarchical authority to challenge. These constraints operated upon a pre-existing emotional landscape in which nurses had formed deep familial bonds with residents and

already carried a cumulative burden of grief. The pandemic intensified the pre-existing moral distress, which was characterised by powerlessness, provision of futile care that violated core values, broken promises to families, and staff suffering without adequate support. The data also extend Jameton's framework in important ways whereby residents with dementia could not comprehend the restrictions causing their distress, resulting in moral anguish rooted in the impossibility of consolation, while the lasting psychological effects reported by participants evidence the moral residue that result from unresolved, cumulative moral distress.

The next chapter presents the core category that was developed following the analysis of the data in this study.

Chapter 8: Research findings- the core category of interpersonal relationships

8.1: Introduction

This chapter presents the findings relating to the core category of *interpersonal relationships*. According to Strauss and Corbin (1998), a core category is a broad and abstract concept that integrates all other categories, explains the study's central phenomenon, and accounts for the greatest variation within the data. In this study, interpersonal relationships fulfil the criteria of a core category as outlined by Corbin and Strauss (2015). Specifically, it provides the conceptual link between the three main categories identified in the analysis: *end-of-life care wishes and preferences*, *end-of-life care organisation and delivery*, and *moral distress*. The identification of interpersonal relationships as the core category is conceptually important because it demonstrates how the quality, depth, and nature of relationships between nurses and residents, nurses and family members, and members of the nursing team shaped the delivery of end-of-life care for people living with dementia in nursing homes during the COVID-19 pandemic. These relationships influenced not only how care was organised and provided but also how nurses interpreted, negotiated, and responded to the challenges associated with delivering end-of-life care under pandemic-related restrictions. The participants' accounts revealed the relationships that were developed in caring for residents with dementia at the end of life in the nursing homes. These relationships were described in three tiers: relationships with residents, relationships with residents' relatives, and relationships with the team members, and these helped to develop the sub-categories and the structure of this chapter.

8.2: Relationships with residents

From the participants' accounts it was evident that close relationships existed between nurses and the residents they cared for in the nursing homes. According to these narratives, the close bonds stemmed from spending long periods with the residents when providing care. Most participants explained that the close relationships they developed with their residents accounted for the way they provided care. The nursing home residents were

regarded as the participants' own biological families, especially those that did not have any or contact with their relatives. These relationships can be understood as the mode through which residents experienced a sense of belonging and a sense of security (Nolan et al. 2008). For people living with dementia, whose cognitive decline progressively erodes their capacity to form new relationships or navigate unfamiliar social contexts, the continuity and depth of these existing bonds is particularly vital; the relationship itself becomes a form of cognitive structure that sustains the person's sense of identity and place.

"A lot of our staff get very close to these residents; it's like part of their family"

(Jane, RGN, Staff Nurse, Ash Nursing Home).

"We have got a few here that have not got family, in this environment they become your family and that is why we are so emotional because they become your life. ... we get to know them very well...."

(April, RGN, Senior Nurse, Ash Nursing Home).

Jane's observation that staff get 'very close' to residents, 'like part of their family', describes a relational depth that exceeds traditional professional boundaries. April's account strengthens this. The phrase the residents 'become your life', suggests total relational involvement. Her specific reference to residents 'that have not got family' shows that for these individuals, the nurse-resident relationship is not supplementary to familial bonds but substitutive of them, meaning that the nurse is the sole source of the sense of belonging that Nolan et al. (2008) identifies as essential to well-being in care environments. This finding connects directly to the moral distress documented in Section 7.3: when the pandemic disrupted these relationships through isolation, PPE barriers, and the replacement of familiar staff with agency workers, it was not only a professional inconvenience but a violation to the relational foundations of residents' emotional security. The moral distress experienced by the nurses was, importantly, the anguish of watching these established relational supports collapse under conditions they could not control.

These family-like relationships were said to assist the nurses to know their residents well and understand their needs, including their wishes and preferences. Some participants felt that they spent more time with the residents than their own biological families due to the amount of time they were on duty. Close proximity and the long-term nature of these care settings

were seen to contribute to the development of such close bonds. The participants' accounts also showed that the nurses invested their emotions when caring for their residents, which facilitated the development of these relationships. According to Nolan et al. (2008), this emotional investment is central to creating a sense of significance for residents.

"As a nurse when you know somebody for a very long time, you know them very well- you know what makes them laugh, when they have a meal, their jokes, music they like. I cannot do my job without my heart, so part of my heart is with them, they are like my family"
(Rose, Staff Nurse, RGN, Oak Nursing Home).

"In this environment they become your family.... I am here four days out of seven. I see them more than I see my own family sometimes"
(April, RGN, Senior Nurse, Ash Nursing Home).

Rose's account demonstrates that she knows what makes her residents laugh, their mealtime routines, their jokes, their musical preferences. This illustrates accumulated relational knowledge that comes from knowledge of the whole person rather than the patient. Her assertion that 'I cannot do my job without my heart' makes an explicit claim that emotional engagement is not an optional addition to competent nursing care but a prerequisite for it, directly challenging models of professional detachment. This relational knowledge is particularly critical in the context of end-of-life care for people with dementia as documented in Section 7.1, when residents with advanced dementia can no longer articulate their wishes, it is precisely this kind of intimate, accumulated knowledge; knowing what comforts them, what distresses them, what brings meaning to their days that enables person-centred care. April's statement that she sees the residents more than her own family shows the level of investment that underpins these relationships. In addition, it also reveals two opposing views derived from this dataset: the very conditions that produce deep relational care (long shifts, consistent staffing) are the same conditions that risk depleting the nurse's personal and familial resources. This connects to the moral distress findings where nurses described being 'in pieces' and 'physically drained' revealing the emotional cost of disproportionate relational investment where staff's own well-being is not sufficiently supported.

The participants further explained that in addition to the long hours spent looking after the same residents, the number of years they worked in the same nursing home also helped them to get closer and more familiar with the residents.

"The privilege of working in a nursing home, as opposed to a hospital environment, is that you are with these people day in day out, you work long shifts. Hopefully, you have the pleasure of looking after them for a fair number of years-and the unit I worked on, we did tend to have people there for an exceptionally long time. So, they become like your extended family"
(Dawn, Staff Nurse, RGN, Cedar Nursing Home).

Dawn's description of nursing home work as a 'privilege' is in connection to the relational continuity that nursing home care uniquely offers. This continuity, shown in the phrase being 'with these people day in day out' for 'a fair number of years', is what Nolan et al. (2008) identifies as the sense of continuity, essential to enriched care. Dawn's account also reveals that understanding a person with dementia is not an event but a process that unfolds over months and years, through thousands of small interactions that gradually accumulate into deep relational knowledge. This has direct implications for the end-of-life care findings in Section 7.2, where participants described the detrimental impact of agency staff who lacked this accumulated knowledge on which person-centred end-of-life care depended.

Positioning themselves as 'family of the residents' during the pandemic is what was seen to compel the nurses to go beyond their professional role and stand in place of the families to advocate for the residents in the absence of their biological families. During this time, the nurses worked to represent families' views to challenge or question decisions made by doctors which they felt would not benefit the resident. This advocacy function reveals an important dimension of the interpersonal relationship that goes beyond emotional support into the territory of moral agency. The nurses used their relational knowledge of residents to contest medical decisions that they considered harmful.

"I have never had a problem with a doctor before, but I had, one who was quite funny with me and wanted someone to go into hospital, and I fought for the resident to be cared for in the home...."
(April, RGN, Senior Nurse, Ash Nursing Home).

"The doctor said, "I think we should start on end of life." So, end-of-life medications were started, but I thought it was too soon.... they were still drinking, so could be reversible maybe not take them into hospital but treat them here and try everything first before going straight to end-of-life medication."

(Hannah, RMN, Senior Nurse, Ash Nursing Home).

April's account of 'fighting' for a resident to remain in the nursing home and Hannah's challenge to what she considered premature commencement of end-of-life medication demonstrate that interpersonal relationships with residents functioned not only as emotional bonds but as sources of moral authority from which nurses challenged the medical hierarchy. Hannah's clinical argument 'they were still drinking, so could be reversible', is based on the intimate, longitudinal knowledge of the resident that only a relational caregiver possesses. This connects directly to the moral distress findings in Section 7.3, where participants described the blanket prescribing of end-of-life medication as 'completely wrong and disgusting'. In those instances, the nurses' relational knowledge and moral agency were overridden by medical authority. Here, by contrast, the nurses successfully deployed their relational knowledge to resist decisions they considered harmful. The difference between these outcomes successful advocacy versus powerless complicity illustrates the contingent nature of nurses' moral agency within the inter-professional hierarchy which depended on the individual doctor's willingness to listen, which was itself a function of the interpersonal relationship between nurse and physician. When this relationship was absent or hostile, moral distress intensified.

Standing in place of family was a concept widely discussed by all participants across the four nursing homes. As the participants believed that people should not be on their own when dying, they made sure that, in the absence of the residents' biological families, they stepped in to support the dying residents emotionally according to the residents' wishes. This surrogate family role represents the nurses' attempt to maintain the dying resident's sense of security and belonging (Nolan et al. 2008) in the absence of biological kin to ensure that the relational environment remained enriched even with the pandemic disruptions.

"I had to be the mother, I had to be the daughter, I had to be the father, I had to be all the relatives. ...we are very much like family; we become close to these people"

(April, RGN, Senior Nurse, Ash Nursing Home).

April's statement demonstrates how she was simultaneously fulfilling the deepest aspiration of her professional identity (ensuring no one dies alone) and bearing an unsustainable emotional burden (being everything to everyone). This connects to the moral distress findings where April described working 'like a machine' and being 'in pieces'. The surrogate family role, while relationally meaningful, was emotionally devastating when performed under conditions of extreme staffing pressure and without adequate support. It is evident that while April was striving to maintain the residents' senses of security and belonging, her own sense of security as a practitioner operating within a supportive, adequately resourced environment was profoundly compromised.

Furthermore, the COVID-19 pandemic forced the participants to extend their efforts beyond their expected professional responsibilities. When relatives could not bring in necessities, nurses would enlist their own family members and community members to help, demonstrating a remarkable sense of community spirit.

"My husband was going driving around getting medications and other supplies for us, there were so many other people that helped us."

(April, RGN, Senior Nurse, Ash Nursing Home).

April's account of her husband driving around to obtain supplies reveals the extent to which the professional-personal boundary had dissolved during the pandemic. The nursing home's needs had spilled over into the nurse's private life, recruiting family members into an informal supply chain. While this demonstrates admirable commitment and community resilience, it also exposes a structural failure whereby the formal systems of supply and support were so inadequate that nurses had to mobilise personal resources to maintain basic care. This is a form of institutional constraint, according to Jameton's moral distress framework, where the nurse is compensating for systemic failure through personal sacrifice, a strategy that is neither sustainable nor equitable.

Despite the participants identifying themselves as the family of the residents, there were times when they would be required to step back from this intimate role to their professional role as nurses. Following the death of a resident, the nurses would be expected to assume a professional nursing role to support bereaved relatives and staff. Swapping between the two

roles could be challenging, particularly when they were emotionally attached to the deceased.

"So, following a resident's death we have to say to the distressed staff, look, this is a resident, this is you.... you need to detach yourself from the situation...."

(Pam, RGN, Senior Nurse, Holly Nursing Home).

Pam's account reveals a profound contradiction at the heart of nursing home end-of-life care. The same relational depth that participants had described as essential to good care 'I cannot do my job without my heart', 'they become your family', is now identified as something from which staff must 'detach.' The instruction to separate 'this is a resident, this is you' attempted to establish a professional boundary but simultaneously created a form of moral conflict whereby the nurses were required to invest deeply enough to provide person-centred care, then withdraw quickly enough to remain professionally functional. This dynamic threatened the nurses' sense of purpose and significance as the emotional investment that nurses regarded as central to their professional identity was repeatedly suppressed (Nolan et al. 2008). The moral distress findings in Section 7.3 demonstrated this clearly where nurses described residents as family, also described being 'in pieces' and 'needing help' which shows that the relational depth that enriched care at the same time worsened the emotional pain caused by the loss of a resident.

"We get to know them very well.... So, everybody feels it when someone goes."

(April, RGN, Senior Nurse, Ash Nursing Home).

"It is hard because as a nurse when you know somebody for an exceptionally long time, you know them well...I cannot do my job without my heart, so part of my heart is with them. They are like my family... It is very emotional because you care for them like your father, like your mother, it is like you are part of the family....and when the end is coming, it is difficult"

(Pam, RGN, Senior Nurse, Holly Nursing Home).

Pam's metaphor of having 'part of my heart' with the residents represents the risks of cumulative loss as, figuratively speaking, each resident death chips that part of the nurse's

heart away, which over a career, the repeated emotional trauma results in moral residue. In the context of dementia care, this grief is unique and anticipatory in nature which makes it even more complicated. The person with advanced dementia may have already been 'lost' in some cognitive sense long before the physical death, yet the relational bond endured. The physical death then marks the final ending of a relationship that the nurse could have sustained through years of a resident's progressive cognitive decline. April's observation that 'everybody feels it when someone goes' illustrates the collective nature of this grief, positioning it as a shared team experience rather than an individual vulnerability, a distinction that connects to the team relationships explored in Section 8.4.

8.3: Relationships with residents' relatives

The relationships that the participants formed with dying residents extended to the residents' families and loved ones. The quality of relationships between staff and family carers is central to creating enriched care environments (Nolan et al. 2008). Families need to experience a sense of significance (feeling that their knowledge and contribution are valued), a sense of belonging (feeling included in the care community), and a sense of security (trusting that their relative is well cared for). The data in this section reveal how nurses actively cultivated these senses through their relationships with residents' families, and how the pandemic disrupted this relational work with consequences for both care quality and the emotional well-being of all parties involved.

"Her daughter was a nurse, and we had a close relationship with her.... we are very much family; we become close to these people because again their families become our families too. We get to know them very well as well"
(April, RGN, Senior Nurse, Ash Nursing Home).

"Because a lot of staff here are from the local area, so they know the family as well"
(Hannah, RMN, Senior Nurse, Ash Nursing Home).

April's observation that 'their families become our families too' describes a relational circle extends outward from the resident to encompass their kin network. Hannah's point about staff being from the local area shows that in these nursing homes, the professional and personal communities overlapped, meaning that nurse-family relationships were embedded

within pre-existing social networks which strengthened the sense of belonging for the families. In these cases, families were not leaving their loved ones with strangers but with members of their own community. However, this very integration also intensified the moral distress documented in Section 7.3: when nurses were forced to enforce visiting restrictions on families they knew personally, from their own communities, presenting both professional and social dilemmas.

Moreover, the nurse-family relationships were described to be particularly helpful in caring for people living with dementia at the end of their lives. The participants explained that they valued their relationships with the residents' families because they possessed knowledge about the dying residents' needs, wishes, and preferences which they found essential for developing person-centred end-of-life care plans. This directly connects to the findings in Section 7.1, where participants identified ACPs and family consultation as the primary means of understanding the end-of-life wishes of residents with advanced dementia who could no longer express them.

"So having that good relationship with them, being honest and open is really helpful for caring for somebody with dementia at the end of their life..."
(Ivy, RGN, Staff Nurse, Oak Nursing Home).

Ivy's emphasis on honesty and openness as the foundations of helpful relationships reflects the principle that enriched care environments depend on transparent, trusting communication between stakeholders (Nolan et al. 2008). For end-of-life care for people with dementia families were asked to share intimate knowledge about their relative's preferences, to participate in difficult conversations about prognosis and treatment, and to trust that the care team will honour commitments made. The pandemic's disruption of face-to-face contact undermined this trust-building process at precisely the moment when trust was most needed which intensified the moral distress described in Section 7.3, where nurses described families 'begging' on the phone for reassurance they were increasingly unable to provide.

While the nurses encouraged the development of good relationships with the residents' families, barriers and challenges existed. Timing of interactions was identified as one challenge: engaging with families when their relatives were too unwell or dying was emotionally difficult. In addition, complex family dynamics could impede effective communication.

"It becomes very difficult and like I said at the beginning, when we meet the relatives, we are meeting them at that point when it's - they're at their lowest [when their loved ones are dying]"

(Emily, RGN, Staff Nurse, Ash Nursing Home).

Emily's account highlights important contradictions in the development of nurse-family relationships. She notes that the nurse meets the family when they are 'at their lowest' (emotionally vulnerable), which may disrupt the trust-building process that is identified as necessary for families to develop a sense of security and belonging within the care setting. This finding suggests that the relational infrastructure supporting end-of-life care for people with dementia ideally needs to be established long before the dying phase begins. However, this was not possible during the pandemic due to residents' conditions deteriorating rapidly, and the visiting restrictions.

The nurse-family relationships were seen to help the nurses to ensure that the dying residents' relatives were emotionally supported.

"But for the relatives it might be the first time they have ever seen somebody die and it's somebody who is really special to them, so therefore, you also give as much support, and you talk to and explain things...you just make it clear that if there's anything they're worried about them they come and see you when you are on duty"

(Ben, RMN, Staff Nurse, Cedar Nursing Home).

"And because they are super anxious in normal times, and in these times, they are even more anxious because they know that they are only going to get that one visit when things are close to the end. So, it is important that they feel supported."

(Ivy, RGN, Staff Nurse, Oak Nursing Home).

Ben's account reveals how the nurses in this study ensured that families who were less familiar with deaths were well supported. His statement 'they come and see you when you are on duty' personalises the support, offering himself as a specific, named point of contact. This personalisation is central in promoting the family's sense of security where the relatives

feel supported by having a specific person they can contact who knows their relative and who can be relied upon.

However, the pandemic visiting restrictions disrupted the ongoing relational support. Families who knew they would get only one visit became 'super anxious', requiring nurses to manage this high-intensity distress within compressed timescales. This connects directly to the moral distress of Section 7.3: nurses were attempting to provide families with a sense of security and belonging within encounters that were morally demanding, structurally inadequate, and practically impossible to sustain these senses.

Family dynamics were identified as another barrier preventing the development of nurse-family relationships.

"And then you get pulled into family dynamics and it is difficult sometimes to keep out of that.... There are some families that will try to drag us into things, and it can be difficult"

(May, RGN, Staff Nurse, Ash Nursing Home).

May's language 'pulled into', 'drag us into' positions the nurse as a reluctant participant drawn into pre-existing relational conflicts. Her account reveals a dimension of interpersonal relationships that acknowledges that not all family relationships enhance care, some actively impede it. For end-of-life care for people with dementia, where family input is essential for understanding the resident's wishes, dysfunctional family dynamics can create an additional layer of moral distress.

Moreover, the pandemic visiting restrictions resulted in reduced contact and poor communication with the residents' families. This disrupted the formation of nurse-family relationships. Recognising the importance of maintaining these relationships, nurses had to design practical ways of maintaining contact despite the challenges.

"So, I used to use my own phone, and I would take pictures and with the consent of the family so, "Can I take a picture? Your mum's here. Can she talk to you?" You know, I would scrub this phone spotlessly clean, you know. Then I bought another phone, and I would leave my other phone at work, so it would only be used at work, and I had another one for home, so the families could see their relatives."

(Ben, RMN, Staff Nurse, Cedar Nursing Home).

Ben's account is a typical example of relational improvisation under crisis conditions. The detail of buying a second phone at personal expense to facilitate video calls between residents and families reveals the lengths to which individual nurses went to bridge the relational gap created by the pandemic visiting restrictions. His meticulous infection control practice ('I would scrub this phone spotlessly clean') shows how he simultaneously navigated the duty to maintain infection control and the moral imperative to sustain human connection.

Ben's actions represent an attempt to preserve families' sense of continuity and belonging through technological mediation when physical contact was impossible. However, this account also exposes a critical structural limitation whereby the maintenance of human connection during the pandemic depended on individual initiative and personal expenditure rather than institutional provision. The moral distress findings in Section 7.3 showed that nurses felt their efforts went unrecognised by 'the outside' and Ben's account adds a material dimension to this invisibility.

8.4: Relationships with team members

From the participants' accounts, it was evident that the nurses formed family-like relationships within their teams which fostered peer support and collaborative working in the delivery of end-of-life care for people with dementia in the nursing homes. Nolan et al. (2008) highlight the importance of regular engagement between residents and families, and equally by staff. The data in this section reveal how team relationships served as the primary mechanism for maintaining staff well-being under conditions that, as the moral distress findings in Section 7.3 documented, were profoundly challenging.

"We are very much family here...."

(April, RGN, Senior Nurse, Ash Nursing Home).

".... this is a nursing home where it is more like a family..., it's more family orientated here, which is nice"

(Hannah, RMN, Senior Nurse, Ash Nursing Home).

The familial metaphor, which has threaded through every tier of interpersonal relationships in this study; residents as family, residents' families as family, and now colleagues as family. Hannah's clause 'which is nice' understates the significance of the nursing team relationships. The family-like quality of team relationships was not only 'nice' but potentially essential to professional nursing home practice. This would be identified as team cohesion as the primary source of staff's sense of belonging and security within a working environment that the pandemic had rendered insecure and overwhelming. However, the familial model of team relationships, while emotionally supportive, may also create barriers to seeking formal psychological help. If the team is positioned as 'family', then the expectation may be that emotional needs are met informally within the group, rather than through professional support services, a pattern that may help explain April's earlier admission in Section 7.3 that 'I have never managed to talk to anyone yet about the Covid thing.'

The participants positioning themselves as a 'family of staff' helped to facilitate collaborative working and to ensure that residents with dementia received the best possible end-of-life care to achieve care goals based on residents' wishes and preferences.

*"We all need to be working together ... We all respect each other's views....
we do work together; we all respect each other's part in the cog and that is
why it works"*
(Florence, Senior Nurse, RGN, Ash Nursing Home).

Florence's metaphor of 'each other's part in the cog' positions the team as an interdependent mechanism in which each member's contribution is essential to the functioning of the whole. In the context of end-of-life care for people with dementia which, as the findings in Section 7.2 demonstrated, requires coordination across multiple domains (physical symptom management, emotional support, spiritual care, family communication). Florence's account presents evidence of a sense of purpose (shared care goals) and a sense of achievement (successful teamwork); senses that are essential to staff's capacity to sustain their caring role (Nolan et al. 2008).

The team relationships also encouraged peer support within the nursing teams whereby the participants assumed the responsibility to support the less confident or experienced team members.

"...supporting junior staff or new members of staff or staff who are not confident...."

(Ivy, Staff Nurse, RGN, Oak Nursing Home).

Ivy's brief account points to an informal mentoring system embedded within the team's familial culture. This support mechanism is particularly significant for end-of-life care for people with dementia, where the skills required: interpreting non-verbal cues, managing complex symptom burdens, providing emotional support to families, navigating clinical uncertainty, are not easily acquired through formal training alone but require the kind of situated, relational learning that mentoring provides. The moral distress findings revealed that the pandemic's reliance on agency staff undermined this mentoring system whereby unfamiliar staff lacked not only knowledge of individual residents, but access to the team's accumulated practice wisdom and the supportive relationships through which it was transmitted.

The participants also described another instance where the team relationships were helpful. They explained that these relationships helped them to support each other emotionally, particularly when dealing with death and dying within the nursing homes.

"You've obviously got to be very caring and - Not only like other residents and their family but the staff as well..."

(Jane, RGN, Staff Nurse, Ash Nursing Home).

"I always do like a debrief with the staff involved and especially on the day of somebody dying. I think it can be quite traumatic, so we always do...."

(Florence, Senior Nurse, RGN, Ash Nursing Home).

Jane's extension of caring to include 'the staff as well' positions staff well-being not as separate from patient care but as integral to it. Florence's account of routine debriefing following deaths demonstrates an institutional practice that directly addresses the moral residue identified in Section 7.3. These debriefs help to provide a sense of security (knowing that emotional support is available), a sense of significance (feeling that one's emotional response is validated and valued), and a sense of belonging (shared grief processed collectively) (Nolan et al. 2008). However, the pandemic's staffing pressures likely

compromised, as there was neither time nor emotional capacity for structured debriefing. Emily highlighted the importance of debriefing, particularly for inexperienced staff encountering death for the first time.

"When somebody dies it is quite a taxing experience. Often times you don't get a chance to talk about it after....and sometimes you find even with your staff around you, some of them it will be their first experience of death, and some of them are so young sometimes you have to be seen to be supporting them because they will just breakdown and some of them, even when they're older, they may have been closer to that person"
(Emily, Staff Nurse, RGN, Ash Nursing Home).

Emily's acknowledgement that 'often times you don't get a chance to talk about it after' reveals a gap between the aspiration of debriefing (described by Florence) and the reality of practice, where workload pressures frequently prevent its implementation. This gap constitutes a structural limitation that contributes to moral residue whereby staff carry the emotional weight of residents' deaths without adequate opportunity for processing. Also, this account shows that staff vulnerability is not solely a function of experience as older, more experienced staff 'may have been closer to that person', hence challenging the assumption that emotional resilience correlates with seniority. In dementia care, where relationships are built over years, it is precisely the most experienced and relationally invested staff who may be most affected by loss. The interpersonal relationships of this chapter is, therefore, connected to the moral distress of Section 7.3 as it is evident that the depth of relationship that enables quality end-of-life care for people with dementia is the same depth that produces the most acute grief and moral distress when that care is constrained or when the person dies, that is, the relationship is simultaneously the source of the best care and the deepest pain.

8.5: Summary of category

In summary, interpersonal relationships emerged as the core category connecting all findings in this study, revealing that they constituted the foundation of quality end-of-life care for people living with dementia in nursing homes during the COVID-19 pandemic. The three relational domains, relationships with residents, families, and nursing team members, each

served distinct yet interconnected functions. Nurse-resident relationships provided the relational knowledge necessary for delivering person-centred care, while nurse-family relationships facilitated communication, trust, and advocacy, enabling residents' wishes and preferences to be respected and upheld. Relationships within nursing teams fostered peer support, collaborative practice, and opportunities for emotional reflection, helping staff to manage the complex demands of end-of-life care. The findings also revealed a fundamental relational paradox: the depth of relational investment that enabled the highest quality care was also the source of the greatest moral distress when care could not be delivered in accordance with professional and personal values. Furthermore, the family-centred model of care most highly valued by participants was also the model most vulnerable to the relational disruptions imposed by the pandemic.

The next chapter discusses the grounded theory generated in this study and the Relational Paradox as a key theoretical idea.

Chapter 9: A grounded theory of interpersonal relationships

9.1: Introduction

This chapter introduces the grounded theory of this study and the relational paradox that was revealed within the findings. Analysis of the data generated three main categories: *end-of-life care wishes and preferences*, *end-of-life care organisation and delivery*, and *moral distress*. Through the constant comparative method, *interpersonal relationships* was developed as the core category. As the central organising concept within the grounded theory, interpersonal relationships linked and explained the processes underlying all three categories, providing a comprehensive account of nurses' experiences of delivering end-of-life care to people living with dementia during the COVID-19 pandemic. The grounded theory of interpersonal relationships puts forward the idea that *the nature and quality of interpersonal relationships shaped end-of-life care for people with dementia in nursing homes during the COVID-19 pandemic*.

9.2: Interpersonal relationships and the Relational Paradox

The grounded theory developed in this study explains how the relationships nursing home nurses formed with residents living with dementia, residents' relatives, and multidisciplinary team members influenced the delivery of end-of-life care during the COVID-19 pandemic. The findings demonstrate that nurses developed close, family-like bonds with those involved in residents' care, creating a relational foundation that shaped both care practices and experiences. These relationships enabled nurses to work towards achieving what they perceived as a 'good death' for residents while enhancing the end-of-life experience for both residents and their families. Many participants described extending their professional responsibilities beyond formal role expectations to ensure that residents received compassionate, person-centred end-of-life care.

However, the findings also reveal that the pandemic substantially disrupted these interpersonal relationships, limiting nurses' ability to provide the level and type of care they considered appropriate. Restrictions on visiting, social interaction, and care delivery altered

established patterns of relational engagement and, in many cases, prevented residents and families from experiencing meaningful connection at the end of life. Consequently, participants perceived that both residents and their relatives experienced emotional distress arising from separation and disrupted communication.

The disruption of relationships also had significant consequences for nurses themselves. Participants frequently described experiences of moral distress when organisational restrictions prevented them from delivering care that aligned with their professional values and ethical responsibilities. The emotional impact of these experiences appeared to be intensified by the close relationships nurses had developed with residents and families. Family-like bonds, accumulated relational knowledge of residents' preferences and family wishes, and a strong sense of professional obligation combined to heighten feelings of psychological burden when nurses were unable to act in ways they believed were in the residents' best interests.

These findings revealed a key theoretical concept within this study: the *Relational Paradox*, which captures the dual nature of close interpersonal relationships in end-of-life dementia care. On the one hand, such relationships facilitated high-quality, compassionate, and person-centred care by enabling nurses to understand residents' needs, advocate for families, and provide emotionally sensitive support. On the other hand, the same relationships increased nurses' vulnerability to emotional distress when external constraints limited their capacity to fulfil the responsibilities and commitments that arose from those relationships.

Rather than responding to isolated clinical challenges, nurses were continually required to negotiate competing interpersonal, organisational, ethical, and professional obligations. These competing demands shaped communication, decision-making, emotional wellbeing, and the delivery of person-centred care throughout the pandemic. The Relational Paradox therefore provides a theoretical lens through which these interconnected experiences can be understood as part of a broader relational and organisational process rather than as discrete challenges.

This concept highlights the dynamic interaction between organisational systems, interpersonal relationships, and professional practice. It demonstrates that the quality of end-of-life care depends not on the absence of competing demands, but on the capacity of individuals and organisations to recognise, negotiate, and respond to such tensions in ways that sustain compassionate relationships despite uncertainty, disruption, and constraint. In

doing so, the Relational Paradox extends existing understandings of relationship-centred care by revealing how the very relationships that support high-quality end-of-life care can also become a source of emotional and ethical vulnerability when nurses' ability to act on those relationships is restricted.

9.2.1: Defining the Relational Paradox

Building on literature concerning relational ethics and relationship-centred end-of-life care (Gómez-Vírseda et al. 2020, Tomaselli et al. 2020), alongside literature on moral distress arising when nurses are constrained from acting according to their ethical commitments (Jameton 1984, De Brasi et al. 2021), this study proposes a definition of the Relational Paradox. The Relational Paradox identified from the findings of this research is described as the simultaneous experience whereby close interpersonal relationships functioned both as the primary mechanism enabling high-quality end-of-life care and as a source of moral distress when nurses were prevented from fulfilling perceived relational obligations. This Paradox highlighted that interpersonal relationships functioned simultaneously as the foundation of quality end-of-life care for people with dementia, the primary source of moral distress when that care was constrained, and the principal mechanism through which staff sustained their well-being under crisis conditions.

9.2.2: Existing theories informing the Relational Paradox

Relational Paradox is not presented as a standalone theory but as a concept informed by several established theoretical frameworks, including Paradox Theory (Smith and Lewis 2011), Relational Dialectics Theory (Baxter and Montgomery 1988), Relational-Cultural Theory (Miller 1976), and the Central Relational Paradox (Miller and Stiver 1997). Although developed within different disciplines, these theories provide complementary perspectives for understanding the competing relational, organisational, ethical, and professional demands identified in this study. The following sections briefly describe the core ideas underpinning each theory, examples of their application, and their relevance to the findings.

9.2.2.1: *Paradox theory*

Paradox Theory proposes that individuals and organisations frequently encounter competing yet interdependent demands that cannot be permanently resolved and must instead be continually managed and negotiated (Smith and Lewis 2011). The theory has been widely

applied in organisational and healthcare research to understand tensions such as efficiency versus compassion, standardisation versus individualisation, and organisational control versus professional autonomy (Mannion and Exworthy 2017, Aronson 2021, Mannion et al. 2023). Smith and Lewis (2011) also applied the theory within organisational management to explain how organisations sustain performance while balancing competing priorities such as stability and change.

In the present study, Paradox Theory provides the overarching framework for understanding how nurses continually balanced competing obligations during the COVID-19 pandemic. The concept of Relational Paradox extends this perspective by demonstrating how these tensions were experienced through interpersonal relationships and influenced the delivery of dementia end-of-life care.

9.2.2.2: Relational Dialectics Theory (RDT)

Relational Dialectics Theory (RDT) argues that relationships are characterised by ongoing tensions between competing yet interconnected forces that require continual negotiation (Baxter and Montgomery 1988). RDT has been widely applied to family communication and interpersonal relationships (Baxter 1988, Baxter and Braithwaite 2008). Within healthcare, Amati and Hannawa (2014) used RDT to examine physician-patient communication at the end of life, highlighting the contradictory demands that arise during difficult conversations. More recently, the theory has been applied to understand tensions within healthcare team communication and professional relationships (Mikkola et al. 2025).

RDT is relevant to the present findings because it helps explain how relationships simultaneously enabled trust, connection, and compassionate care while also creating vulnerability to emotional and moral distress when nurses were unable to fulfil perceived relational obligations. The theory therefore provides a useful lens for understanding the coexistence of relational fulfilment and relational burden within dementia end-of-life care.

9.2.2.3: Relational-Cultural Theory (RCT)

Relational-Cultural Theory (RCT) proposes that human growth, wellbeing, and meaning are fundamentally shaped through relationships characterised by empathy, mutuality, and connection (Miller 1976, Jordan and Hartling 2010). The theory has been widely applied within counselling, psychotherapy, and mental health research to understand resilience, trauma recovery, depression, substance misuse, and relational disconnection (Duffey and Somody 2011, Frey 2013, Lenz 2016). RCT has also informed professional education and

research exploring the impact of connection, culture, and marginalisation on helping relationships (Frey 2013).

RCT aligns closely with the findings of the present study because nurses derived meaning, professional fulfilment, and resilience through relationships with residents and families. The theory also helps explain why disruptions to these relationships during the pandemic contributed to emotional suffering and moral distress.

9.2.2.4: The Central Relational Paradox

The Central Relational Paradox is a key concept within RCT which describes how individuals simultaneously seek connection while engaging in behaviours that limit authentic engagement because of fears of vulnerability, rejection, or disconnection (Miller and Stiver 1997). The concept has been applied extensively in counselling, psychotherapy, and group therapy to explain how people seek relationships while simultaneously protecting themselves from relational hurt (Duffey and Somody 2011, Miller and Stiver 1997). It is also foundational within relational psychotherapy, where it is used to explain why individuals withdraw from authentic connection despite strongly desiring it (Miller and Stiver 1993).

While the Relational Paradox identified in this study differs in focus, the concept provides a useful lens for understanding how close relationships can create both connection and vulnerability. Unlike the Central Relational Paradox, where tension arises from movement towards and away from connection, the Relational Paradox identified in this study was identified when organisational constraints limited nurses' ability to act on existing relational commitments. Consequently, relationships functioned simultaneously as enablers of high-quality care, sources of moral distress when care was constrained, and mechanisms through which nurses sustained resilience during organisational disruption.

9.2.2.5: Integrating the theories

Together, these theories provide a theoretical foundation for understanding Relational Paradox. Paradox Theory explains the coexistence of competing demands; Relational Dialectics Theory explains how these tensions operate within relationships; Relational-Cultural Theory highlights the importance of connection for wellbeing and professional meaning; and the Central Relational Paradox demonstrates how close relationships can create both connection and vulnerability. Building on these perspectives, Relational Paradox emerged as the core category and central explanatory process underpinning the theory of interpersonal relationships in dementia end-of-life care, explaining how nurses negotiated

competing relational obligations while striving to provide compassionate, person-centred care during organisational disruption.

9.2.3: The Relational Paradox: dementia end-of-life care during organisational disruption

The Relational Paradox as the theoretical lens underpinning the theory of interpersonal relationships in dementia end-of-life care in this study, clarifies how dementia end-of-life care was maintained, adapted, or compromised during periods of organisational disruption during the COVID-19 pandemic. Participants in this study consistently described situations in which fulfilling one relational or professional obligation created tension with another. Efforts to protect residents from infection often reduced opportunities for meaningful family presence; organisational policies designed to promote safety could constrain person-centred care; and nurses sought to provide compassionate emotional support while simultaneously managing increased clinical responsibilities. These tensions were experienced not as isolated incidents but as recurring features of practice that required continual interpretation, adaptation, and negotiation.

At the heart of the interpersonal relationships theory is, therefore, the core social process of negotiating Relational Paradox, through which nurses continually found themselves simultaneously striving to maintain safety while preserving connection, uphold organisational policies while responding compassionately to individual needs, and support families while limiting physical presence to balance competing interpersonal, organisational, ethical, and professional obligations.

9.2.4: The dimensions of the Relational Paradox

Four dimensions were identified within the Relational Paradox for this study. Together, these dimensions provide the explanatory structure through which this concept can be understood which is outlined in the following section.

9.2.4.1: *Protection versus connection*

The first dimension concerns the tension between protecting residents from infection and preserving meaningful interpersonal relationships. Infection prevention measures were implemented to reduce the risk of viral transmission, yet these same measures frequently

disrupted opportunities for physical presence, emotional closeness, and shared decision-making between residents, families, and healthcare professionals. Nurses therefore sought to protect residents while simultaneously recognising that protection could result in isolation, loneliness, and altered experiences of dying. Rather than resolving this tension, participants continually adapted their practice to preserve connection wherever possible within organisational constraints.

9.2.4.2: Safety versus compassion

The second dimension reflects the relationship between organisational safety requirements and compassionate dementia end-of-life care. Participants consistently described the importance of adhering to infection prevention guidance while also recognising that compassionate care often required flexibility, physical presence, touch, and emotional responsiveness. These competing obligations were experienced not as mutually exclusive priorities but as parallel responsibilities requiring ongoing professional judgement. Compassion therefore became something that nurses continually adapted rather than abandoned, demonstrating how relational care persisted despite significant organisational restrictions.

9.2.4.3: Organisational accountability versus person-centred care

A third dimension emerged through the interaction between organisational responsibilities and the principles of person-centred dementia care. Organisational policies sought to promote consistency, accountability, and risk reduction during an evolving public health emergency. However, participants also described situations in which standardised procedures conflicted with the individual preferences, communication needs, and end-of-life wishes of residents and families. Nurses therefore negotiated between organisational expectations and individualised care, exercising clinical judgement to preserve dignity while remaining accountable to organisational requirements.

9.2.4.4: Professional responsibility versus emotional presence

The final dimension concerns the emotional labour associated with dementia end-of-life care during organisational disruption. Participants described maintaining professional composure while supporting residents, relatives, colleagues, and one another throughout periods of significant uncertainty and loss. Simultaneously, they experienced grief, moral distress, fatigue, and concerns regarding their own wellbeing. Emotional presence therefore became both a professional responsibility and a personal challenge. Rather than eliminating these

tensions, nurses continually balanced emotional engagement with professional resilience, illustrating the ongoing negotiation that characterises Relational Paradox.

Taken together, these dimensions demonstrate that Relational Paradox is not defined by individual organisational policies or isolated interpersonal experiences. Rather, it reflects the continuous negotiation of competing relational obligations across multiple levels of dementia end-of-life care in nursing homes. The dimensions are mutually reinforcing and should be understood as interconnected expressions of the substantive grounded theory rather than discrete categories. They collectively explain how organisational disruption reshaped interpersonal relationships and how nurses adapted their practice to sustain compassionate, relationship-centred care under exceptionally challenging circumstances.

9.2.5: The conceptual model of the Relational Paradox

To illustrate the substantive grounded theory developed through this study, a conceptual model of Relational Paradox was constructed (Figure 10). The model visually represents how organisational disruption influences interpersonal relationships and consequently shapes dementia end-of-life care in nursing homes.

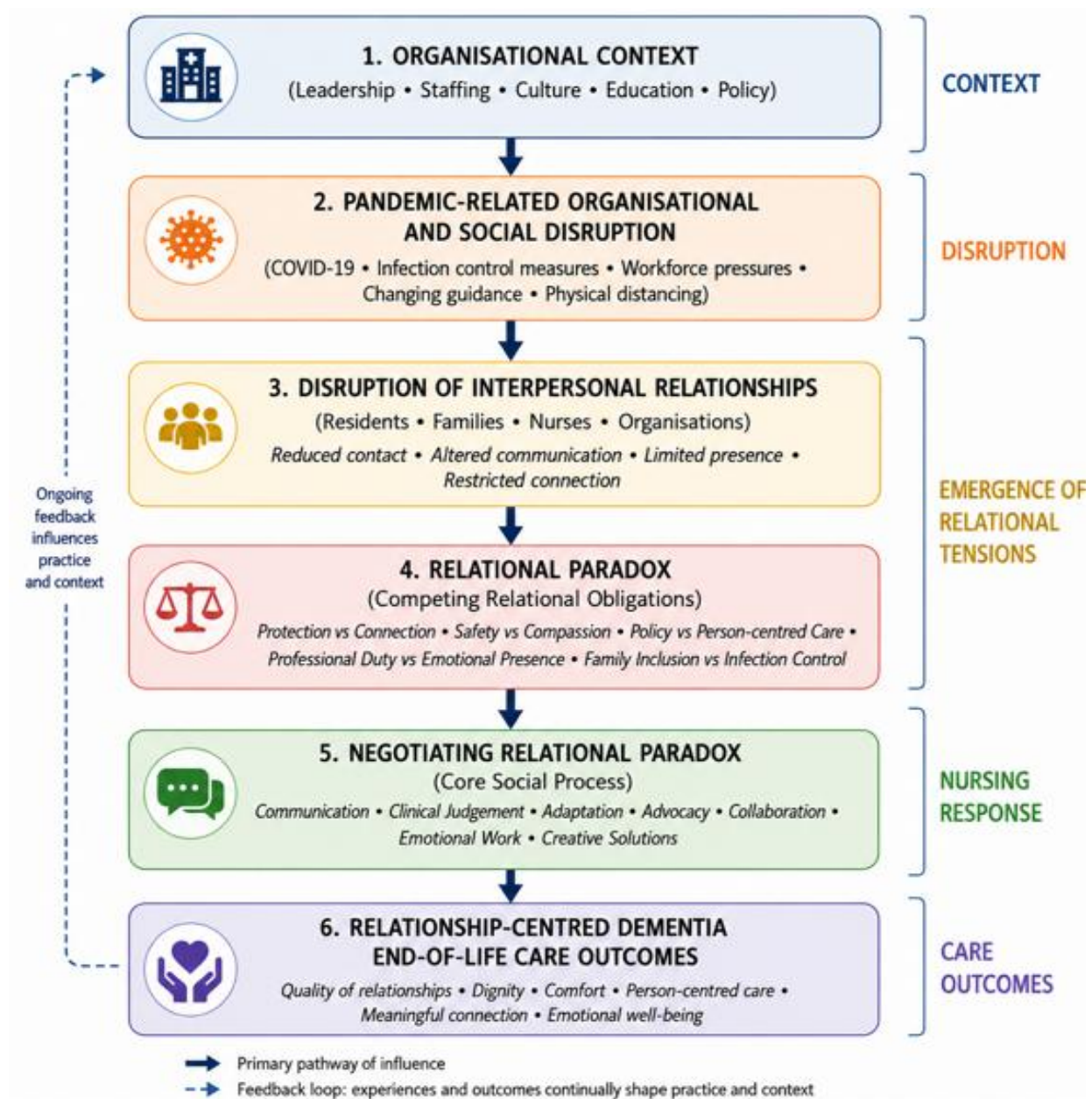


Figure 10: The conceptual model of Relational Paradox

At the outer level of the model are the organisational conditions influencing care delivery, including leadership, organisational culture, workforce capacity, communication systems, family involvement, specialist education, and pandemic-related restrictions. These contextual factors shape nurses' ability to establish, maintain, and sustain relationship-centred care.

The model proposes that organisational disruption acts as a catalyst that alters established relationships between residents, families, and healthcare professionals. During the COVID-19 pandemic, visiting restrictions, infection-control measures, and staffing pressures disrupted communication, family involvement, and shared decision-making, creating additional challenges for end-of-life care.

In response, nurses engaged in the central process of negotiating Relational Paradox, the core social process identified in this study. This involved continuously balancing competing interpersonal, ethical, organisational, and professional obligations while striving to maintain compassionate, person-centred care.

Four interrelated dimensions of Relational Paradox were identified: 1) Protection versus connection: balancing infection prevention with the need for meaningful relationships. 2) Safety versus compassion: balancing organisational safety requirements with compassionate care practices. 3) Organisational accountability versus person-centred care: balancing standardised procedures with individual wishes and preferences. 4) Professional responsibility versus emotional presence: balancing professional obligations with emotional engagement and support.

The model demonstrates that organisational conditions influence interpersonal relationships, which in turn shape the emergence and intensity of relational tensions. How nurses negotiate these tensions influences the experiences of residents, families, and staff, as well as the quality of end-of-life care provided.

The model also incorporates feedback processes. Positive relational experiences promoted trust, communication, and collaboration, strengthening nurses' capacity to negotiate future challenges. Conversely, unresolved tensions, organisational constraints, and moral distress could weaken relationships and reduce the capacity to sustain relationship-centred care.

The consequences of negotiating Relational Paradox occurred at multiple levels. For residents, successful negotiation supported dignity, comfort, and care aligned with their wishes. For families, it enhanced communication and involvement in care. For nurses, it contributed to professional fulfilment and resilience. However, when tensions could not be

effectively managed, outcomes included social isolation, reduced family involvement, compromised person-centred care, emotional burden, and moral distress.

The model therefore proposes that the quality of dementia end-of-life care depends not on the absence of competing demands, but on the capacity of nurses and organisations to recognise, negotiate, and respond to relational tensions while sustaining meaningful relationships. Relational Paradox is consequently conceptualised as a dynamic process through which dementia end-of-life care is continually shaped and experienced during periods of organisational disruption.

9.2.6: The novel contribution of the Relational Paradox

While The Paradox Theory, Relational Cultural Theory, The Central Relational Paradox, and Relational Dialectics Theory each provide useful frameworks for understanding relational tensions, the grounded theory (*The nature and quality of interpersonal relationships shaped end-of-life care for people with dementia in nursing homes during the COVID-19 pandemic*) developed in this study extends these perspectives by demonstrating how interpersonal relationships simultaneously function as:

1. the foundation of quality dementia end-of-life care,
2. the source of moral distress when care is constrained, and
3. the mechanism through which nurses sustain resilience during organisational disruption.

This triadic relationship has not previously been conceptualised within dementia end-of-life care in nursing homes during major healthcare crises. While existing theories explain relational tensions, contradictory demands, or the importance of connection, none explicitly conceptualise interpersonal relationships as simultaneously functioning as the mechanism through which high-quality dementia end-of-life care is achieved, the source of moral distress when such care is constrained, and the resource through which staff sustain resilience during organisational disruption.

9.3: Summary of chapter

This chapter presented the substantive grounded theory generated from the study: *the nature and quality of interpersonal relationships shaped end-of-life care for people with dementia in nursing homes during the COVID-19 pandemic*. Three main categories emerged

from the analysis: *end-of-life care wishes and preferences*, *end-of-life care organisation and delivery*, and *moral distress*. These categories were integrated through the core category of *interpersonal relationships*, which provided the central explanation for nurses' experiences of delivering dementia end-of-life care during a period of significant organisational disruption.

The findings demonstrated that nursing home nurses developed close, family-like relationships with residents, relatives, and colleagues. These relationships facilitated person-centred end-of-life care by enabling nurses to understand residents' wishes, support families, advocate for individual needs, and promote a good death. However, the COVID-19 pandemic disrupted established patterns of interaction through visiting restrictions, infection-control measures, staffing pressures, and rapidly changing guidance, limiting opportunities for connection and altering care experiences for residents, families, and staff.

The concept of Relational Paradox explains how interpersonal relationships simultaneously functioned as both enablers of high-quality end-of-life care and sources of moral distress when care was constrained. The stronger the relationships nurses developed with residents and families, the greater their commitment to providing compassionate care. Yet these same relationships intensified emotional suffering when organisational restrictions prevented them from meeting perceived relational obligations.

The study situated Relational Paradox within four complementary theoretical perspectives. *Paradox Theory* which provided the overarching framework for understanding the coexistence of competing demands; *Relational Dialectics Theory* which explained how such tensions operate within relationships; *Relational-Cultural Theory* which highlighted the centrality of connection to wellbeing and professional meaning; and the *Central Relational Paradox* which offered insight into how relationships can simultaneously create connection and vulnerability.

Four dimensions of Relational Paradox were identified: *protection versus connection*, *safety versus compassion*, *organisational accountability versus person-centred care*, and *professional responsibility versus emotional presence*. Together, these dimensions illustrate how nurses continually negotiated competing interpersonal, ethical, professional, and organisational obligations while striving to preserve dignity, compassion, and meaningful relationships.

The chapter concluded by presenting a conceptual model of Relational Paradox, demonstrating how organisational disruption influences interpersonal relationships, generates relational tensions, and shapes care outcomes. The model proposes that the

quality of dementia end-of-life care depends not on the absence of competing demands but on the ability of nurses and organisations to recognise, negotiate, and respond to relational tensions in ways that sustain meaningful connections. Ultimately, the grounded theory positions interpersonal relationships as the central mechanism through which dementia end-of-life care is both enabled and challenged during periods of organisational disruption.

The following chapter presents a discussion of the findings of this study.

Chapter 10: Discussion

10.1: Introduction

This chapter provides a critical discussion of the key findings presented in chapters seven and eight, situating them within the broader empirical and theoretical literature on end-of-life care for people living with dementia in nursing homes, moral distress in nursing practice, and the impact of the COVID-19 pandemic on care delivery in long-term care settings. This study, involving four nursing homes in South Wales, set out to explore the experiences of registered nurses (RNs) in the provision of end-of-life care for residents with dementia, with particular attention to the relational, ethical, and organisational dimensions of that care both before and during the COVID-19 pandemic. The scoping review conducted at the beginning of this study indicated that the experiences of RNs in caring for people living with dementia at the end of life in the South Wales region were under-researched. Moreover, the available evidence was limited to quantitative or mixed-method studies which offered little insights about RNs' experiences in nursing homes. As such, conducting this grounded theory study has helped to provide original insights regarding the RNs' experiences.

The findings revealed four interconnected categories: *end-of-life care wishes and preferences*, *end-of-life care organisation and delivery*, *moral distress*, and the core category of *interpersonal relationships* that together construct a complex account of care provision under conditions of unprecedented constraint. These categories led to the grounded theory, which was: '*The nature and quality of interpersonal relationships shaped end-of-life care for people with dementia in nursing homes during the COVID-19 pandemic*', which has been introduced in the preceding chapter.

Central to the development of these findings is the identification of the Relational Paradox as the key theoretical concept, revealing how interpersonal relationships functioned simultaneously as the primary enabler of quality end-of-life care and the principal site of moral distress when that care was constrained. This dual function represents a significant contribution to the existing literature, which tends to treat relational care and moral distress as parallel rather than interdependent concepts. The discussion that follows explores the significance of this interconnection, drawing upon Jameton's (1984) foundational concept of

moral distress, Epstein and Hamric's (2009) theory of moral residue to interpret the findings and articulate their implications for knowledge, practice, policy, and future research.

The discussion is presented in themes that reflect on the integrated nature of the findings. It begins by examining the centrality of interpersonal relationships and their intersection with moral distress, before considering the pandemic's disruption of end-of-life care practices, the ethical implications of medical decision-making during the crisis, and the contributions and limitations of the study. The strengths, limitations, and dissemination plan for this study, the researcher's reflection on the research process, and a conclusion are also included in this chapter.

10.2: Interpersonal relationships as the relational foundation of end-of-life care

The findings of this study demonstrate that relationships between nurses and residents, nurses and families, and among care team members collectively formed the relational infrastructure through which high-quality end-of-life care for people living with dementia was achieved. Rather than functioning as a peripheral feature of care, relationships emerged as the primary mechanism through which clinical knowledge was acquired, personhood was maintained, ethical decisions were negotiated, and emotional support was sustained.

These findings support the work of Nolan et al. (2008) and Watson (2019). Nolan et al. (2008) argue that high-quality care is grounded in positive relationships between residents, families, and staff. They propose that meaningful engagement promotes wellbeing, mutual support, and improved care outcomes. Watson (2019) extends this work by applying it to people with advanced dementia living in care homes at the end of life, arguing that relationship-centred care is essential because individuals with advanced dementia depend heavily on interactions with care staff and family members. Collectively, these authors contend that quality care depends not only on meeting physical needs but also on fostering relationships that provide security, belonging, continuity, purpose, achievement, and significance for older people, families, and care staff.

The present study extends this body of knowledge by demonstrating that relational closeness may also generate emotional and ethical vulnerability when nurses are unable to fulfil responsibilities arising from those relationships. Furthermore, it provides contemporary empirical evidence of how the COVID-19 pandemic disrupted the maintenance of these

relationships, with significant consequences for both the quality of care delivered and staff wellbeing.

Furthermore, participants frequently described relationships with residents using familial language, referring to them as 'family' or 'extended family'. Similar findings have been reported by Canham et al. (2017) and Hartigan et al. (2021), who identified the development of family-like relationships as a defining feature of long-term dementia care. However, this study extends existing knowledge by demonstrating that these relationships served not only emotional purposes but also important clinical functions. Through prolonged engagement with residents, nurses developed nuanced understandings of individual behaviours, preferences, communication styles, and signs of deterioration. This relational knowledge was particularly important for residents living with advanced dementia as communication increasingly relied on non-verbal forms of expression.

These findings align with contemporary understandings of embodied selfhood in dementia, which argue that personhood and relational capacity persist despite cognitive decline (Watson 2019). Recent research continues to emphasise that people living with advanced dementia remain socially and emotionally responsive, making relational continuity a therapeutic necessity rather than a desirable addition to care (Abbott-Anderson et al. 2025). The present findings indicate that person-centred end-of-life care for individuals with dementia cannot be understood separately from the relationships through which that personhood is recognised and sustained.

Relationships with families constituted a second critical relational tier. Participants consistently described relatives as essential partners in care planning and decision-making, particularly where cognitive impairment prevented residents from communicating their wishes directly. This finding supports emerging evidence that family members function as co-producers of care, contributing unique biographical knowledge that is fundamental to personalised end-of-life care (Gonella et al. 2024, Hovenga et al. 2024). However, this study revealed that during the pandemic these partnerships became increasingly difficult to maintain as visiting restrictions disrupted communication pathways and reduced opportunities for collaborative decision-making.

Recent studies have demonstrated that family members experienced considerable distress when excluded from care home environments and decision-making processes during the pandemic, reporting feelings of separation, anxiety, reduced ability to advocate for relatives, and concerns regarding the quality of care received (Parmar et al. 2021, Sadler et al. 2021,

Eriksson and Hjelm 2022, Dixon and Stubbs 2025). Family carers reported feeling isolated and powerless, while residents experienced diminished connectedness and emotional support (Dixon and Stubbs 2025, Gonella et al. 2024). The present findings support these observations and further show that exclusion of families also undermined nurses' ability to access essential information needed for effective advance care planning and personalised end-of-life care.

Team relationships formed the third relational dimension identified in this study. Participants described colleagues as a "second family," emphasising the importance of trust, emotional support, and shared experiences in managing the demands of end-of-life care. Such findings are consistent with research demonstrating that peer support and collaborative team cultures are protective factors against burnout, compassion fatigue, and moral distress among care home staff improving resilience, job satisfaction, and psychological well-being (McGilton et al. 2022, Midtbust et al. 2022, Ariander et al. 2024, Vinkers and Landeweer 2025, Rahman et al. 2026).

This study revealed that the pandemic disrupted these supportive structures through workforce shortages, sickness absence, and increased reliance on agency staff. As a result, opportunities for informal debriefing and collective sense-making diminished at precisely the time they were most needed. Consequently, relational disruption occurred not only between residents and families but also within staff teams themselves, with significant implications for care quality and workforce sustainability.

10.3: Communication challenges in end-of-life dementia care

A significant finding emerging from this study is the central role of communication in shaping the quality of end-of-life care for people living with dementia in nursing homes. Although communication was embedded across all categories of the findings, the pandemic brought existing vulnerabilities in communication processes into sharp focus. Participants described communication not simply as the transmission of information, but as a relational process through which trust, understanding, decision-making, emotional support, and person-centred care were achieved. Consequently, disruptions to communication had profound implications for residents, families, nurses, and the wider multidisciplinary team.

The findings show that communication challenges operated at multiple levels: between nurses and residents, between nurses and families, and between nursing home staff and

external healthcare professionals. These difficulties were intensified by COVID-19 restrictions and often became a source of significant moral distress. In this regard, communication emerged not merely as a practical aspect of care delivery but as a fundamental mechanism through which relationships were established and maintained.

10.3.1: Communication with residents living with dementia

Communication with residents living with advanced dementia was particularly challenging during the pandemic. Participants in this study highlighted that many residents relied heavily on non-verbal communication, including facial expressions, eye contact, touch, gestures, tone of voice, and physical presence. Such findings align with evidence demonstrating that people with advanced dementia continue to communicate meaningfully through relational forms of interaction, even when verbal abilities have declined significantly (Watson 2019).

The widespread use of personal protective equipment (PPE) were seen to create unprecedented barriers to effective communication. Face masks obscured facial expressions, reduced opportunities for emotional connection, and made speech more difficult to understand. Participants described situations where residents became frightened, confused, or distressed because they could not recognise familiar staff members. Similar findings have been reported across international studies (Ariander et al. 2024, Jones et al. 2023), where PPE was found to disrupt interpersonal communication and contribute to feelings of alienation among nursing home residents with dementia. In these studies, staff frequently reported that masks and face shields removed many of the visual cues necessary for reassurance and meaningful interaction

For residents with dementia, these communication barriers were compounded by difficulties understanding the reasons for infection control measures. Unlike cognitively intact individuals, many residents could not comprehend explanations relating to viral transmission, isolation, or visitor restrictions. Participants therefore found themselves repeatedly attempting to explain situations that residents could neither understand nor retain, creating frustration and emotional distress for both parties. This supports broader evidence indicating that pandemic restrictions had a particularly detrimental impact on people with dementia because many lacked the cognitive capacity required to contextualise these changes (Dixon and Stubbs 2025, Abbott-Anderson 2025).

10.3.2: Communication with families

Communication with families represented another critical challenge. Prior to the pandemic, this study showed that face-to-face conversations enabled nurses and family members to build trusting relationships, share concerns, exchange information, and engage in collaborative care planning. These informal interactions often occurred during routine visits and provided opportunities for ongoing discussion about residents' changing needs and preferences. Research has consistently demonstrated that effective communication between family members and nursing home staff is fundamental to building trust, promoting family involvement, and supporting person-centred care (Puurveen et al. 2018, Hoek et al. 2021). Regular, collaborative communication enables families to participate in care planning and decision-making while strengthening partnerships that enhance residents' quality of life and care outcomes (Oliver et al. 2020, Hoek et al. 2021, Hovenga et al. 2022, Hayward et al. 2022, Marion et al. 2024).

The introduction of visiting restrictions during the pandemic abruptly removed these opportunities. Participants described how communication became increasingly dependent on telephone calls, emails, video conferencing, and scheduled updates. While these approaches provided some continuity, they were frequently perceived as inadequate substitutes for in-person interactions. Research conducted following the pandemic similarly found that family members experienced significant distress arising from reduced communication and limited opportunities to maintain meaningful relationships with residents and staff. Families consistently reported valuing regular, honest, and sensitive communication, particularly as residents approached the end of life (Gonella et al. 2024, Dixon and Stubbs 2025).

Importantly, participants reported that communication often became more emotionally demanding during this period. Nurses were required not only to relay clinical information but also to manage family anxiety, grief, anger, and uncertainty. Many participants described having difficult conversations regarding deterioration, hospital transfer decisions, end-of-life care, and impending death remotely rather than face-to-face. Delivering such sensitive information over the telephone was frequently described as distressing and professionally unsatisfactory.

These findings support broader literature illustrating that remote communication technologies cannot fully replicate the emotional and relational dimensions of in-person end-of-life discussions. While technology enabled some form of connection, it often lacked the intimacy,

empathy, and non-verbal cues necessary for complex conversations concerning death and dying (Spacey and Porter 2023, Yoon and Paek 2023, Gonella et al. 2024). Moreover, Ellis and Astell (2017) highlighted the limitations of conventional communication approaches and emphasised the importance of meaningful interpersonal interaction for people with advanced dementia, particularly those who are non-verbal. This supports an argument that remote communication methods may be particularly challenging for some residents with dementia.

10.3.3: Communication and advance care planning

Communication challenges also had significant implications for advance care planning (ACP). Effective ACP depends upon open, timely, and ongoing discussions involving residents, families, nurses, and medical practitioners to explore, document and review individuals' goals, values, and preferences for future care (Rietjens et al. 2017, NHS 2022, Sedini et al. 2022, Spacey and Porter 2023, Nakanishi et al. 2024). However, participants in this study reported that staffing shortages, visiting restrictions, and increased workloads often reduced opportunities for these conversations. Spacey and Porter (2023) found that communication difficulties, particularly those associated with remote technologies, significantly disrupted advance care planning processes during the pandemic. Staff frequently expressed concerns regarding their ability to engage families effectively and establish meaningful dialogue about future care preferences.

The present study extends this understanding by demonstrating how failures in communication contributed directly to moral distress. Participants described situations where residents deteriorated rapidly before meaningful discussions could occur, leaving nurses uncertain whether the care provided aligned with residents' wishes and values. Such circumstances were particularly problematic for residents with advanced dementia, whose ability to communicate preferences independently was already limited.

10.3.4: Communication with external healthcare professionals

Another significant communication challenge concerned interactions between nursing home staff and external healthcare professionals, particularly general practitioners, and specialist services. Participants reported frustrations regarding delayed responses, reduced face-to-face reviews, and increased reliance on telephone consultations. While remote assessments were often necessary during the pandemic, nurses frequently expressed concern that

important clinical information was being lost when practitioners did not physically assess residents.

These findings align with evidence showing that pandemic-related service reconfiguration altered traditional communication pathways between care homes and healthcare providers. Staff often perceived decision-making processes as becoming more distant, less collaborative, and increasingly dependent on incomplete information. Such experiences contributed to feelings of powerlessness and moral distress, particularly when nurses disagreed with clinical decisions but lacked opportunities for direct multidisciplinary discussion (Spacey and Porter 2023, Ariander et al. 2024).

10.3.5: Communication as a relational process

Taken together, the findings demonstrate that communication should be understood as a relational rather than purely informational process. This study has demonstrated that effective communication facilitated the development of trust, preserved personhood, supported shared decision-making, and enabled relationship-centred care. Conversely, communication breakdowns contributed to relational disconnection, uncertainty, emotional suffering, and moral distress.

A particularly important contribution of this study is the recognition that communication and relationships were mutually reinforcing. Strong relationships supported effective communication, while effective communication strengthened relationships. When pandemic restrictions disrupted communication pathways, they simultaneously weakened relational connections between residents, families, nurses, and healthcare professionals. Consequently, communication challenges functioned not simply as practical obstacles to care delivery but as central mechanisms through which the relational foundations of end-of-life care were undermined.

This finding highlights that future pandemic preparedness planning and nursing home policy should recognise communication as an essential component of care rather than an ancillary activity. Investment in staff communication training, family engagement strategies, digital communication infrastructure, and protected time for sensitive discussions may therefore be as important as clinical and infection-control interventions in maintaining high-quality end-of-life care for people living with dementia. Evidence suggests that communication training improves staff competence and interactions with people living with dementia (Eggenberger et al. 2013), while more recent research emphasises communication skills, relationship-

building, and family-centred approaches as fundamental components of end-of-life care (Peerboom et al. 2023). Likewise, family involvement remains critical for resident wellbeing, continuity of care, and decision-making at the end of life (Tupper et al. 2020, Gonella et al. 2024). Studies have also demonstrated the value of digital technologies in maintaining connections when in-person visiting is restricted (Hardy et al. 2022, Vu et al. 2024). Furthermore, high-quality end-of-life discussions require adequate time, organisational support, and opportunities for relationship-building between staff, residents, and families (Peerboom et al. 2023, Stenman et al. 2023). Consequently, several authors have recommended that future policies should facilitate safe family presence at the end of life and provide alternative methods of contact when visiting restrictions are necessary (Bolt et al. 2021, Gilissen et al. 2020).

10.4: Moral distress, moral injury, and the Relational Paradox

The findings relating to moral distress constitute another important contribution of this study. Consistent with Jameton's (1984) original conceptualisation, participants frequently described situations in which they knew the ethically appropriate action to take but were unable to act due to institutional constraints. During the pandemic, these constraints primarily involved visiting restrictions, staffing shortages, remote clinical decision-making, and rapidly changing organisational policies (Ariander et al. 2024, Dixon and Stubbs 2025).

However, this study extends existing understandings of moral distress by demonstrating that it was fundamentally relational in origin. Nurses' distress emerged not simply because professional standards were compromised but because the people affected were individuals with whom they had developed meaningful and enduring relationships. In this context, moral distress was experienced as both an ethical and relational injury.

This finding resonates with contemporary literature describing the transition from moral distress towards moral injury during the pandemic. Moral distress is understood as the psychological, emotional, and spiritual distress that may arise when individuals perpetrate, witness, learn about, or are unable to prevent actions that violate their deeply held moral beliefs and expectations (Litz et al. 2009, Greenberg et al. 2020, Williamson et al. 2020), or when they experience a betrayal of what they perceive to be morally right in high-stakes situations (Shay 2014). Recent studies have demonstrated that healthcare professionals working in long-term care settings progressed to experience substantial moral injury because

of pandemic restrictions, particularly when they felt unable to provide compassionate, person-centred care (Jones et al. 2023, Ariander et al. 2024, Zee et al. 2024).

Participants' descriptions of feeling 'destroyed,' 'broken,' and emotionally overwhelmed indicate experiences extending beyond traditional definitions of occupational stress. Rather, they reflected the enduring consequences of repeated exposure to situations in which they perceived themselves as failing residents despite their best efforts. The emotional intensity of these accounts supports recent arguments that moral distress must be understood within its relational context, particularly in dementia care where close interpersonal attachments are integral to effective practice (Kim et al. 2025).

The findings of this study also offer substantial support for Epstein and Hamric's (2009) concept of moral residue. Participants described ongoing emotional suffering long after the immediate crisis had passed, often recalling specific deaths and difficult situations in considerable detail. These accounts show the accumulation of unresolved ethical experiences over time, reinforcing the crescendo effect described within the moral distress literature (Epstein and Hamric 2009).

A significant theoretical contribution of this study is the identification of the concept of the Relational Paradox. The findings indicate that the same relational closeness that enabled outstanding person-centred care simultaneously increased vulnerability to moral distress when care was compromised. The more deeply nurses knew and cared about residents, the more painful it became when circumstances prevented them from providing the care they believed residents deserved.

This paradox challenges simplistic approaches to reducing moral distress. Strategies promoting emotional detachment may reduce psychological burden but risk undermining relationship-centred dementia care, which depends on meaningful interpersonal connections, reciprocity, and responsiveness between staff and residents (Novy et al. 2023, Gurung and Chaudhury 2025). Conversely, encouraging deeper relational engagement without providing adequate organisational and psychological support may exacerbate moral suffering, as nursing staff frequently experience moral distress when institutional constraints prevent them from delivering care that aligns with their professional and personal values (Midtbust et al. 2022, Levy et al. 2024). The challenge for nursing home policy and practice is therefore not to eliminate the paradox but to support nurses in sustaining meaningful relationships while developing organisational structures, resources, supervision, and support

mechanisms that mitigate the emotional consequences of relational care (Ryan 2022, Gurung and Chaudhury 2025).

10.5: The COVID-19 pandemic as a relational crisis in end-of-life care

The findings of this study demonstrate that the COVID-19 pandemic's impact on end-of-life care for people with dementia in nursing homes was, at its core, a relational crisis. While the pandemic disrupted many dimensions of care, the data consistently showed that the most profound and distressing consequences were those that severed, weakened, or altered the interpersonal relationships upon which quality care depended. The findings of this study diverge from much of the early COVID-19 pandemic literature, which was understandably dominated by concerns regarding infection prevention mortality reduction, and organisational preparedness, often leaving the relational, emotional, and moral consequences of prolonged separation, restricted contact, and altered caregiving relationships comparatively underexplored (Bolt et al. 2021, Dufour et al. 2022, Dyer et al. 2022, Festa et al. 2023). The present study positions these relational disruptions not as secondary consequences of infection control measures but as their primary and most damaging impact on end-of-life care quality.

The visiting restrictions imposed on nursing homes constituted the most widely discussed source of relational disruption. Participants described the disconnection of family contact at the point of greatest need as a fundamental violation of the conditions necessary for a 'good death,' an event defined throughout the data by the presence of meaningful human connection. This finding is consistent with a substantial body of pandemic-era research documenting the devastating impact of visiting restrictions on nursing home residents and their families (Hugelius et al. 2021, Hartigan et al. 2021, Gadbois et al. 2024). However, the present study extends this literature by demonstrating the specifically dementia-related dimensions of this harm. Participants described residents with dementia who repeatedly called for absent family members yet could not comprehend the explanation for their absence, a form of suffering that was qualitatively distinct from that experienced by cognitively intact individuals, who could at least rationalise the restrictions even if they could not accept them. This inability to provide consolation through rational explanation constituted a unique form of moral distress for the nurses, who found themselves witnessing incomprehensible suffering that they could neither alleviate nor adequately explain.

The restriction of therapeutic touch, a primary communicative channel for residents living with advanced dementia, represented a second dimension of relational disruption that had disproportionate consequences for this population. Participants described touch as serving a compensatory function, partially offsetting the relational deficit created by visiting restrictions by providing reassurance through a pre-verbal, embodied medium. Its restriction during the pandemic therefore created what might be termed a 'double deprivation': both primary (family presence) and compensatory (therapeutic touch) sources of relational comfort were simultaneously withdrawn. This finding connects to the growing literature on embodied selfhood in advanced dementia (Kontos 2005, Watson 2019, Boddington et al. 2024, Sunjaya et al. 2025). The pandemic's assault on these embodied channels of communication thus struck at the very foundations of personhood in advanced dementia, where selfhood is increasingly understood as relational, embodied and expressed through non-verbal forms of connection rather than solely through cognitive or linguistic capacities (Boddington et al. 2024, Serbser-Koal et al. 2024, Bøgmose et al. 2025).

Staffing disruptions constituted a third dimension of relational crisis. The loss of familiar staff through Covid-related sickness, compounded by the influx of agency workers unfamiliar with individual residents, produced what participants described as a 'double disruption' of the relational environment; residents lost both their family connections and the familiar care staff upon whom their sense of security depended. For people living with dementia, for whom environmental and relational stability serve a therapeutic function, this dual disruption was identified as actively harmful rather than merely inconvenient. This finding contributes to the emerging literature on the dementia-specific consequences of staffing instability in long-term care (Ariander et al. 2024, Jaarsma et al. 2024) and reinforces the argument that workforce policy in nursing homes must be understood not merely as a human resources issue but as a care quality issue with direct implications for the well-being and mortality of vulnerable residents.

10.6: Ethical dimensions of medical decision-making during the pandemic

Among the most ethically grave findings of this study were participants' accounts of medical decision-making practices during the pandemic that they perceived as fundamentally compromising the standard of care owed to nursing home residents with dementia. The reported blanket prescribing of end-of-life medication for entire nursing home populations,

based on categorical assumptions about age, setting, and diagnosis rather than individual clinical assessment, raises profound questions about the treatment of older people in residential care during the crisis. Participants described a clinical algorithm in which ‘elderly + dementia + deterioration’ was treated as sufficient grounds for initiating end-of-life pathways, bypassing the individualised assessment that should have preceded any such decision.

This finding resonates with broader concerns documented in the post-pandemic literature about the disproportionate impact of COVID-19 on nursing home populations and the potential for structural ageism to have influenced clinical decision-making during the crisis (Gordon et al. 2020, Harper 2021). The perception that general practitioners withdrew from nursing homes, replacing face-to-face clinical encounters with remote consultations and pre-emptive prescribing, constituted a source of acute moral distress for participants who possessed intimate knowledge of individual residents yet lacked the professional authority to override medical decisions they judged to be harmful. This represents a specific mechanism through which hierarchical power structures within healthcare generated moral distress in nursing home nurses, a mechanism that the pandemic exposed and exacerbated but that, as participants indicated, predated the crisis.

The finding that specialist palliative care was perceived as inequitably distributed, with cancer diagnoses attracting significantly greater palliative care input than dementia, adds a further dimension to the ethical critique. This perceived diagnostic discrimination in access to palliative care services has been extensively documented in the literature (Hartigan et al. 2021, Bolt et al. 2022) and reflects a systemic bias within healthcare systems that privileges conditions with clearer prognostic trajectories over the more uncertain and prolonged dying trajectory of dementia. The pandemic intensified this inequity by further restricting the already limited specialist palliative care support available to nursing homes, leaving nurses to manage complex end-of-life situations without the expert guidance that they had identified as transformative when available.

10.7: Advance care planning: aspirations and failures under pandemic conditions

Participants consistently identified advance care plans as essential instruments for preserving residents’ wishes and guiding care delivery, detailing the relational knowledge

that familiar staff possessed. This finding aligns with the substantial evidence base supporting advance care planning as a cornerstone of quality end-of-life care for people with dementia in long-term care settings (Dixon et al. 2021, Hartigan et al. 2021, Spacey and Porter 2023, Nakanishi et al. 2024). However, the present data revealed a fundamental contradiction: the pandemic period during which advance care planning was most urgently needed was precisely the period in which it was least achievable. Staff shortages prevented nurses from conducting comprehensive assessments, visiting restrictions precluded the family consultations upon which surrogate decision-making for people with advanced dementia depended, and the rapid deterioration trajectories associated with COVID-19 infection compressed the timeframe within which care preferences could be established.

This finding is consistent with the critical realist review conducted by Spacey and Porter (2023), which demonstrated that the COVID-19 pandemic disrupted advance care planning discussions in care homes, particularly those involving relatives and surrogate decision-makers. The present study extends this understanding by revealing the moral distress consequences of this disruption: nurses who regarded advance care planning as foundational to person-centred care were forced to provide end-of-life care to residents whose wishes were unknown, in conditions that foreclosed the possibility of establishing them. For people living with advanced dementia, who are wholly dependent on others to articulate their preferences, this failure in the care pathway was not merely procedural but existential, they died among professionals who, in some cases, did not know their histories, their values, or their fears. The data in this study thus demonstrate that advance care planning in dementia care is not a standalone clinical process but is embedded within, and dependent upon, the interpersonal relationships and organisational conditions that the pandemic systematically dismantled.

In summary, this chapter argues that end-of-life care for people living with dementia in Welsh nursing homes was fundamentally shaped by interpersonal relationships, with the Relational Paradox providing the central theoretical lens through which the findings are understood. The study demonstrates that relationships with residents, families, and colleagues formed the relational infrastructure of high-quality, person-centred end-of-life care by enabling communication, preserving personhood, supporting advance care planning, and facilitating ethical decision-making. However, the COVID-19 pandemic disrupted these relationships through visiting restrictions, communication barriers, staffing shortages, remote clinical decision-making, and organisational constraints, transforming the very relationships that enabled good care into sources of profound moral distress. Nurses experienced distress not

simply because care standards were compromised, but because they were unable to meet obligations towards people with whom they had developed close and meaningful relationships. Communication emerged as a relational process central to maintaining trust, collaboration, and continuity of care, yet its disruption undermined relationships across all levels of care.

The findings further reveal that moral distress and moral injury were rooted in relational loss, powerlessness, and the inability to uphold residents' wishes, particularly when advance care planning processes failed, family involvement was restricted, and ethically troubling medical decisions were perceived to diminish personalised care. Through the lens of the Relational Paradox, the pandemic is conceptualised as a relational crisis in which the relational foundations of end-of-life care were systematically weakened, exposing nurses to enduring moral suffering while simultaneously highlighting that meaningful relationships remain indispensable to quality dementia end-of life care. The chapter therefore concludes that the challenge for policy and practice is not to reduce relational engagement, but to provide organisational structures, resources, and support systems that enable nurses to sustain therapeutic relationships while mitigating the moral burden that arises when those relationships are constrained.

10.8: Contributions to knowledge

This study makes several important contributions to the body of knowledge relating to end-of-life care for people living with dementia in nursing homes, moral distress in nursing practice, and the impact of the COVID-19 pandemic on care delivery within long-term care settings.

Firstly, the study addresses a significant gap in the literature by providing an in-depth exploration of registered nurses' experiences of delivering end-of-life care to people living with dementia in nursing homes in South Wales. Although existing research has examined dementia care, end-of-life care, and the impact of the COVID-19 pandemic in care home settings, there is limited qualitative evidence that captures the experiences of registered nurses working within Welsh nursing homes. The findings therefore contribute new empirical knowledge regarding the realities of providing end-of-life dementia care within this specific geographical and professional context.

Secondly, this study contributes an original substantive grounded theory: “The nature and quality of interpersonal relationships shaped end-of-life care for people with dementia in nursing homes during the COVID-19 pandemic.” While previous studies have identified relationships as important within dementia care, this study demonstrates that interpersonal relationships were not simply one aspect of care provision but were the central mechanism through which person-centred end-of-life care was achieved. The findings show that relationships influenced communication, advance care planning, symptom management, decision-making, family involvement, emotional support, and nurses’ experiences of care delivery. In doing so, the study extends current understanding of relationship-centred care and highlights the fundamental role of interpersonal relationships in maintaining quality end-of-life care during both routine practice and times of crisis.

Thirdly, the study extends existing knowledge of moral distress by demonstrating that it was fundamentally relational in nature. Consistent with Jameton’s (1984) conceptualisation, participants experienced moral distress when organisational constraints prevented them from acting in ways they believed were in residents’ best interests. However, the findings show that nurses’ distress arose not only from ethical conflicts but also from disruptions to relationships that they considered central to providing compassionate care. This study therefore advances understanding by proposing that moral distress in nursing home dementia care should be viewed as both an ethical and a relational phenomenon.

A key theoretical contribution of the study is the development of the Relational Paradox as a central theoretical lens. This concept explains how the same close interpersonal relationships that enabled nurses to provide compassionate, person-centred care simultaneously increased their vulnerability to moral distress when external constraints prevented them from delivering the care they believed residents deserved. Existing literature has largely explored relational care and moral distress as separate concepts. This study demonstrates their interdependence and proposes a new way of understanding nurses’ experiences in long-term dementia care settings. The Relational Paradox therefore offers a novel theoretical lens through which future research, practice, and policy can examine the emotional and ethical consequences of relationship-centred care.

The findings also contribute to understanding the impact of the COVID-19 pandemic by conceptualising the pandemic as a relational crisis rather than solely an infection-control, workforce, or organisational crisis. While previous studies have focused primarily on mortality, service pressures, and infection prevention measures, this study demonstrates that the most profound impact on residents, families, and nurses resulted from the disruption of

interpersonal relationships. Visiting restrictions, communication barriers, limitations on touch, workforce instability, and reduced access to external healthcare professionals collectively undermined the relational foundations of care. This perspective provides a new understanding of how public health measures can affect the quality of end-of-life care for people living with dementia.

Finally, the study contributes new knowledge regarding advance care planning in dementia care by demonstrating that advance care planning is fundamentally a relational process dependent upon ongoing communication, trust, continuity of care, and family involvement. The findings reveal how pandemic-related restrictions disrupted these relational foundations, resulting in missed opportunities to establish and document residents' wishes. This extends existing literature by showing that successful advance care planning depends not only on clinical processes and documentation but also on the quality of relationships between residents, families, and healthcare professionals.

Overall, this study contributes original empirical, theoretical, and conceptual knowledge to the fields of dementia care, end-of-life care, nursing home research, and moral distress. The grounded theory developed through this research provides a deeper understanding of how interpersonal relationships shape care experiences and outcomes for people living with dementia, their families, and the nurses who care for them. Most importantly, the study identifies the Relational Paradox as a novel theoretical contribution that advances understanding of both relationship-centred care and moral distress within nursing home settings. This paradox may exist in many settings, but dementia care in nursing homes intensifies it because of several factors: relationships are long-term, residents are highly dependent, communication often relies on relational knowledge, families are central to decision-making, and end-of-life trajectories are uncertain.

10.9: Implications for practice

This study has demonstrated that the quality of end-of-life care for people living with dementia in nursing homes is heavily dependent on the maintenance of effective interpersonal relationships, communication, continuity of care, and organisational support. The findings therefore have several practical implications for care home nurses, managers, healthcare professionals, and policymakers.

10.9.1: Supporting nurses in conducting difficult conversations with families.

A significant finding of this study was the shift in nurses' communication practices during the COVID-19 pandemic. Visiting restrictions meant that nurses frequently had to communicate resident deterioration, discuss end-of-life decisions, and break news of impending death or death itself via telephone rather than in person. Participants described these conversations as emotionally challenging and professionally unsatisfactory due to the absence of visual cues, the inability to provide immediate emotional support, and concerns about relatives' understanding of information.

Care home organisations should therefore implement training and support programmes aimed specifically at remote end-of-life communication. This could include training in conducting difficult conversations remotely; communication frameworks and guidance for discussing deterioration and end-of-life issues with relatives; role-play and simulation exercises to build confidence in delivering sensitive information; and access to senior clinical support and debriefing following particularly distressing conversations. Such measures may improve communication quality while reducing anxiety and moral distress among nursing staff.

10.9.2: Strengthening family engagement during periods of restricted access.

The findings demonstrated that family members were essential partners in care and decision-making. When visiting restrictions were introduced, opportunities for informal communication and relationship-building were significantly reduced. This not only affected families but also limited nurses' ability to provide person-centred care based on residents' preferences and life histories.

Care homes should develop structured family communication plans that can be activated during future outbreaks or emergencies. These plans could include: designated family liaison roles; scheduled communication updates for relatives; standardised procedures for informing families about changes in residents' conditions; and enhanced use of digital technologies to facilitate communication when face-to-face contact is restricted. Importantly, future emergency preparedness plans should prioritise safe family presence at the end of life whenever possible.

10.9.3: Preparing nurses for expanded and changing roles during healthcare crises.

The pandemic altered nurses' responsibilities significantly. Participants described assuming additional clinical, emotional, communication, and decision-support roles as access to external healthcare professionals became more limited. Nurses often became the primary point of contact for residents, relatives, GPs, and specialist services while simultaneously managing increased workloads and staffing shortages.

These findings highlight the need for care home organisations to prepare nurses for role expansion during future crises. Practical strategies for emergency preparedness should include: education on leadership and autonomous clinical decision-making; enhanced palliative and end-of-life care training; access to specialist palliative care advice and mentorship; development of frameworks for remotely discussing deterioration and end-of-life care with family. Ensuring nurses possess the necessary skills and support to adapt to changing roles may increase confidence and improve care delivery during periods of service disruption.

10.9.4: Improving support for verification of expected death.

Participants reported difficulties associated with verifying expected deaths during the pandemic, particularly when access to medical practitioners was limited. Delays in verification could increase the potential for prolonging distress for families, affecting burial arrangements, and mounting emotional burden on nursing staff caring for deceased residents.

The findings highlight a need to further develop registered nurses' competencies in verification of expected deaths, where permitted by local policy and professional regulations. Practical strategies include: providing accredited verification of expected death training; developing clear local protocols and responsibilities; strengthening collaboration between nursing homes, GPs, and palliative care services; and ensuring timely access to professional support when verification difficulties arise. Such approaches may reduce delays and improve the quality of end-of-life care following residents' deaths.

10.9.5: Supporting nurses experiencing moral distress.

The study found that nurses experienced substantial moral distress arising from visiting restrictions, perceived compromises in resident care, difficulties advocating for residents, and challenges associated with end-of-life decision-making. The findings further demonstrated that repeated exposure to these situations resulted in lasting emotional consequences.

Care home providers should therefore recognise moral distress as an occupational risk associated with end-of-life dementia care and implement formal support mechanisms, including: regular reflective practice sessions; clinical supervision; structured debriefing following resident deaths; peer support groups; and access to psychological support services. These interventions may help nurses process ethically challenging experiences and reduce the accumulation of moral residue.

10.9.6: Promoting continuity of relationships in dementia end-of-life care

A key finding of this study was that relationships were central to understanding residents' preferences, recognising deterioration, and maintaining personhood at the end of life. Frequent staffing changes and increased reliance on agency staff during the pandemic disrupted these relationships and were perceived as detrimental to care quality.

Care home managers should therefore prioritise workforce strategies that promote continuity of staffing. These may include: consistent staff allocation to residents; reducing avoidable reliance on temporary staff; supporting staff retention through professional development and wellbeing initiatives; recognising relational care as a core component of high-quality dementia care; and provision of protected relational time. Maintaining continuity of relationships may enhance person-centred care and improve end-of-life experiences for residents and families.

In conclusion, the implications arising from this study demonstrate that improving end-of-life care for people living with dementia in nursing homes requires more than clinical interventions alone. Organisations must support nurses in managing complex communication responsibilities, prepare them for changing clinical roles during periods of crisis, strengthen processes surrounding verification of death, provide support for moral distress, and prioritise the relational aspects of care. By implementing these practical

strategies, care homes may be better equipped to deliver compassionate, person-centred end-of-life care during both routine practice and future healthcare emergencies.

10.10: Implications for policy

At the policy level, the findings challenge the adequacy of pandemic policy frameworks that treated nursing homes as homogeneous sites for infection control without adequately considering the relational and ethical dimensions of care provision within them. The blanket visiting restrictions imposed on Welsh nursing homes, while epidemiologically motivated, produced a relational catastrophe for dying residents with dementia and their families that participants described as fundamentally wrong. This finding supports the growing policy consensus in the post-pandemic period that visiting rights for dying residents should be treated as non-negotiable elements of end-of-life care, protected even under conditions of heightened infection risk (Department of Health and Social Care 2022, Scottish Government 2022).

The findings also raise serious policy questions about the standard of medical care provided to nursing home residents during the pandemic. The reported withdrawal of general practitioners from face-to-face clinical engagement, the blanket prescribing of end-of-life medications without individual assessment, and the reduction of complex personhood to categorical risk profiles all point to a systemic failure in the duty of care owed to this population. Policy responses should include clear professional standards for medical engagement with nursing home residents during health emergencies, regulatory safeguards against blanket prescribing practices, and mechanisms through which nursing home nurses can escalate concerns about clinical decisions they perceive as harmful without fear of professional reprisal.

Additionally, the persistent inequity in access to specialist palliative care for people dying with dementia compared to those dying with cancer demands a policy response that extends beyond the pandemic. The present findings add the lived experience of frontline nursing home staff to the body of evidence calling for equitable palliative care commissioning that recognises dementia as a terminal condition with complex palliative care needs deserving of specialist input equal to that afforded to other life-limiting conditions.

10.11: Implications for nursing education

The findings have important implications for the education and preparation of nurses entering long-term care settings. The data revealed that the skills required for quality end-of-life care for people with dementia, interpreting non-verbal cues, building relational knowledge over time, managing complex family dynamics, navigating ethical uncertainty, and processing cumulative grief, are not adequately addressed by existing educational frameworks that privilege acute care competencies. This finding is consistent with longstanding critiques of nurse education's undervaluation of gerontological and long-term care content (Nolan et al. 2006, Kim et al. 2025) and suggests the need for curriculum reform that elevates relational competencies alongside clinical ones.

The study also underscores the need for education that prepares nurses for the moral and emotional demands of nursing home work, including the development of moral resilience; the capacity to sustain one's moral integrity and well-being in the face of morally distressing situations. Semler (2023) has argued that moral resilience can be cultivated through education that combines ethical reasoning, self-care strategies, and organisational advocacy skills. The present findings demonstrate that such education must also address the specific relational and dementia-related dimensions of moral distress identified in this study, including the experience of anticipatory grief, the management of surrogate family roles, and the navigation of the Relational Paradox whereby emotional closeness is simultaneously essential and costly.

10.12: Recommendations for future research

Several avenues for future research emerge from the present findings. First, longitudinal studies are needed to track the long-term psychological trajectories of nursing home nurses who provided end-of-life care during the pandemic. The moral residue reported by participants suggests that the psychological impact of the pandemic may be progressive rather than resolving, and longitudinal designs would enable the crescendo effect theorised by Epstein and Hamric (2009) to be empirically examined over time.

Second, research is needed that directly includes the perspectives of people living with dementia in the generation of knowledge about end-of-life care experiences. The present study, like much of the existing literature, relied on nurses' accounts as representatives for

residents' experiences. While this was methodologically appropriate given the advanced dementia of the residents in question, future studies employing creative and inclusive methodologies, such as participatory observation, sensory ethnography, or the use of wearable technologies to capture physiological indicators of comfort and distress, could complement caregiver accounts and reduce the epistemological dependency on substitute reporting.

Third, intervention studies are warranted that test approaches to mitigating moral distress in nursing home settings. While the present study identified the sources, mechanisms, and consequences of moral distress in considerable depth, it did not evaluate potential interventions. Future research should design and test organisational interventions such as structured reflective practice programmes, ethics consultation services, and peer support models, with particular attention to their effectiveness in nursing home as opposed to acute care settings, where most existing moral distress interventions have been developed and tested (Amos and Epstein 2022).

Fourth, comparative research across different care settings, healthcare systems, and cultural contexts would strengthen the transferability of the present findings. The study was conducted in Welsh nursing homes within a specific healthcare and regulatory framework, and the experiences of nurses in other national contexts where pandemic restrictions, medical engagement patterns, and staffing structures may have differed, could reveal both universal and context-specific features of the phenomena examined.

Fifth, future research should explore the family perspective in greater depth, examining how families experienced the disruption of their relationships with nursing home residents during the pandemic and the impact of this disruption on their bereavement trajectories. The present data contained compelling accounts of family distress mediated through the nurses' perspective, but direct exploration of family experiences would provide a more complete understanding of the relational crisis that the pandemic produced.

Finally, given that the grounded theory integrated in this study is new and original, then it needs to be tested, developed, and refined further through further research focussing on interpersonal relationships and how it shapes the delivery of care.

10.13: Strengths of this study

One of the key strengths of this study was that data was collected from four nursing homes owned by different organisations, which ensured a variation in terms of size and ownership. This provided a broader understanding of the nurses' end-of-life care experiences, which would help with the transferability of the findings.

Furthermore, my role as a Nurse Assessor was an advantage during the data collection phase. As stated earlier, data for this study were collected in the middle of the COVID-19 pandemic when lockdown measures were in place. During the lockdown non-essential visits were restricted which would have meant pausing the data collection for this study. Many types of research were halted during this time. However, as I was allowed access to the nursing homes during this period for my work, I was able to combine my data collection with these visits. This highlights the advantage of conducting this type of research by healthcare professionals who have little restriction at times where access is limited, which means that research activities can still go on in such circumstances.

One could argue that with everything going on in the nursing homes during the pandemic, conducting interviews would be considered non-essential. However, the nurses used the interviews as an opportunity to speak to someone and share their experiences. This was important as during the pandemic staff and residents in nursing homes were isolated and having someone interested to listen to them was considered by the study participants to be beneficial. A sense of fulfilment is achieved through attainment of meaningful or valued goals and feeling satisfied with one's efforts (Nolan et al. 2008). The findings of this study revealed that the participants felt frustrated as their efforts, throughout a period they considered taxing, were not recognised and appreciated by the outside others which could have resulted in the lack of a sense of achievement. As such, the participants felt that they were being heard and their hard work recognised during the interviews, hence fulfilling this particular sense. Therapeutic benefits of research is an interesting area, particularly in times of adversity. As such it would be worth exploring further and writing a paper on it in the near future.

Another important strength of this study was the robustness of the research methodology used. The researcher adhered to the techniques and procedures of grounded theory throughout the research process which enhanced the rigour of the findings. Consequently, the use of grounded theory methodology has offered a novel understanding of the

experiences of registered nurses in caring for people with dementia at the end of life in nursing homes.

10.14: Limitations of this study

Several limitations must be acknowledged. First, the study was conducted within four nursing homes in Wales, and the findings, while rich in depth and detail, may not be directly transferable to nursing homes in other geographical, cultural, or healthcare contexts. The specific regulatory framework governing Welsh nursing homes, the patterns of medical engagement, and the local workforce dynamics may have shaped the experiences reported in ways that are context specific. However, the grounded theory methodology employed in the conduct of this study does not claim statistical generalisability but rather theoretical transferability, and the resonance of the findings with the broader international literature supports their relevance beyond the immediate study context.

Second, the reliance on nurses' accounts as the sole data source means that the experiences of other stakeholders, particularly residents with dementia, their families, and medical practitioners, are represented only through the lens of the nursing participants. This is a significant limitation given the study's emphasis on interpersonal relationships, which by definition involve multiple parties. Future research incorporating multi-stakeholder perspectives would provide a more balanced and comprehensive account of the relational dynamics of end-of-life care.

Third, data collection occurred during the pandemic, which may have introduced both advantages and limitations. The proximity of data collection to the experiences being described likely enhanced the vividness and emotional immediacy of participants' accounts but may also have limited their capacity for reflective distance. Furthermore, the pandemic context may have influenced participants' willingness to discuss certain topics, particularly those involving criticism of medical colleagues or institutional practices, due to concerns about professional repercussions. The researcher sought to mitigate this through the establishment of trust, the assurance of anonymity, and the use of open-ended interviewing techniques, but the possibility of self-censorship cannot be entirely excluded.

Fourth, the study focused exclusively on registered nurses, excluding the experiences of healthcare assistants, nursing assistants, and non-clinical staff who, as the findings themselves demonstrated, played significant roles in end-of-life care delivery, particularly

during the pandemic. The activities workers who sang hymns, the housekeepers who sat with dying residents, the kitchen staff who provided companionship, these individuals' experiences of moral distress and relational care remain unexplored and represent an important gap in the evidence base.

Finally, during the conduct of this study, I was aware of how my personal beliefs, assumptions and experiences can influence the research process and how data is interpreted (Corbin and Strauss 2015). For instance, I possessed prior knowledge and experience from my former role as a nursing home nurse and current role as a Nurse Assessor, which both involved some aspects of end-of-life care for people with dementia in nursing homes. I was conscious of this and made sure that I maintained a reflexive account to take note of how my prior knowledge and experiences could influence the way I interpreted the data. I had the knowledge and experience of the challenges that nurses faced when caring for people with dementia at the end of life in nursing homes which could have influenced my interpretation of the findings in this study. Furthermore, I was also aware of the restrictions in my own cultural beliefs about discussing death and dying. In addition, being a practicing Christian, I had my own understanding of the spiritual needs of people at the end of life. As such, I ensured that my interpretation of the findings was based solely on the participants' accounts supported by relevant literature and not based on my own cultural/religious beliefs, or prior knowledge or experience of the study area. In addition, I kept a record of responses to data in the form of a reflective diary, memos, and field notes (Corbin and Strauss 2015). This helped to prevent the influence of beliefs and assumptions (personal biases) on how data were interpreted.

10.15: Dissemination

I intend to communicate the findings of this research through activities such as publication in peer-reviewed journals, for example the Journal of Advanced Nursing, Nurse Education Today, Journal of Nursing Education, and by presenting at international nursing research conferences, to highlight the role of interpersonal relationships in end-of-life care for people with dementia in long-term care settings, and for people providing care in adversity.

The research and findings will also be presented at the Cardiff University Postgraduate Research Students/Staff Annual Symposium to help others understand the grounded theory methodology and the development of a grounded theory. The experiences encountered when conducting this research will also be shared.

I also plan to hold seminars in the nursing homes that were involved in this study for feedback, and to share the research findings to acknowledge their contribution and inform them of the key findings which could be useful in developing strategies to enhance end-of-life care for people with dementia in the nursing homes.

10.16: Reflection on the research study

Reflection is described as learning from experience (Wain 2017), fostering self-awareness (Delves-Yates 2021) and providing opportunities to improve practice (NMC 2019).

Furthermore, reflection enables individuals to develop new insights that are essential for personal and professional growth (Johns 2010). Undertaking this study provided several valuable insights and learning opportunities.

At the outset of the study, I felt nervous and uncertain, as this was my first experience of conducting qualitative research using grounded theory methodology. Throughout the research process, I recognised the importance of self-awareness, openness to learning, and seeking regular guidance from my supervisors. Despite my initial apprehension and lack of confidence, I found the process of applying the theoretical principles of grounded theory to an actual research study both engaging and rewarding. This experience enhanced my understanding of qualitative research and increased my confidence as a researcher.

I also found the ethics application process to be complex and demanding, requiring the provision of extensive information before approval could be granted. The process was lengthy and required considerable attention to detail. However, it proved to be a valuable learning experience, enabling me to appreciate the rationale behind ethical governance and the importance of protecting research participants. Having been advised by fellow students about the likely timescales involved in obtaining ethical approval, I was able to plan other research-related activities during this period, including conducting further reading and drafting sections of the thesis. This helped me to use my time effectively and maintain progress with the study.

Given the sensitive nature of the research topic, I initially assumed that participants might find it difficult to openly discuss experiences related to death and dying, particularly during a period when deaths in nursing homes had increased as a result of the COVID-19 pandemic. However, I was pleasantly surprised by how smoothly the recruitment process progressed and by the willingness of participants to share their experiences. Participants engaged openly with the interview questions and provided rich, detailed accounts that offered valuable

insights into their experiences. These contributions were instrumental in the development of the grounded theory. Conducting this study and applying grounded theory methodology enabled me to develop valuable research knowledge and skills, increasing my ability to undertake future research independently and with greater confidence.

10.16.1: Reflection on insider/outsider status and the potential impact on the study

I considered myself an insider within the research setting because, as a registered nurse and Nurse Assessor, I shared professional experiences with the participants in providing end-of-life care for people living with dementia in nursing homes. Through my previous experience of working in nursing homes, I had developed a comprehensive understanding of the policies, procedures, and standards associated with this area of care. In addition, my role as a Nurse Assessor involved monitoring standards of care within nursing homes, including care provided to people living with dementia at the end of life. However, I had no previous experience of working during a pandemic with prolonged visiting restrictions such as those imposed during this pandemic. My prior experience had been limited to managing short-term outbreaks of illnesses such as influenza or gastroenteritis, making the participants' experiences during COVID-19 particularly unique.

This professional background proved valuable during data analysis, as it enhanced my understanding of participants' accounts and the context in which their experiences occurred. My familiarity with the nursing home environment also facilitated access to research sites and established rapport with many participants. Nevertheless, I remained aware of the potential influence that my pre-existing relationships and professional role could have on the research process. Given my senior monitoring role, participants may have felt cautious about discussing aspects of their practice due to concerns about judgement or the possibility of issues being escalated if unsafe practices were disclosed.

To minimise this risk, I employed critical reflection throughout the research process and used reflective notes and memos to support careful interpretation of the data. I also made a conscious effort to distinguish between my own professional experiences and the participants' perspectives, ensuring that the analysis remained grounded in the data. This process helped to minimise the influence of personal assumptions and potential bias.

Furthermore, my familiarity with participants may have contributed to the development of an environment characterised by trust, openness, and mutual understanding during the interviews. This may have enabled participants to feel more comfortable sharing their experiences than they would have with a researcher from a different professional background (Burns et al. 2012).

My role as a Nurse Assessor also enabled me to continue data collection during the pandemic, as I was granted access to nursing homes in order to fulfil my monitoring responsibilities. During lockdown periods, when only essential visits were permitted, this role facilitated access to research settings that might otherwise have been unavailable. Nevertheless, I ensured that all infection prevention and control measures were followed and, where possible, aligned my research activities with my routine monitoring visits to minimise disruption to care and reduce the number of visits required.

Conversely, I also viewed myself as an outsider because I was employed by the local health board rather than by the nursing homes themselves. I had no direct employment relationship or organisational commitment to the participating nursing homes. Consequently, I made a clear distinction between my responsibilities as a researcher and those associated with my Nurse Assessor role, ensuring that participants understood the separate purposes and expectations of each role. Reflexivity was therefore essential in increasing awareness of how my insider and outsider positions could influence participants, data collection, and data analysis. Maintaining this reflexive approach throughout the study contributed to the credibility and trustworthiness of the findings (Burns et al. 2012).

10.17: Conclusion

The findings of this study reveal that end-of-life care for people living with dementia in nursing homes is, at its core, a relational endeavour. The quality of interpersonal relationships between nurses and residents, between nurses and families, and among team members determines the quality of care that dying residents receive, the capacity of families to participate meaningfully in the dying process, and the ability of nurses to sustain their professional and personal well-being in the face of repeated loss. The COVID-19 pandemic constituted an unprecedented assault on these relational foundations, severing the connections upon which quality care depended and generating moral distress of a severity

and duration that many participants had not yet begun to process at the time of data collection.

The study's identification of the relational paradox, that the depth of emotional investment which enables the best care also produces the deepest distress, carries implications that extend well beyond the pandemic context. As long-term care systems internationally confront the challenges of an ageing population with increasing dementia prevalence, the question of how to sustain deep, meaningful, relational care for dying people with dementia while adequately supporting the nurses who provide it will become increasingly urgent. The present study suggests that answering this question will require structural changes that value relational continuity, invest in workforce stability, create robust systems of emotional support for staff, and ensure that the relational dimensions of care are protected even under conditions of crisis. Failing to do so risks not only the well-being of the current nursing workforce but the quality of end-of-life care for the generation of people with dementia who will depend upon their compassion, skill, and relational presence in the years ahead.

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Appendices

Appendix i: Data extraction table for studies selected in scoping review

A: Study author, year of publication, title, methods, setting, population, aim

Study	Methods	Setting	Population	Aim
1. Huang et al. 2018. End of life care discussions for residents with dementia in Long- Term care facilities	Self-administered standardised questionnaires. Stratified random sampling and postal surveys. Sample size was estimated using G*Power 3. Predictive analytics software (IBM SPSS Statistics 22.0). Frequencies, percentages, means, standard deviations, and ranges were included as descriptive statistics to identify the demographic characteristics of participants, discussions about EOL care, and other relevant main variables. Frequency distributions of discussions about EOL care were measured using chi-square tests, mean-difference-related main variables with one-way analysis of variance, and Scheffe's post hoc analysis to	48 Long-term care facilities Taiwan	Physicians, registered nurses, and social workers who work in long-term care facilities rated Grade A or higher	To explore the factors related to the end-of-life care discussions of registered nurses, social workers, and physicians with residents with dementia and their families.

	determine any possible differences among the various professional groups. <i>p</i> -values of .05 were considered statistically significant.			
2. Midtbust et al. 2018. Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences	Qualitative descriptive study Sampling- not specified- participants recruited by managers of the nursing homes 4 focus groups and 20 individual in-depth interviews Data analysis: thematic analysis- NVivo 11 qualitative data analysis software used for the coding of the text	Nursing Homes Norway	Licensed practical nurses and registered nurses in part or full-time positions 10 registered nurses and 6 licensed practical nurses- focus groups. A total of 20- in individual interviews	To examine health professionals' experiences of potential barriers and facilitators in providing palliative care for people with severe dementia in long-term care facilities
3. Monthaisong 2018. Nurses' experiences providing care for people with dementia: An integrative literature review	An integrative literature review All the studies used a qualitative methodology included a reflective journal, phenomenological, ethnographic, grounded theory, descriptive exploratory approaches, an organizational development approach, a pragmatic exploratory approach, and a meta-ethnographic analysis of qualitative studies Data analysis: Thematic analysis	A literature search was performed using Internet search engines, such as CINAHL Complete, OVID, MEDLINE Complete, MEDLINE in PubMed, and ProQuest Nursing and	19 articles were taken forward to explore what research had been conducted involving the experiences of nurses providing care for people with dementia	To review the experience of registered nurses providing care for dementia patients including theoretical perspectives that have been used to provide care for people with dementia

		Allied Health Source		
4. Bükki et al. 2016. End of life care in nursing homes: Translating focus group findings into action	Qualitative 3 focus group interviews Purposive sampling Data analysis: Thematic content analysis	X1 300- beds Nursing homes Germany	Nursing home staff (nurses, care managers, physicians)	To explore views, attitudes, and concerns among staff and to embark on a process that facilitates end-of-life care on an institutional level
5. De Witt Jansen et al. 2016. Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study	Qualitative Index contacts in each of these settings were approached for participation in the first instance, and subsequent participants were contacted through an onward process of nominative sampling Semi-structured, face-to-face interviews Data analysis: Thematic analysis, facilitated by NVIVO 10 software	10 nursing homes Northern Ireland, UK	24 registered nurses caring for people dying with advanced dementia	To explore hospice, acute care and nursing home nurses' experiences of pain management for people with advanced dementia in the final month of life. To identify the challenges, facilitators and practice areas

				requiring further support.
6. Koppitz et al. 2016. Decision-making in caring for people with dementia at the end of life in nursing homes	Qualitative (Part of a larger two-phase retrospective descriptive study) Sampling- not specified Constructivist Grounded Theory (Charmaz) Individual in-person semi-structured interviews Facilitated by: Atlas.ti software program (Version 7.1.6)	4 nursing homes in the Canton of Zurich, Switzerland	32 Nursing staff members with tertiary, secondary, and assistant-level education involved in daily clinical decision-making	To examine the decision-making process of symptom management for people living with dementia in nursing homes in their terminal phase of life.
7. Livingston et al. 2016. Care at the end of life for people with dementia living in a care home: a qualitative study of staff experiences and attitudes	Qualitative (part of a larger intervention study between Jewish Care (a health and social care charity for the Jewish community) and a university (University College London)) Sampling- not specified Individual interviews (used an interview guide constructed from the literature, comprising open-ended questions) Data analysis: Thematic analysis facilitated by Atlas.ti 5.6 software	x1 120-bed Nursing home where the staff and residents' religion differed London, UK	58 permanent staff providing direct care	To examine barriers and facilitators to care home staff delivering improved end-of-life care for people with dementia

8. Waldrop and Kirkendall 2009. Comfort measures: a qualitative study of nursing home-based end of life care	Exploratory, descriptive Qualitative study Sampling-? Semi-structured in-depth interviews Open-ended questions Data analysis: Grounded theory techniques	X 1 120 bed nursing home that is part of a continuum of care from independent living to residential care, rehabilitation, intermediate, dementia and skilled care USA	42 staff members including administrators, nurses, certified nursing assistant, social workers, and housekeepers	To explore how staff recognize that a resident is dying and to present a typology of comfort measures
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B: Study author, year of publication, title, findings and conclusion/recommendation

Author/ Year of publication/ Title of study	Findings	Conclusion/ recommendation
1.Huang et al. 2018. End of life care discussions for residents with dementia in Long- Term care facilities	Questionnaires were returned by 478 out of 529 participants (response rate = 94.1%). Fewer than 10% of the participants reported often discussing end-of-life care with residents with dementia and their families. Physicians were significantly more likely to discuss life-sustaining treatment than nurses and social workers. The frequency of professionals discussing advance directives and life-sustaining treatment for residents with dementia was predicted by higher confidence in end-of-life care skills and greater perceived facility support.	Most professionals did not frequently discuss end-of-life care with residents with dementia and their caregivers. Discussions of end-of-life care in long-term care facilities should be promoted by enhancing the confidence of these professionals in providing end-of-life care and creating a supportive environment for end-of-life discussions and care.
2.Midtbust et al. 2018. Perceived barriers and facilitators in providing	The major findings indicate that healthcare professionals experience a lack of continuity as the main barrier to facilitating palliative care. Time	The findings indicate that healthcare professionals experienced several structural barriers that prevented the provision of palliative care to people with severe dementia in long-term care facilities. Increasing demands for economic rationality led to a lack of continuity of care. Organizational changes,

palliative care for people with severe dementia: the healthcare professionals' experiences	pressure and increased efficiency requirements especially affect the weakest and bedridden residents with dementia. The healthcare professionals feel conflicted between wanting to spend more time caring for each individual resident and feeling pressure to help everyone. Although resources are scarce, dying residents are always given priority by healthcare professionals, either by the hiring of extra personnel or the reorganization of tasks in a way that facilitates someone staying with the terminal resident. Advanced care planning was highlighted as a facilitator in providing palliative care, but the extensive use of temporary staff among nurses and doctors and the relocation between the sheltered and long-term wards threaten the continuity in planning and providing palliative care	such as measures to increase the competence and the proportion of permanent employees and the prevention of burdensome end-of-life transitions, should be implemented to improve continuity and quality of care
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3.Monthaisong. 2018. Nurses' experiences providing care for people with dementia: An integrative literature review	Four themes related to the nurses' experiences of providing care for people with dementia included encountering with painful emotions, working under severe conditions, meeting holistic care needs, and experiencing inadequate knowledge. Factors contributing to appropriate care for people with dementia and barriers to meet the optimal care were identified in this article	Nurses' experiences included struggling with painful emotions and working under difficult circumstances and there was the need for meeting spiritual care needs of patients. Nurses identified lack of knowledge of dementia and the need for improved effective communication when they provided care to these patients and their family members. Relevance to clinical practice: Understanding nurses' experiences of providing care for people with dementia may help nurses to utilize positive care experiences to practice. Nurses should therefore be aware of how some experiences may facilitate or hinder the provision of optimal care.
4.Bükki et al. 2016. End of life care in nursing homes: Translating focus group findings into action	Seventeen themes emerging from the focus group discussions were grouped into the four categories: Workload and efficacy, Aims and attitudes, Leadership, and Communication. The 17 themes included: workload; ethical conflicts; additional resources; "living palliative care"; deleterious effect of restorative aims; lack of training; fear; knowledge and skills; rituals; lack of attachment, frustration, and abuse; team; discouragement;	Providing good end-of-life care may promote professional resilience and personal integrity. Therefore, team issues, fears, and avoidance should be addressed.

	resilience enhanced by good care; style of communication; avoidance; the “palliative” status; legal concerns and hospital admissions. The nursing home staff expressed willingness to care for the dying	
5.De Witt Jansen et al. 2016. Nurses’ experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study	3 core themes were identified: challenges administering analgesia, the nurse–physician relationship, and interactive learning and practice development. Patient-related challenges to pain management were universal across care settings; nurse- and organisation-related barriers differed between settings. A need for interactive learning and practice development, particularly in pharmacology, was identified	Achieving pain management in practice was highly challenging. Several barriers were identified; however, the manner and extent to which these impacted on nurses differed across hospice, nursing home and acute care settings. Needs-based training to support and promote practice development in pain management in end-stage dementia is required.
6.Koppitz et al. 2016. Decision-making in caring for people with	‘Recount and reflect’ plays a vital role in the care of people living with dementia in terminal phase, enabling symptom recognition and	Highly trained nurses need to support health care assistants through counselling, coaching, and leadership to help reduce the symptom burden experienced by people living with dementia. Relatives are necessary to maintain an exchange of

dementia at the end of life in nursing homes	facilitating symptom management. A process of thinking during action enables nursing staff members to understand what, when, and how symptom changes have taken place	ideas regarding the appropriate treatment to reduce symptom burden.
7.Livingston et al. 2016. Care at the end of life for people with dementia living in a care home: a qualitative study of staff experiences and attitudes	The staff felt warmly towards the residents and felt they could recognise when they were near death. Care staff, nurses and doctors did not see themselves as a team and communicated poorly with relatives about approaching death. The staff used opaque euphemisms and worried about being blamed. They were often unaware of or had concerns about the validity of advance care plans. They knew of the religious rituals around death but frequently misunderstood religious tradition	The staff require education and support about discussing and implementing plans around care at the end of life in dementia and about cultural issues around death to improve practice. This would enable the staff to implement advance care plans, knowing that they will be supported. Education would encompass communicating the complicated, unpredictable path of dementia near the time of death explicitly but sensitively, including recognising that people often do not hear difficult messages and are unable to take on large quantities of information at once. The staff need to know about the resident's religious and cultural ideas as well as ritual practice
8.Waldrop and Kirkendall. 2009. Comfort measures: a qualitative	Nursing home staff members identified physical, behavioural, and social indicators of an approaching death. Comfort care is the	The terms comfort measures and comfort care are widely used in nursing homes, but definitions and modes of delivery vary. In-depth exploration can be utilized to compare of current and existing practices and contribute knowledge about whether palliative care is provided in nursing homes and if so, how.

study of nursing home-based end of life care	interrelationship between: (1) symptom management (e.g., pain, dyspnoea, anorexia, and dry mouth), (2) family care (e.g. emotional support, death education), (3) interpersonal relationships (e.g., with residents, family) and (4) complementarity between interdisciplinary roles. Comfort care is holistic and person-centred focusing on the interrelationship between physical, psychosocial, and spiritual issues	Ultimately program comparisons can lead to improvements in nursing home-based end-of-life care and standards for the delivery of palliative care in this setting
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Appendix ii: Ethics approval letter



School of
Healthcare Sciences
Ysgol y Gwyddorau
Gofal Iechyd

Interim Head of School and Dean / Pennaeth yr Ysgol Dros Dro a Deon Professor David Whitaker

16 December 2020

Tidziwe Malinki-Madeya
Cardiff University
School of Healthcare Sciences

Dear Tidziwe Malinki-Madeya

Research project title: Research project title: Registered Nurses experiences of caring for people with dementia at the end of life in nursing homes

SREC reference: REC739

The School Of Healthcare Sciences Research Ethics Committee reviewed the above application amendments electronically on 16 December 2020.

Ethical Opinion

The Committee gave

a favourable ethical opinion of the above application on the basis described in the application form, protocol and supporting documentation

Additional approvals

This letter provides an ethical opinion only. You must not start your research project until all appropriate approvals are in place.

Amendments

Any substantial amendments to documents previously reviewed by the Committee must be submitted to the Committee via HCAREethics@cardiff.ac.uk for consideration and cannot be implemented until the Committee has confirmed it is satisfied with the proposed amendments. You are permitted to implement non-substantial amendments to the documents previously reviewed by the Committee but you must provide a copy of any updated documents to the Committee via HCAREethics@cardiff.ac.uk for its records.

Monitoring requirements

The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.

The Committee must be informed when your research project has ended. This notification should be made to HCAREethics@cardiff.ac.uk within three months of research project completion.



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2015



Registered Charity No. 1136855
Elusen Gofrestredig Rhif. 1136855

Complaints/Appeals

If you are dissatisfied with the decision made by the Committee, please contact the School's Research Ethics Officer, " " on HCAREethics@cardiff.ac.uk in the first instance to discuss your complaint. If this discussion does not resolve the issue, you are entitled to refer the matter to the Head of School for further consideration. The Head of School may refer the matter to the Open Research Integrity and Ethics Committee (ORIEC), where this is appropriate. Please be advised that ORIEC will not normally interfere with a decision of the Committee and is concerned only with the general principles of natural justice, reasonableness and fairness of the decision.

Please use the Committee reference number on all future correspondence.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its [Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data](#) and our [Research Integrity and Governance Code of Practice](#).

Yours sincerely,



Registered Charity No. 1136855
Eusen Gofrestredig Rhif. 1136855

Appendix iii: Nursing home consent letters

8th October 2020

Dear Ted,

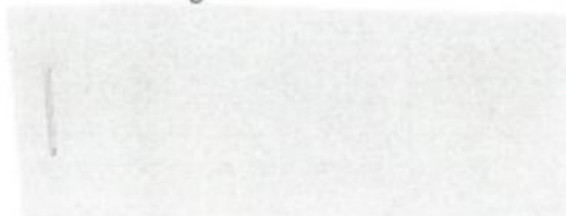
Re: Research Study: Registered Nurses experiences of caring for people with dementia at the end of life in Nursing Homes.

Many thanks for asking both myself and my team to support your research in this specific area. As a team we are delighted to be able to participate.

As a forward thinking team, very committed to the delivery of robust Nursing we welcome the opportunity to help develop ideas and practice in fellow professionals.

Looking forward to working with you and I await to hear from you soon.

Kind regards



Registered Manager/RN

Thursday 8th October 2020

Dear Ted,

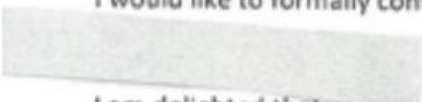
Re: Research Study- Registered Nurses experience of caring for people with dementia at the end of life in nursing homes

I would like to formally confirm that we are willing to fully support your study within The

I am delighted that you have chosen our nursing home as part of your research study and we are very excited to be involved and very much look forward to working with you.

Thank you.

Kind Regards



Home Manager

From: [REDACTED]
Sent: 12 October 2020 08:49
To: Tidziwe Malinki-Madeya (Cardiff and Vale UHB - North West Locality) <Tidziwe.Malinki-Madeya@wales.nhs.uk>
Subject: RE: Research

Hi Ted,

I am sorry for the delay in replying. Thank you for inviting [REDACTED] to participate into the research study, regarding Registered nurses experiences of caring for people with dementia at the end of life in nursing homes. I would like to support you with this study. Could you send me the participant information sheets when you have them.

Kind regards,
[REDACTED]

14/10/2020

Dear Ted,

Re: Research Study: Registered Nurses experiences of caring for people with Dementia at the end of life in Nursing Homes.

Thank you so much for asking us to be part of your research into the above, and no doubt being able to celebrate your success once completed!

We have so much to be able to share with you and really look forward to assisting this worthwhile project.

Kindest regards,

General Manager

Appendix iv: Study recruitment poster

CARDIFF
UNIVERSITY

PRIFYSGOL
CAERDYDD

AN INVITATION TO PARTICIPATE IN A RESEARCH STUDY



CONTACT INFORMATION

To find out more about this study, please contact:

- Tidziwe Malinki-Madeya
- 07976 604 920
- malinki-madeya@cardiff.ac.uk

EXPLORING REGISTERED NURSES EXPERIENCES OF CARING
FOR PEOPLE WITH DEMENTIA AT THE END OF LIFE IN NURSING HOMES

Chief Investigator: Tidziwe Malinki-Madeya

The purpose of this research study is to explore Registered Nurses experiences of caring for people with dementia at the end of life in nursing homes.

Participation in this study is voluntary and involves:

- A one-off face to face (in the nursing home) or virtual (Zoom/Skype/Teams) interview which will last approximately 30 minutes
- The interviews will be conducted between January 2021 and June 2021. Dates and times for the interviews will be flexible to suit the participant's schedules

To participate in this research, you must:

- Be a Registered Nurse (Registered General Nurse or Registered Mental Health Nurse)
- Have an active status on the Nursing and Midwifery Council Register
- Be practicing in the nursing home sector at present
- Have an experience of caring for people with dementia at the end of life in a nursing home setting

Appendix v: Participant information pack

A: Invitation letter

Registered Nurses experiences of caring for people with dementia at the end of life in nursing homes. Invitation letter to Participants v2_13 December 2020



Tidziwe Malinki-Madeya

Email:

malinki-madeya@cardiff.ac.uk

Work telephone: 07976 604 920

To: [Insert participant's name and Nursing Home address]

Date: [Insert date]

Dear.....,

Re: Invitation to participate in a research project about Registered Nurses experiences of caring for people with dementia at the end of life in nursing homes

My name is Tidziwe and I am a PhD Student in the School of Healthcare Sciences, Cardiff University. I am conducting a study about Registered Nurses experiences of caring for people with dementia at the end of life in nursing homes.

I would like to invite you to consider taking part in this study as you are a Registered Nurse. Your Nursing Home has agreed that nursing staff can take part. I have been granted permission by your Manager to ask you if you would like to take part.

I have attached a Participant Information Sheet, which provides more detail about the study and how you can take part. Please take some time to read the information provided and to decide if you would like to be involved. If you are interested in taking part, please contact me via the email address or telephone number provided above so that we can arrange a suitable date and time for a one off 30-minute interview.

Please contact me if you have any questions, queries or require further information about any aspect of this study and how you can participate.

Thank you for taking the time to read this letter.

Regards,

Tidziwe Malinki-Madeya
(PhD student)

B: Participant Information Sheet

Registered Nurses experiences of caring for people with Dementia at the end of life in Care Homes.
Participant Information Sheet v2_13 December 2020



Registered Nurses experiences of caring for people with Dementia at
the end of life in Nursing Homes.

PARTICIPANT INFORMATION SHEET

Registered Nurses experiences of caring for people with Dementia at the end of life in Care Homes.

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

This research study is being carried out by myself, Tidziwe Malinki-Madeya (PhD student, School of Healthcare Sciences, Cardiff University), under the supervision of Professor Jane Hopkinson (Professor of Nursing, School of Healthcare Sciences, College of Biomedical and Life Sciences, Cardiff University) and Dr Raymond Samuriwo (Lecturer, School of Healthcare Sciences, College of Biomedical and Life Sciences, Cardiff University). The research will be written up as a Thesis and submitted as part of my examinations towards a Doctorate in Healthcare studies. This research is aimed to make a contribution towards the improvement of end-of-life care for people with dementia.

Thank you for reading this.

1. What is the purpose of this research project?

The research project aims to explore Registered Nurses experiences of caring for people with Dementia at the end of life in Nursing Homes.

Registered Nurses play a key role in delivering end of life care to people with Dementia in nursing homes. Understanding the experiences of the nurses may provide important knowledge about this aspect of patient care. The purpose of this study is to provide insights that can be used to inform nurse education, training and research about the end-of-life care for people with dementia and their loved ones. The findings of this study will be shared through conference presentations and in a published article.

2. Why have I been invited to take part?

You have been invited because you are a Registered Nurse working in a nursing home, with an experience in caring for people with dementia at the end of life.

3. Do I have to take part?

Your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, I will discuss the research project with you and ask you to sign a consent form. If you decide not to take part, you do not have to explain your reasons. Your decision to take part or not to take part will not affect the terms of your employment in any way.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

4. What will taking part involve?

If you decide to take part, I (Tidziwe Malinki-Madeya) will contact you by post, email or telephone (whichever will be the most convenient for you) to arrange a mutually convenient time and place for a single interview. The interview can be held at your place of work. Arrangements will be in place to reimburse your travel expenses if you will need to use public transport to attend the interview on receipt of your travel ticket.

The interview will be on a one-to one, face to face basis and held in a private environment. The one-off interview should last approximately 30 minutes. Permission has been granted by your Manager for you to be interviewed if you agree to take part at a convenient time within your working day workload permitting. However, if this is not possible for you, the interviews will be arranged to be conducted on a date and time that will suit you.

You will be asked to sign a consent form on the day of the interview indicating your understanding of the study and the processes involved and your willingness to participate.

Due to the ongoing COVID-19 pandemic, face to face interviews may not be possible at certain times based on government restrictions. In such cases, interviews via telephone, Teams, Skype, or Zoom will be arranged.

The interview will be audio-recorded so that it can be transcribed, anonymised, and analysed by me. Once you have been interviewed, you do not need to do anything else. Following the interview, you will not be expected to actively participate in any other way.

The interview will explore your experiences of caring for people with dementia at the end of life in a nursing home setting. You will be asked to talk about one or more people with dementia who you have cared for in the last days and weeks of their life. The data that you and the other participants will provide will then be analysed.

5. Will I be paid for taking part?

No. There will be no payment for taking part in this study. However, I anticipate that your experiences will generate knowledge that can be used to improve the end-of-life care for people with dementia and their families.

6. What are the possible benefits of taking part?

There will be no direct benefit to you from taking part in this study.

7. What are the possible risks of taking part?

Due to the nature of this study, there are no known risks of physical harm in taking part. However, discussing death and dying may be emotionally challenging. If at any point during the interview you feel that you would like to withdraw from the study, you will be free to do so. I will share the contact details of organisations or services that will be able to provide you with additional support if you wish access their services. These services will include counselling and mental health and wellbeing.

(contact details: Cardiff and Vale Action for Mental Health (cavamh)- 02920 222 000; Counselling Services in Primary Care (Referral via GPs)- 02920 336 114; Samaritans- 02920 344 022/ www.samaritans.org.uk; Supportline- 01708 765 200/ www.supportline.org.uk; Community Advice and Listening Line (C.A.L.L.)- 0800 132 737/ www.callhelpline.org.uk).

8. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information. All Nursing homes involved will be anonymised in order to protect their identity.

However, in exceptional cases, the researcher may be legally or professionally required to over-ride confidentiality and disclose information obtained from (or about) you to statutory bodies or relevant agencies where the researcher has reason to believe that there is risk to safety of others or where poor/unsafe practice is observed. Where appropriate, the research team will notify you of the need to break confidentiality (but this may not be appropriate in all cases).

9. What will happen to my Personal Data?

Personal data, according to the General Data Protection Regulation (GDPR) means any information relating to an identifiable living person who can be directly or indirectly identified. This may include information such as an individual's name, address, email address or date of birth.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

If you have no access to the internet, printed copies of the above-mentioned documentation and privacy notices will be made available at your request.

I will anonymise all the personal data collected from, or about, you in connection with this research project, with the exception of your consent form. Your consent form will be retained for the duration of the research and may be accessed by the researcher and, where necessary, by members of the University's governance and audit teams or by regulatory authorities. Anonymised information including transcripts will be kept for a period of up to fifteen years following the completion of the study should the data be required for audit, further analysis or publication according to the University's data retention policy.

Note that it will not be possible to withdraw any anonymised data that has already been published or in some cases, where identifiers are irreversibly removed during the course of a research project, from the point at which it has been anonymised.

10. What will happen to the results of the research project?

The information collected from the interviews will be written up in a thesis that will be submitted by me (Tidziwe Malinki-Madeya) to the School of Healthcare Sciences at Cardiff University. Direct quotations from the interviews will be included in the thesis, but without any identifiable information. It is my intention to publish the results of this research project in academic journals and present findings at conferences. Participants/nursing homes will not be identified in any report, publications, or presentations.

A final copy of the report can be sent to you once the study is completed if you request one from the researcher, Tidziwe Malinki-Madeya. Due to the ongoing COVID-19 pandemic, face to face meetings with the participants to provide feedback may not be possible. As such, participants will be advised via the agreed contact details on how to access the results of the study. In addition, the researcher will send 'thank you' letters to the participants at the end of each interview which will contain further information on accessing results of the study and indicate closure and end of involvement for the study.

11. What if there is a problem?

If you wish to complain or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Tidiwe Malinki-Madeya who will do her best to address your concerns. If your complaint is not managed to your satisfaction, please contact Dr Kate Button, the Chair of the School Research Ethics Committee at ButtonK@cardiff.ac.uk or Professor David Whitaker, the Head of School, Whitakerd@cardiff.ac.uk or 02920 874703.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

12. Who is organising and funding this research project?

This research study is being organised and carried out by myself Tidiwe Malinki-Madeya (Research student, School of Healthcare Sciences, Cardiff University) under the supervision of Professor Jane Hopkinson (Professor of Nursing, School of Healthcare Sciences, College of Biomedical and Life Sciences, Cardiff University) and Dr Raymond Samuriwo (Lecturer, School of Healthcare Sciences, College of Biomedical and Life Sciences, Cardiff University).

The research is self-funded.

13. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the School of Healthcare Sciences Research Ethics Committee, Cardiff University.

14. Further information and contact details

Should you have any questions relating to this research project, you may contact me during normal working hours using the details below:

Tidiwe Malinki-Madeya
Cardiff University
School of Healthcare Sciences
12th Floor, Eastgate House
35-43 Newport Road
Cardiff
CF24 0AB

Work telephone number: 07976 604 920

Email: madeya-madevate@cardiff.ac.uk

Due to the ongoing COVID-19 pandemic, there will be no or limited access to University buildings at times. In such cases, the best way to contact me will be via email or telephone.

Thank you for considering taking part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.

C: Consent form

Registered Nurses experiences of caring for people with dementia at the end of life in nursing homes. Consent form v2_13 December 2020



CONSENT FORM

Title of research project: Registered Nurses experiences of caring for people with dementia at the end of life in nursing homes.

SREC reference and Committee: REC739, School of Healthcare Sciences Research Ethics Committee

Name of Chief/Principal Investigator: Tidziwe Malinki-Madeya

**Please
initial box**

I confirm that I have read the participant information sheet (Version 2, dated 01 December 2020) for the above research project.	
I confirm that I have understood the information sheet (Version 2, dated 01 December 2020) for the above research project and that I have had the opportunity to ask questions and that these have been answered satisfactorily.	
I understand that my participation is voluntary, and I am free to withdraw at any time without giving a reason and without any adverse consequences to my employment or legal rights. I understand that if I withdraw, data that has already been obtained may be kept by Cardiff University for up to 5 years following the completion of the project.	
I understand that data collected during the research project may be looked at by individuals from Cardiff University or from regulatory authorities, where it is relevant to my taking part in the research project. I give permission for these individuals to have access to my data.	
I consent to the processing of my personal information provided for the purposes explained to me. I understand that such information will be held in accordance with all applicable data protection legislation and in strict confidence unless disclosure is required by law or professional obligation.	
I understand who will be able to access the interview recordings, how the data will be stored and what will happen to the data at the end of the research project.	

This document is also available in Welsh language on request

Appendix vi: Interview guide



INTERVIEW GUIDE

Preparation

- Ensure mobile phones are switched off or turned on silent during the interview to minimise disruptions
- Ensure the audio recorders/laptops have adequate power to last for the entire interview
- Ensure all equipment to be used for the interview i.e. audio recorders and/or laptops/ PCs are tested well before the interview to ensure they are in good working order
- Ensure a private and comfortable space is arranged for the interview
- Agree with participant on pseudonyms to be used during the interviews for patients and organisations to maintain anonymity
- Ensure a consent form is completed and signed before commencing the interview. Obtain verbal consent for online virtual interviews and ensure an electronic copy of the signed consent form is received on the same day of the interview
- Introduction of researcher, research topic and aim of interview

Areas of focus for the interview questions:

- Participants' experiences of looking after a person with dementia at the end of life in a nursing home setting- both positive and/or negative

- Participants' knowledge and understanding of the needs of people with dementia at the end of life
- Challenges faced when caring for people with dementia at the end of life in nursing homes
- Demographic information

Indicative Questions

Participants' experiences

1. Can you tell me about an experience of caring for a person living with dementia at the end of life that sticks in your memory
(***prompts***: negative or positive)

Needs of people with dementia at the end of life

2. How do you tell than an individual living with dementia in your care is approaching the end-o-life phase?

(***Prompts***: how do you diagnose the end-of-life phase? What are the signs and symptoms that you look for? What are the challenges in diagnosing the end-of-life phase?)

3. What is/are the goal/goals of care in end of life for people living with dementia in nursing homes?

4. What are the specific needs of people living with dementia and their families at the end of life?

(***Prompts***: Physical needs? Emotional/psychological? Spiritual?)

5. What are the main components of end-of-life care for people living with dementia?
(prompts: Advance care planning, symptom management/control, emotional support, spiritual well-being)

6. Who are the people/professionals involved in the provision of end-of-life care for people living with dementia at the end of life in nursing homes?

Challenges/Barriers

7. What are the challenges that you face when providing care to people living with dementia at the end of life in the nursing home?

(**Prompts:** what are the barriers to people living with dementia receiving optimal end of life care? How has the current COVID-19 pandemic impacted on the delivery of end-of-life care for people living with dementia at the end of life?).

8. In your experience, do you find end-of-life care for people living with dementia different from that of other life-limiting conditions?

(**Prompts: if yes, can you tell me how it varies?**

Demographic Questions

9. Tell me about yourself professionally

(**Prompts:** what is your age range? what are your qualifications/part registered on NMC register? How long have you been working as a registered nurse and how long have you worked in nursing homes? What is your current grade? What is your religious background? What is your cultural background? What training have you received in relation to end of life and dementia?)

Additional information

10. Is there anything else you would like to add?

Thank you for taking time to answer my questions and for sharing your experiences.

Appendix vii: Field notes

FIELD NOTE 13- 19/04/2021: INTERVIEW 13

Date: 19 April 2021

Participant: April (senior nurse, registered nurse)

Venue: Ash Nursing home (participant's place of work)

Time: 08.30 hours

Duration: 48 mins 14 secs

Preparation

I made sure that I had all required for my interview i.e. interview schedule, consent forms, COVID-19 questionnaires, participant information sheets. I also ensured that my digital recorder was in good working order, and I ensured I packed the charger for the recorder in case I needed to re-charge the batteries.

Context

I travelled to the nursing home using my own car on the morning of the interview. I was made welcome into the nursing home and was shown where to conduct my interviews. I was offered a drink.

This face-to-face interview took place in the participant's place of work as per their choice. The participant was identified through an advert for the study that was posted in the nursing home. The participant showed interest to participate in the study through the gatekeeper who was the manager of the nursing home. An invitation letter was sent to the participant, via the nursing home manager, alongside a participant information sheet, consent form, and COVID-19 participant self-declaration questionnaire. Arrangements for the interview were then made, that is, date, time, and venue.

On the day of the interview, self-introductions were made. The researcher confirmed that the participant had read the information sent to them and re-explained the purpose of the study and the interview. The participant clearly understood all the information provided and required no further clarification. Written informed consent was obtained from the participant. Ethical issues of confidentiality and anonymity were discussed. Consent to audio record the interview was sought from the participant. The participant was reminded of her right to withdraw from the study if she wished to,

and the researcher's professional obligation to report any unsafe or dangerous practice that could be disclosed during the interview.

COVID-19 guidelines were adhered to during this visit to the nursing home. The interview took place in an empty bedroom on the first floor of the home. I made sure that this room offered a quite environment and was well lit and ventilated. Windows were opened to lower the temperature in the room as it was quite warm.

Staff were informed of the interview taking place and were asked not to disturb. The nurse had chosen to have her interview before the commencement of her shift to avoid disrupting the home's routine and care provision.

Throughout the interview April was very emotional, she broke down into tears on several occasions as she narrated her story. I offered her to discontinue the interview, but she explained that she was grateful for this opportunity to speak to someone and opted to complete the interview although she was aware that it would be challenging. I made sure that I was stopping and pausing the recording to give her breaks until she was ready to proceed. I offered her some tissue and water to drink. April's emotions were mostly related to or triggered by her accounts describing situations such as the manner in and the rate at which residents with Covid infection were dying, how staff were struggling with the critical shortages and the use of agency staff who were unfamiliar with the residents and their needs, people with dementia being prevented from seeing their relatives due to the visiting restrictions, and how end-of-life medications were being prescribing during the pandemic.

I was concerned with April's emotional well-being following this interview, so I sign-posted her to organisations outlined in the Participant information sheet for further support. She reassured me that she was going to speak to someone. I also referred her to her manager to seek support as required.

After the interview I thanked April and gave her a 'thank you card' which also indicated my end of involvement with her. I was pleased to learn that she was able to go back and continue with her duties after the interview.

This interview really affected me emotionally. After the interview I sat in my car for a while trying to make sense of the conversation I had just had with April. I became very emotional and literary cried which took me by surprise. I realised that I was unprepared as a researcher for such deep emotions. When I got home, I made sure that I had a relaxing long bath then went for a walk with my son afterward to relieve the emotional stress. I also arranged to meet with my supervisors to discuss this event and seek advice in terms of how to manage similar situations should they arise in any of the following interviews. My supervisors were supportive and reassuring and sign-posted to the services available in the university. Fortunately, I was able to complete the rest of the interviews.

This has been a particularly important learning experience for me.

Interview recorded in File E- DS250148.

Appendix viii : Reflective journal

REFLECTIVE DIARY 1

This note was written following the first batch of interviews from Nursing Home 1.

I was pleased that the recruitment process went very well. I had a good response from the advertisement of my research from the nurses. Most of the nurses in the four nursing homes involved were willing to participate in my study. This response 'surprised' me as it was far more than what I had expected.

I was quite nervous prior to these interviews as it was my first time to conduct qualitative interviews. The pilot interviews I had completed assisted to improve my confidence. However, I was also excited to finally commence my data collection. I became anxious about going into the nursing homes as we were in the middle of the COVID-19 pandemic. I was reassured by the fact that Covid -19 checks were completed prior to entering the nursing home. The nursing home had also confirmed that safety measures had been put in place as per government guidelines.

The first four interviews went well. However, I struggled a bit as I relied on asking the participants questions directly from the interview schedule which at times disrupted the flow of the discussions. I also felt that the opening question was too broad which led to the participants initially not sure how to narrate their story. I also felt I should have probed further on certain areas to obtain more detailed information. I restructured the opening question to enable the participants to narrate their stories much better. I also practiced my interview guide questions so that I could maintain the flow of the conversation based on the response to the opening question.

These four interviews provoked a lot of emotions in the participants. The nurses broke down to tears whilst narrating their stories. As much as I was aware that discussing death and dying can raise emotional responses, I was not fully prepared for this response from the nurses. I was not prepared to a point that I did not even have some tissue paper to offer them. At times I felt like I was going to cry too as I was touched with the nurses' stories and reactions. Following these interviews, I felt very emotionally drained, and I had to take some time to reflect and for relaxation. I went for long walks to clear my head which helped. I was now more prepared of these emotional reactions recurring in my following interviews which I believed I could handle better.... and of course, remember to bring a box of tissues with me! The nurses, however, found this experience 'therapeutic' as they felt good to express their feelings and share their experiences (unburdening)- this assisted me to develop the category 'Off-loading'.

I was not 'surprised' or 'shocked' with most of the nurses' accounts as I am a nurse and normally work in the same area. The nurses' accounts seemed familiar to what I see in my normal practice. This in line with Strauss and Corbin Grounded Theory which acknowledges that a researcher cannot fully ignore prior literature around their subject area and that prior knowledge and experiences are allowed to strengthen the overall quality of the research, categorisation and theoretical assumptions (Strauss and Corbin 1998). Strauss and Corbin therefore advise researchers to ensure that their prior knowledge and experiences does not affect the data/theory generation. (Corbin and Strauss 2015). In agreement, Charmaz (2006) Constructivist Grounded Theory acknowledges that it is impossible to erase/escape one's previous knowledge or experience and state that previous knowledge is used to strengthen the research. Charmaz (2006) urges researchers to keep an open mind and be flexible in their approach to collecting and analysing data. Singh and Estefan (2018) suggest that Charmaz's GT is suitable for researchers who are not able to separate themselves from their personal and professional experiences as existing knowledge that informs their research. Strauss and Corbin Grounded Theory also considers the researcher's prior knowledge and experience by recognising that it is not possible for a researcher to fully blind prior knowledge, experience and expertise relating to their area of study (Sebastian 2019).

What is next?

- To stay motivated- seek support from supervisors, as necessary.
- Work on my questioning skills, especially probing further to gain more clarity and information
- Keep a box of tissues handy for the participants when they get emotional during the interviews.
- To be mindful of my prior knowledge and experience and ensure that these do not affect my analysis and interpretation of the data.

Appendix ix: Memo10: Development of the main categories

MEMO 10:

- Further discussions with supervisors on data analysis:
- Axial Codes- similar codes to be merged and some axial codes to be renamed:
 - Disenabling factors and Enabling factors to Facilitators of a good death.
 - Anticipatory guidance to Plans, preferences and wishes for end-of-life care or Advanced Care Planning or Constructions of death and dying or What matters to me.
- Approach to care and navigating individual care needs to Person centred care.
- Disease trajectory to Dementia and the trajectory of death.
- To leave the codes Off-loading and Package of care as they are.

-Three major categories developing from the data analysed so far:

- 1. Plans, preferences and wishes of end-of-life care or what matters to patients and their families or Advance care planning. (Patients/family constructions).**
- 2. End of life care organisation and delivery. (Social and cultural constructions).**
- 3. Nurses motivation for facilitating a good death. (Nurses' own constructions).**

Core Category*- (What drives nurses are driven to provide what is considered 'quality end of life care').

To consider whether the core category fits in with the basic social process. Reflecting on the data, the nurses demonstrated that they had shared constructions of death and dying and their understanding of a good death despite their different cultural, religious and social backgrounds.

- To continue developing the categories as further data is collected.
- Theoretical sampling- The category of dementia and the trajectory of death require further development. Further interviews are required to clarify if there is a

difference between end-of-life care for people with dementia and those with other conditions; and the impact of dementia and disease trajectory on the provision of end-of-life care.

List of interview prompts submitted by student discussed and agreed. Comments from Supervisors incorporated. Student advised deciding which Nurses/nursing homes to involve according to the ethics clearance obtained for the study.

Reflectivity: Student advised keeping her reflective diary up to date. To document on the Covid context of interviews: stages/steps and decisions on sampling, and wider reading of literature in relation to data analysis stages in grounded theory.

Student also advised reflecting on her role/background as a Nurse Assessor.

Student advised deciding the perspective of her analysis i.e., the organisation's, nurse assessor's or the nurse's. Student felt, reflecting on the data, that the nurses' perspective would be more suitable in trying to answer the research question or exploring the nurses' shared understanding of providing end of life care which is as close to the patients' wishes.

Appendix x: Sections of codebooks (open, axial, selective)

A. Open codes

Name	Description	Files	References
Acceptance	Family accepting that their relatives are approaching the end-of-life phase	12	19
Access to services	Access to services and support for end-of-life care for people with dementia in nursing homes	3	3
Advance care planning and last wishes	Choices, wishes and decisions about end-of-life care	12	67
Anticipation	Prediction and preparation of end-of-life phase and needs	11	26
Appreciation	Participants' feelings about being involved in the research and being given the opportunity to share their experiences	10	17
Carer experience	Carer's knowledge of the needs and condition of dying residents	9	23
Challenges	Problems/difficulties faced in providing end of life care for people with dementia in nursing homes	17	110
Competence and confidence	Ability of nurses to provide end of life care for people with dementia	4	6
Complexity of needs	Level of needs for people with dementia at the end of life	2	2
Conversations	Discussions with family about end of life	8	17

B. Axial codes

Name	Description	Files	References
Advance care plan		0	0
Advance care planning and last wishes	Choices, wishes and decisions about end-of-life care	12	67
Conversations	Discussions with family about end of life	8	17
Decisions	End-of-life care decisions made by people living with dementia and their families/relatives	10	35
Family involvement	Involvement of family in the end-of-life discussions, decisions, and care provision	15	56
Dementia and the trajectory of death		0	0
Acceptance	Family accepting that their relatives are approaching the end-of-life phase	12	19
Diagnosing end-of-life	Signs and symptoms indicating that a resident is approaching the end-of-life phase	17	68
Disease trajectory	End of life phase or advanced dementia progression	14	40

C. Selective codes (main categories)

Name	Description	Files	References
End-of-life care organisation and delivery (social and cultural constructions)		0	0
Dementia and the trajectory of death		14	94
Acceptance	Family accepting that their relatives are approaching the end-of-life phase	11	18
Diagnosing end-of-life	Signs and symptoms indicating that a resident is approaching the end-of-life phase	14	48
Disease progression	End of life phase or advanced dementia progression	11	28
End-of-life care		14	313
Goals of EOL Care	End of life care objectives	13	56
Holistic approach	Addressing all aspects of care i.e., physical, environmental, psychological, emotional, and spiritual needs.	3	4
Navigating individual care needs	Staff understanding of care needs for people living with dementia in nursing homes	14	242

Appendix xi

Consolidated criteria for reporting qualitative studies (COREQ) checklist

No. Item	Guide questions/description	Comments/Notes
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	TM conducted all semi structured interviews.
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	PhD student
3. Occupation	What was their occupation at the time of the study?	Registered nurse/nurse assessor
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	TM attended courses and training in qualitative research including data collection and interviews as part of her PhD programme.
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	TM was known to the participants professionally as a Nurse Assessor. The participants were made aware of the researcher's separate role as a research student.
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal	TM made participants aware that this was a research project aimed to explore registered nurses' experiences of caring for people with dementia at the end of life

	goals, reasons for doing the research	in nursing homes. TM also explained that the knowledge gained from this study was intended to inform the development of better end-of-life care and improve the end-of-life experiences for nursing home residents living with dementia and their families.
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	TM's background and professional and personal interest, and previous experience in end-of-life care for people living with dementia has been reported. TM has also reported how reflexivity has been maintained in the analysis and interpretation on the data to minimize bias.
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	This is a Strauss and Corbin Grounded Theory study
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Participants were initially selected using purposive sampling which was followed by theoretical sampling until data saturation was reached according to the Straussian Grounded Theory approach.
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Participants were approached via their managers who acted as gatekeepers. Posters were used to advertise the study. TM attended staff handover meetings to

		introduce herself and the study. Emails with further information were sent to those who expressed interest.
12. Sample size	How many participants were in the study?	18 registered nurses participated in the study
13. Non-participation	How many people refused to participate or dropped out? Reasons?	The study was offered to 37 registered nurses in the four nursing homes and all agreed to take part. 18 were interviewed- interviews stopped when saturation was reached. There were none that dropped out of the study.
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Face-to-face interviews were conducted in the nursing homes where the participants worked.
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	There were no other people present during the data collection besides the participants and researchers.
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	The sample consisted of registered nurses (RGNs and RMNs), originally from the UK, East Europe, East Asia and Africa, aged between 30-70 years, and with years of experience of working in nursing homes ranging between 1-25 years. Sixteen participants were female and two were male.
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	An interview guide with questions and prompts was used to collect data. Two pilot interviews were conducted to test the interview guide.
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	Only one-off interviews were conducted. None were repeated with the same participants.

19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio-recorded and converted to MP4 files which were later transcribed. Permission was sought from the participants.
20. Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made by TM during each interview.
21. Duration	What was the duration of the interviews or focus group?	The average duration for the individual interviews was 35-40 minutes.
22. Data saturation	Was data saturation discussed?	When data saturation was reached on all the main categories TM discussed and agreed with her supervisors.
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Transcripts were not returned to participants for comment and/or correction.
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	TM coded the data which was then checked by her supervisors.
25. Description of the coding tree	Did authors provide a description of the coding tree?	There was no description of the coding tree.
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes were generated from the data in an inductive process.
27. Software	What software, if applicable, was used to manage the data?	TM used NVIVO 12 Plus (QSR) computer software to assist her to manage and analyse the data.
28. Participant checking	Did participants provide feedback on the findings?	There was no member check performed for this study.
<i>Reporting</i>		

29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Key findings were supported by participants verbatim direct quotes (unequivocal quotes). Each quote was identified by the participant's pseudonym.
30. Data and findings consistent	Was there consistency between the data presented and the findings?	The findings were drawn from the data and all categories developed were supported by illustrative quotes.
31. Clarity of major themes	Were major themes clearly presented in the findings?	Main categories were integrated around the findings from the open and axial codes generated from the data.
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Deviant and opinions were included in the discussion. Opinions presented by one participant only were also included in the discussion.