A Critical Realist Informed Evaluation of End-of-Life Care for People with Dementia in Hospitals

Hadeel Alhatamleh

Faculty of Health and Social Sciences

Bournemouth University

This thesis is submitted in partial fulfilment of the requirements of Bournemouth University for the degree of Doctor of Philosophy

June 2025

Copyright statement

Abstract

A Critical Realist Informed Evaluation of End-of-Life Care for People with Dementia in Hospitals

Background:

End-of-life care for individuals with dementia in hospital settings is often inconsistent and poorly adapted to their complex needs. The rising prevalence of dementia and its status as a leading cause of death in the UK underscore the urgent need to understand and improve end-of-life care practices in acute care. However, current approaches are limited by a lack of explanatory insight into what works, for whom, and under what circumstances.

Aim:

To develop explanatory programme theories that inform context-sensitive interventions to enhance the quality and sustainability of end-of-life care for people with dementia in hospitals.

Methods:

This study employed a two-phased qualitative research design underpinned by critical realist evaluation. Critical realist evaluation provided both the conceptual framework and analytical lens to explore how interventions in end-of-life care for people with dementia in hospitals succeed or fail. The evaluation was structured around identifying intervention mechanisms, internal contextual mechanisms, external contextual mechanisms, and agency, and examining how their interaction shaped care outcomes. Data were collected through semi-structured interviews and focus groups with hospital staff and bereaved relatives. The analysis drew on both inductive and deductive thematic coding to surface key mechanisms and contextual factors, enabling the development of explanatory programme theories grounded in the lived realities of hospital-based dementia care.

Findings:

Four interrelated programme theories were developed. The training and education theory illustrates how contextual enablers and constraints influence staff learning and communication practices, recommending scenario-based and video-assisted training.

The advance care planning theory identifies mechanisms related to personalised care, anticipatory decision-making, and communication, shaped by structural factors such as staffing and policy clarity. The multidisciplinary care theory explains how integrated, cross-disciplinary collaboration and role clarity support holistic assessment and care continuity. The person and family-centred approach theory addresses the emotional and psychological dimensions of care, proposing tailored support mechanisms while recognising resource limitations and cultural sensitivities.

Conclusion:

This study's primary contribution lies in its application of critical realist evaluation to develop transferable and evidence-informed programme theories. These theories identify how, why, and in what contexts end-of-life care interventions might succeed or fail for people with dementia in hospitals. They offer a foundation for designing multi-component, context-sensitive interventions that address the realities of hospital practice. Further research is needed to translate these theories into tested interventions and implementation strategies.

Table of Contents

List Tables

List of Figures

Acknowledgement

Before everything, my profound gratitude, deeply from my heart, goes to Allah alone, the Almighty, the Most Merciful, who has been my inspirational source and strength throughout this exceptionally long journey towards my ultimate goals.

I am writing to express my sincere gratitude to my supervisors, Professor Sam Porter, Dr Michelle Board, and Mrs Janine Valantine, for their unwavering guidance, support, and encouragement throughout the duration of my PhD project.

I can’t thank enough the person who I consider myself so blessed and lucky to have in my life, my husband and soulmate, Eslam Al-Hersh. He has been my unwavering support in every moment, through both good and challenging times. The one who unconditionally helped me to be where I am now, during this PhD and even before.

Furthermore, I would like to acknowledge and express my deepest gratitude to my loving family. My father, Riyad Alhatamleh, has been a constant pillar of support throughout my whole educational journey. I dedicate this work to my late mother, Nadia Naser Aldeen, the one I will never forget. Her love and image will live on forever in my memory. My closest confidante, whose prayers never ceased. I can only express my love from the depths of my heart. May Allah (SWT) accept her in the highest degree of paradise. I am immensely proud to be their daughter, and I owe my accomplishments to their unwavering belief in me.

I would also like to extend my gratitude to my friends who believed in my abilities and supported me from near and far. Special thanks to my friends in room BG 406 for your memorable moments filled with enthusiasm and excitement to study at Bournemouth University. I will forever cherish the support extended to me by the university staff, fellow students, and friends who lifted me up and helped me persevere towards my ultimate goals.

I am deeply thankful to the hospital staff who generously gave their time and participated in the interviews and focus groups despite the sensitivity of the topic and the emotional distress it might have caused. I extend special thanks to the bereaved relatives who consented to participate despite their recent loss. Their willingness to share their experiences has contributed greatly to this research.

I would also like to express sincere appreciation to the staff who acted as gatekeepers, particularly the dementia care team, the palliative care team, and the bereavement team. Their support was not limited to introducing my research to potential participants; they also kindly allowed me to shadow them, which helped me build rapport with staff in the hospital. I especially wish to thank the dementia team again for their continuous support, and Ms Nicky Marks, Deputy Research Manager at Yeovil District Hospital, who generously allocated me a workspace in their offices during my fieldwork at the hospital.

Lastly, I would like to acknowledge the generosity of Bournemouth University and Yeovil District Hospital for funding this project. This support has had a significant impact on my academic journey and enabled me to follow my dreams and inspirations

Hadeel Alhatamleh
1 June 2025

Declaration

This thesis has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed: . . . .(candidate)

Date: . . . .

Statement 1

This thesis results from my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed: . . . .(candidate)

Date: . . . .

Statement 2

I hereby give consent for my thesis, if accepted, to be made available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed: . . . .(candidate)

Date: . . . .

Statement 3

I hereby give consent for my thesis, if accepted, to be deposited in the University's Institutional Research Repository.

Signed: . . . .(candidate)

Date: . . . .

Chapter 1: Introduction

1.1. Chapter Overview

This chapter introduces the context, rationale, and theoretical foundations of this study on end-of-life care (EoLC) for individuals living with dementia in hospital settings. Dementia is a growing global health challenge that currently affects more than 50 million people worldwide. This figure is expected to triple by 2050, largely due to increased life expectancy and population ageing World Health Organization (WHO, 2023). In the United Kingdom (UK), nearly one million people are currently living with dementia, with this number projected to exceed one million by 2030 (Alzheimer's Research UK, 2021). Hospitals play a central role in providing care for this population, particularly in the advanced stages of the condition, with approximately one in four hospital beds in the UK occupied by someone with dementia (Royal College of Psychiatrists, 2019).

Despite their importance, hospital settings are often ill-equipped to meet the complex needs of individuals with dementia, especially at the end of life. Challenges include staff shortages, lack of specialist training, poorly adapted environments, and fragmented care processes (Aldridge et al., 2017; Gkioka, 2020a). These factors can compromise, dignity, and person-centred care, raising critical questions about how care is delivered and why existing practices often fall short. Understanding these gaps is essential to improving the quality of hospital-based EoLC for people with dementia.

This chapter is structured to provide a comprehensive introduction to the topic, highlighting the scale and complexity of dementia care, and outlining the theoretical, ethical, and systemic considerations that underpin EoLC. Section 1.2 presents my background as a nurse and researcher, explaining how my personal, professional, and cultural experiences have shaped my interest in this topic. Section 1.3 defines dementia, describing its clinical characteristics, progression, and implications for care. Section 1.4 explores the global and national prevalence of dementia, alongside the common comorbidities that complicate its management and increase healthcare demands.

Section 1.5 examines the range of symptoms associated with dementia and the specific care challenges they create in hospital contexts. Section 1.6 broadens the focus to consider how different cultures and ethical frameworks approach death and dying, laying the foundation for Section 1.7, which introduces the core concepts of EoLC and its relevance to people with dementia. Section 1.8 then explores what specialised EoLC for people with dementia entails, focusing on the principles of person-centred care, communication, and advance care planning (ACP).

In Section 1.9, I outline the clinical signs and symptoms that indicate the end-of-life (EoL) stage in people with dementia, and why they are often missed or misinterpreted. Section 1.10 discusses the hospital context, identifying structural and institutional barriers to high-quality EoLC. This is followed by Section 1.11, which justifies the need for this study by outlining key gaps in the research literature, particularly the lack of studies focusing on family carers' experiences of hospital-based EoLC. Section 1.12 describes the overall structure of the thesis, while Section 1.13 summarises the chapter and provides a transition to the systematic literature review in Chapter 2.

A critical realist perspective underpins this study and is woven throughout the chapter. Critical realism (CR) offers a lens through which to move beyond surface-level descriptions of care and explore the generative mechanisms, institutional constraints, and systemic structures that shape experiences of EoLC in hospital settings (Bhaskar, 1975; Porter, 2015). This approach supports a deeper analysis of why care is delivered in particular ways and how it might be transformed.

By highlighting the perspectives of family carers,who often witness and shape the final phase of care for their loved ones, this study aims to contribute new insights to the field. The chapter that follows sets the stage for this exploration by reviewing the existing literature on dementia EoLC, identifying both what is known and what remains to be understood.

1.2. Researcher Background

As a nurse with clinical and academic experience in both Jordan and the UK, my interest in EoLC for individuals with dementia has been shaped by a combination of professional exposure, personal experience, and cultural reflection.

I began my nursing career in Jordan, where dementia was not widely recognised or diagnosed at the time (Kofahi et al., 2021). While working in an intensive care unit (ICU), I often cared for patients in the final stages of life who were receiving aggressive life-sustaining treatments. These experiences led me to question the appropriateness of such interventions and to reflect on the importance of more compassionate, person-centred approaches to care at the end of life. This early exposure sparked a growing interest in palliative and EoL care.

When I moved to the UK to pursue a Master’s degree in Nursing Studies, I chose dementia as the focus of my dissertation. Although I was unfamiliar with the topic initially, I became increasingly aware of the gaps in care for people with cognitive impairment. Observing how healthcare systems responded, or failed to respond, to the needs of individuals with dementia highlighted a significant area of unmet need. This experience deepened my interest and ultimately led me to pursue a PhD focused on EoLC for people with dementia in hospital settings.

As an international student and non-UK native, I encountered cultural and professional differences that initially posed challenges. Concepts of death, dying, and care are understood and approached differently across cultures, and adjusting to these perspectives in the UK context required reflection and adaptability. However, these differences also allowed me to view healthcare practices with a fresh lens. My work as a bank nurse in a UK nursing home exposed me to the realities of ageing and care delivery in practice and gave me insight into the contrasts between institutional and familial caregiving cultures.

One of the key challenges I faced during this research was my limited experience within the NHS system. I was unfamiliar with specific NHS policies and procedures, particularly those relating to dementia and EoLC in hospital settings. To overcome this, I engaged in shadowing experiences with both dementia and palliative care teams, reviewed policy documents, and sought insight from healthcare professionals. This helped me develop a more grounded understanding of the care environment. Importantly, being somewhat outside the NHS system also allowed me to approach care structures with a critical perspective. I was not constrained by institutional assumptions and was able to identify system-level gaps and contradictions that may be taken for granted by those embedded within the system.

My experience of personal loss also influenced my research journey. Just before I began data collection, my mother passed away in hospital due to end-stage cancer. I paused my PhD to care for her full-time during her final weeks. That experience gave me a deeply personal understanding of what it means to provide EoLC from the perspective of a family member. I witnessed the physical, emotional, and spiritual aspects of caregiving, as well as the difficult decisions around life-sustaining treatments. These reflections raised critical questions about how hospitals deliver care at the end of life, not just in terms of clinical actions, but in how they support families and attend to dignity, presence, and emotional support.

These experiences shaped both my passion for the topic and my position as a researcher. While I came to this project without extensive dementia-specific experience, I believe this enabled me to engage more openly and objectively with participants. I was able to listen carefully, question assumptions, and interpret perspectives without being shaped by prior expectations. From a critical realist standpoint, this position allowed me to explore not just observable practices, but the hidden mechanisms and contextual factors influencing them.

In summary, my professional and personal journey has positioned me to explore EoLC for people with dementia from a reflective, culturally informed, and methodologically critical perspective. This background has driven my commitment to improving care practices that honour both the personhood of individuals with dementia and the voices of those closest to them.

1.3. What is Dementia?

Dementia is a progressive, neurodegenerative syndrome characterised by the deterioration of cognitive functioning, affecting memory, reasoning, language, judgement, and the ability to perform everyday tasks. It is not a part of normal ageing but a major neurocognitive disorder that significantly impacts individuals, families, and healthcare systems worldwide (WHO, 2023).

Rather than being a single disease, dementia is an umbrella term that encompasses a range of conditions, each with distinct causes and clinical features. The most prevalent type is Alzheimer’s disease, which is marked by the accumulation of beta-amyloid plaques and tau protein tangles in the brain, leading to gradual memory loss and cognitive impairment (Scheltens et al., 2021; Lyketsos et al., 2018). Other common subtypes include vascular dementia, often associated with stroke or cerebrovascular disease; Lewy body dementia, characterised by fluctuating cognition and visual hallucinations; frontotemporal dementia, which primarily affects behaviour and language; and mixed dementia, which involves overlapping pathological features of different types.

The symptoms of dementia evolve over time. In the early stages, individuals may experience short-term memory loss, disorientation, and mild language difficulties. As the disease progresses, impairments in problem-solving, attention, and executive functioning become more pronounced, ultimately leading to a loss of independence in daily activities (WHO, 2023). Later stages often involve profound cognitive decline, limited communication, and increased dependency on others for basic care.

Dementia also affects emotional and psychological functioning. Many individuals experience behavioural and psychological symptoms such as agitation, anxiety, depression, apathy, or hallucinations (Lyketsos et al., 2018). These symptoms can fluctuate and are often responses to unmet needs or distressing environments.

In addition to its cognitive and behavioural impact, dementia has important physical implications. Motor symptoms, including unsteady gait, impaired coordination, and muscle weakness, tend to emerge in later stages, increasing the risk of falls and injury

(Demanze and Michel., 2017). These symptoms further contribute to the need for comprehensive, multidisciplinary care.

From a care perspective, dementia poses significant challenges. Its progression is unpredictable and varies across individuals, requiring care plans that are flexible, person-centred, and responsive to changing needs. In hospital settings, these challenges are compounded by time-limited clinical interactions, competing demands, and environments often poorly suited to individuals with cognitive impairment.

A critical realist approach views dementia as a layered phenomenon. At the empirical level, symptoms are observable and measurable. However, the delivery of care is shaped by deeper generative mechanisms, such as healthcare structures, cultural norms, policy constraints, and institutional priorities. This perspective encourages inquiry beyond what is visible, asking not only what is happening but also why care unfolds in particular ways and how it might be improved.

In the next section, I explore the global and UK-specific prevalence of dementia, as well as the common comorbidities that contribute to the complexity of care, particularly at the end of life.

1.4. Prevalence and Comorbidities

Dementia presents a growing global public health concern, with serious implications for healthcare systems, families, and individuals. Its increasing prevalence is primarily driven by global demographic shifts, including ageing populations and longer life expectancy. This section outlines the scale of the problem both globally and within the UK and explores how the frequent co-occurrence of dementia with other chronic conditions, referred to as comorbidities, further complicates care delivery, especially at the end of life.

1.4.1 Global and National Prevalence

Globally, over 50 million people were living with dementia as of 2020, and this figure is projected to rise to 152 million by 2050 (WHO, 2023). Dementia is one of the leading causes of disability among older adults, with prevalence rates increasing sharply with age. The burden of dementia is expected to grow disproportionately in low- and middle-income countries, where healthcare infrastructure may be underdeveloped and under-resourced (Alzheimer’s Disease International, 2019).

The economic cost of dementia is also substantial. In 2010, the global cost of dementia was estimated at $604 billion USD, encompassing direct medical care, long-term care, and informal care provided by family members. By 2030, this figure is projected to exceed $1 trillion USD (Landry & Liu-Ambrose, 2014; Sommerlad & Liu, 2023). These figures reflect not only the direct financial burden but also the physical, emotional, and social toll experienced by carers.

While prevalence rates differ by region, age-standardised rates have declined in some high-income countries, possibly due to improvements in education, cardiovascular health, and lifestyle factors (Mukadam et al., 2019). However, underdiagnosis remains a persistent problem globally, with many individuals receiving no formal diagnosis or receiving it at a late stage, limiting opportunities for early planning and support.

In the UK, dementia is a leading cause of death and a key priority for public health. Approximately 944,000 people were estimated to be living with dementia in 2021, and this number is expected to exceed one million by 2030 (Alzheimer’s Research UK, 2021). Dementia accounts for around 12% of all UK deaths and is the most common cause of death among women Office for National Statistics (ONS, 2020). The financial impact is significant, with total costs projected to rise from £34.7 billion in 2019 to £94.1 billion by 2040 (Wittenberg et al., 2019).

The condition places considerable pressure on health and social care systems, particularly acute hospital settings. Approximately one in four hospital beds in the UK is occupied by a person with dementia (Royal College of Psychiatrists, 2019), many of whom are in the advanced stages of the illness. Despite this, hospitals often lack the appropriate training, resources, and environmental adaptations to meet their needs effectively (Gkioka, 2020a). The situation is further complicated by disparities in care provision across different ethnic groups. For example, the number of people with dementia from ethnic minority backgrounds is expected to reach 50,000 by 2026 and to triple by 2051 (Hossain et al., 2022). Evidence indicates that these populations often face barriers to culturally responsive services (Blakemore et al., 2018).

From a critical realist perspective, these trends highlight not only the growing burden of dementia but also the structural and systemic constraints that shape how care is delivered, or neglected, within healthcare systems.

1.4.2 Comorbidities and Their Impact on Care

Dementia rarely occurs in isolation. Most individuals living with dementia also experience multiple long-term health conditions, referred to as comorbidities. Research suggests that people with dementia have, on average, 4.6 additional chronic illnesses, including cardiovascular disease, diabetes, depression, arthritis, and osteoporosis (Guthrie et al., 2012).

These comorbidities interact with dementia in complex ways. Cardiovascular conditions such as hypertension and heart failure can worsen cognitive impairment, especially in cases of vascular or mixed dementia (National Institute for Health and Care Excellence [NICE], 2018). Management often requires medication adherence and regular monitoring, tasks made challenging by memory loss and impaired decision-making capacity.

Diabetes is another common comorbidity. Poor glycaemic control is associated with both the onset and progression of dementia. Individuals with cognitive decline often struggle to manage diabetes independently, increasing the risk of complications such as hypoglycaemia, infections, and neuropathy (Bunn et al., 2014; Alzheimer’s Society, 2016).

Depression is frequently observed but often underdiagnosed due to overlapping symptoms such as apathy or reduced speech. When untreated, depression exacerbates functional decline and can diminish quality of life (Guthrie et al., 2012). Musculoskeletal conditions like arthritis and osteoporosis further increase fall risk, reduce mobility, and contribute to hospital admissions and prolonged stays (Alzheimer’s Society, 2016).

At the end of life, these coexisting conditions complicate care planning. Healthcare professionals are often required to balance symptom management for dementia alongside treatment for other serious conditions. The risk of polypharmacy, defined as the use of multiple medications, increases, which heightens the chance of adverse drug interactions and side effects (Guthrie et al., 2012; NICE, 2018).

Comorbidities also lead to more frequent and longer hospitalisations, which can be distressing and disruptive for individuals with dementia. Hospital environments are often not well-equipped to address this complexity, particularly when time constraints, training gaps, and siloed care structures impede integrated decision-making (Bunn et al., 2014).

From a systems perspective, the presence of multiple comorbidities requires coordinated input from various healthcare professionals. Without effective communication and collaboration, treatment plans may become fragmented or conflict with the person’s values. This is especially problematic when the individual is unable to articulate their wishes and surrogate decision-makers must act on limited information (Ninkatec, 2022).

A critical realist approach situates these issues within broader structural mechanisms, including biomedical dominance, institutional silos, and workforce limitations, that shape how care is delivered. Understanding these dynamics is essential for designing integrated and compassionate EoLC models that recognise the full complexity of dementia and its comorbidities.

In the next section, I discuss the common symptoms of dementia and explain how they present unique challenges for EoLC in hospital contexts.

1.5. Symptoms and Care Challenges

Dementia manifests through a wide array of cognitive, physical, behavioural, and psychological symptoms that evolve over time and vary across subtypes. These symptoms present significant challenges for care, particularly in hospital settings where individuals are often in the later stages of the condition and nearing the end of life. Understanding these symptoms and how they complicate care delivery is essential for improving the quality of EoLC.

1.5.1 Common Symptoms of Dementia

Dementia is characterised by a broad and progressive range of symptoms that affect cognition, physical function, behaviour, and psychological wellbeing. While the exact presentation can vary depending on the subtype and stage, certain symptoms are common across the spectrum of the disease and have important implications for EoLC.

Cognitive impairment is the hallmark of dementia and includes memory loss, disorientation, reduced attention span, language difficulties, and impaired judgement (WHO, 2023). Short-term memory loss often emerges early, followed by challenges with language, comprehension, planning, and problem-solving (García-Alberca et al., 2017). As the disease advances, individuals may struggle with recognising people, navigating spaces, and making decisions, leading to an increased dependency on others for daily care.

Behavioural and psychological symptoms of dementia (BPSD) are also common and can significantly impact both the individual and those providing care. These symptoms include agitation, aggression, resistance to care, anxiety, depression, apathy, hallucinations, and delusions (Tible et al., 2017; Ballard & Corbett, 2013; Lyketsos et al., 2018). Such symptoms are often expressions of unmet needs or responses to environmental stressors and are frequently misunderstood in clinical settings, leading to suboptimal care.

In addition to cognitive and behavioural issues, physical symptoms are particularly important during the advanced stages of dementia. These include reduced mobility, impaired balance, and increased risk of falls (Demanze and Michel, 2017). Motor deterioration contributes to dependence on others for basic activities such as walking, eating, and personal hygiene. The physical decline also compounds the risk of hospitalisation, particularly when comorbidities or acute illnesses are present.

These overlapping and compounding symptoms shape how individuals experience the progression of dementia and present specific challenges for recognising distress, communicating needs, and delivering person-centred care, especially as individuals approach the EoL.

1.5.2 Challenges in Hospital Settings

The symptoms of dementia, particularly in their advanced stages, present significant challenges within hospital environments, which are typically designed for short-term, acute care rather than long-term, relational support. Individuals with dementia admitted to the hospital may be at heightened risk of receiving care that is reactive, impersonal, or poorly adapted to their needs.

Hospital staff may lack specific training in recognising and responding to cognitive and behavioural symptoms of dementia, which can lead to misinterpretation of distress as non-compliance or delirium (Alzheimer’s Society, 2016; Davies et al., 2014). For example, agitation or resistance to care may be viewed as problematic behaviour rather than a response to fear, pain, or sensory overload. As a result, individuals may be subjected to unnecessary sedation or restraints rather than supported through non-pharmacological, person-centred approaches (Tadd et al., 2011).

Time pressures and performance targets further reduce opportunities for relational care. Staff working in task-focused systems may not have the capacity to observe subtle behavioural cues or provide consistent, familiar support. The lack of continuity between shifts or departments adds to the difficulty of identifying underlying patterns in behaviour or symptoms (Gkioka, 2020a; Sampson et al., 2016).

In many cases, environmental features such as noisy wards, unclear signage, frequent staff changes, and bright lighting can worsen confusion, increase anxiety, and intensify behavioural symptoms (Aldridge et al., 2017; Tadd et al., 2011). These conditions contribute to a hospital experience that is not only distressing but also potentially harmful for people with dementia, particularly when they are nearing the EoL.

From a critical realist perspective, these challenges reflect more than isolated practice gaps; they reveal systemic mechanisms, such as institutional priorities, biomedical assumptions, and structural under-resourcing, that shape how care is delivered. Without addressing these underlying forces, efforts to improve dementia care within hospitals may fail to produce meaningful or sustained change.

1.6. Understanding Death and Dying

To deliver high-quality EoLC for people with dementia, it is essential to understand the broader human experience of death and dying. While death is a biological event, dying is a deeply personal and social process, shaped by cultural, spiritual, emotional, and ethical dimensions (Becker, 1973; Hallenbeck, 2022). These factors influence individual and collective responses to the dying process and affect how care is provided, received, and interpreted, particularly when cognitive capacity is diminished.

1.6.1 The Emotional and Existential Dimensions of Dying

Although clinical definitions of death focus on the irreversible cessation of vital functions, this perspective overlooks the psychological, existential, and relational transitions that often accompany dying (Kastenbaum, 2024; Hallenbeck, 2022). Emotional responses to terminal illness may include fear, anger, sadness, and acceptance. One influential model is Kübler-Ross's (1969) five-stage theory, denial, anger, bargaining, depression, and acceptance, which, although critiqued for its linearity, underscores the emotional complexity of facing death.

People with dementia may still experience these emotions, but often without the ability to verbalise them. For example, distress may be expressed through behaviours such as agitation, withdrawal, or vocalisations (Cohen-Mansfield & Billig, 2018). Interpreting such behaviours requires sensitive, person-centred approaches rooted in relational knowledge (Brooker & Latham, 2015).

Spiritual and existential concerns often intensify at the EoL. These may include fears about separation, meaninglessness, and the unknown (Puchalski et al., 2009). Spiritual needs are frequently overlooked in hospital settings, especially when clinical care is focused on physical symptoms or documentation rather than holistic wellbeing (Gómez-Batiste et al., 2017).

1.6.2 Cultural Perspectives on Dying

Cultural beliefs significantly influence how people interpret and respond to dying, including attitudes toward pain, autonomy, resuscitation, and death rituals (Wong et al., 2022). In some cultures, discussing death is seen as necessary preparation; in others, it may be considered taboo or even harmful (Lin et al., 2025). These beliefs also shape family expectations, decision-making roles, and definitions of a “good death”.

Culturally competent EoLC requires awareness of such differences and the flexibility to respond appropriately. However, healthcare systems often adopt a one-size-fits-all model of dying, which can marginalise minority perspectives and result in care that is misaligned with the person’s values (Calanzani et al., 2013). For people with dementia, who may already be excluded from direct communication, this risk is especially acute.

From a critical realist standpoint, cultural beliefs are understood as both shaping and shaped by structural contexts, including institutional norms and historical legacies. Cultural misalignment in hospital-based EoLC may therefore reflect broader systemic inequities in care access, training, and service design (Porter, 2015).

1.6.3 Ethical Considerations at the End of Life

Ethical decision-making is central to EoLC, particularly when individuals can no longer articulate their preferences. This is a common situation in advanced dementia, where family carers and clinicians often make decisions based on substituted judgement or best-interest principles (Quill & Brody, 1996). The ethical principles of autonomy, beneficence, non-maleficence, and justice all come into play (Beauchamp & Childress, 2019).

One of the most challenging aspects of EoLC in dementia is determining when to initiate or withdraw interventions such as antibiotics, feeding tubes, or resuscitation. While these may prolong life, they can also result in unnecessary suffering if not aligned with the person’s goals of care (Mitchell et al., 2009). ACP is widely recommended to address this, yet it is often absent or incomplete in people with dementia (Samsi & Manthorpe, 2011).

Hospital settings add further complexity. Ethical decisions are often made under time constraints, with limited background knowledge of the patient and fragmented communication among care teams. Moreover, hospital systems may prioritise risk avoidance or legal defensibility over individualised care (Seymour et al., 2011).

From a critical realist perspective, these ethical challenges are not simply dilemmas of individual judgement but are embedded within broader institutional and structural mechanisms. For example, the dominance of curative models of care and the lack of interdisciplinary collaboration may constrain ethical reflection and reduce opportunities for shared decision-making (Porter, 2015; Goodman et al., 2010).

1.6.4 Recognising the Value of Death in Care

For people with dementia, who may no longer be able to express their needs or values, the dying process raises important questions about dignity, identity, and personhood. A “good death” in this context may mean avoiding unnecessary interventions, maintaining comfort, and ensuring the presence of familiar people and environments (Van der Steen et al., 2014).

However, such goals are not always prioritised in hospital-based care, where performance metrics, staff shortages, and clinical risk dominate daily practice (Tadd et al., 2011). These systemic constraints affect how death is managed and may lead to practices that inadvertently undermine dignity and comfort.

Understanding dying as a relational and culturally embedded process enables more compassionate care. For individuals with dementia, this includes engaging families, recognising behavioural signs of distress, and prioritising continuity and presence over procedures and tasks (Sampson et al., 2016).

In the next section, I explore how these conceptual foundations of death and dying are translated into specific approaches to EoLC, focusing on what it means to provide quality care at the end of life, particularly for people with dementia.

1.7. End-of-Life Care Concepts

EoLC refers to the holistic support offered to individuals approaching death, encompassing the physical, emotional, social, psychological, and spiritual dimensions of care. Its aim is not to cure, but to ensure comfort, dignity, and the fulfilment of personal values and preferences National Institute on Aging (NIA, 2020). For people with dementia, who may lose the ability to communicate or make decisions, EoLC becomes particularly complex and ethically charged, requiring proactive, compassionate, and context-sensitive approaches.

1.7.1 What Is End-of-Life Care?

EoLC typically begins when an individual is believed to be in the last year of life and continues through to bereavement support for families (NICE, 2018). It involves managing symptoms such as pain, breathlessness, or nausea; supporting emotional and psychological wellbeing; offering spiritual and cultural care; and facilitating open discussions about treatment goals, preferences, and anticipated decisions (Hanson et al., 2017).

For people with dementia, EoLC must be tailored to the progressive nature of cognitive decline and the resulting loss of decision-making capacity. This calls for early conversations about goals of care, timely documentation of preferences, and regular review of advance care plans (Samsi & Manthorpe, 2011).

Hospitals, however, often focus on acute treatment and short-term outcomes. In such settings, EoLC may be inconsistently implemented or overlooked altogether, especially when dementia is not recognised as a terminal condition (Davies et al., 2014). These limitations can lead to distressing hospital experiences, unnecessary interventions, or missed opportunities for providing dignity-preserving care.

1.7.2 Why Is End-of-Life Care Vital for People with Dementia?

Dementia is a life-limiting illness, yet it is frequently not acknowledged as such by healthcare professionals, leading to delays in palliative involvement or ACP (Mitchell et al., 2009). As the disease progresses, individuals experience a gradual loss of cognitive and functional abilities, often becoming unable to express pain, discomfort, or their preferences regarding care (Van der Steen et al., 2014).

This ambiguity surrounding the timing of death complicates decisions about treatment withdrawal, hospital admission, or artificial feeding, which may not align with the person's values or best interests (Sampson et al., 2016). The inability to recognise dying in dementia results in overuse of life-sustaining treatments, under-treatment of symptoms, and reduced family satisfaction with care (Mitchell et al., 2012).

Moreover, family carers, who are often left to make or validate decisions, may be unprepared for their role or uncertain about the person’s wishes. They report high levels of emotional distress, especially when care appears misaligned with the individual’s values (Etters et al., 2008). Addressing their needs and perspectives is therefore central to the provision of good EoLC in dementia.

1.7.3 A Critical Realist Perspective on End-of-Life Care

From a critical realist perspective, variations in the quality of EoLC are not only the result of clinical decisions or staff knowledge but are also shaped by underlying systemic and structural forces. Institutional norms, policy frameworks, staffing models, and funding mechanisms influence what care is possible, prioritised, or delivered in practice (Porter, 2015).

For example, the hospital’s focus on throughput and biomedical success metrics may discourage early palliative interventions, even when they align more closely with the individual’s needs. Similarly, fragmented care systems, inadequate staff training, and risk-averse cultures limit relational care practices and moral deliberation (Goodman et al., 2010; Tadd et al., 2011).

Understanding these deeper generative mechanisms helps explain why even well-intentioned clinicians may struggle to deliver person-centred, compassionate EoLC for people with dementia. This insight is essential for developing solutions that are not only clinically sound but also structurally and ethically feasible.

In the next section, I examine how these core principles are applied to EoLC specifically for individuals with dementia, focusing on personhood, communication, ACP, and support for families.

1.8. End-of-Life Care for People with Dementia

Delivering EoLC for people with dementia presents unique challenges that demand tailored, person-centred approaches. Dementia affects not only memory and cognition but also communication, emotional expression, behaviour, and physical functioning. These changes complicate how care is delivered, especially in the final stages of life when individuals are often unable to express needs or participate in decision-making. This section explores how EoLC can be adapted to meet the needs of people with dementia, focusing on personhood, communication, family involvement, and structural barriers to best practice.

1.8.1 Person-Centred Care and the Preservation of Personhood

Person-centred care is a core principle in dementia care and becomes especially important at the end of life. It recognises the individual as a whole person, someone with a history, values, preferences, and relationships, not simply a diagnosis (Brooker, 2004). This approach seeks to uphold the person's identity, even when they lose the ability to communicate or engage actively. Maintaining personhood requires continuity of care, relational engagement, and sensitivity to individual preferences and life stories (Van der Steen et al., 2014).

In hospital environments, however, person-centred care is often compromised by task-focused routines, staff shortages, and a culture of clinical efficiency. Staff may focus on physical interventions while neglecting relational aspects such as reassurance, touch, or familiarity, all of which contribute to dignity and comfort in dementia EoLC (Tadd et al., 2011; Sampson et al., 2016).

1.8.2 Communication and Advance Care Planning

As dementia progresses, verbal communication becomes increasingly limited, making it difficult for individuals to express preferences, pain, or emotional distress. This can lead to underassessment of needs and the continuation of interventions that may no longer be appropriate (Sampson et al., 2016). Effective communication strategies, including reading behavioural cues and involving family members, are essential to ensuring that care remains aligned with the person’s values.

ACP is a key mechanism for preserving autonomy as dementia advances. ACP allows individuals to express their care preferences while they retain capacity, helping to guide decisions around resuscitation, hospital admission, and artificial nutrition later in the disease course (Samsi & Manthorpe, 2011). However, evidence suggests that ACP is underused in dementia care, particularly in hospitals, where reactive decision-making often dominates (Davies et al., 2014; Mitchell et al., 2009).

Barriers to effective communication and ACP in hospitals include staff uncertainty, limited training, and discomfort with EoL conversations. Additionally, institutional policies may not support timely or inclusive dialogue, especially in the context of short admissions or fragmented care (Gkioka et al., 2020b; NICE, 2019).

1.8.3 The Role of Family Carers

Family carers are central to EoLC in dementia. They often act as advocates, historians, and interpreters, helping staff understand the person’s needs and preferences. Their involvement is particularly important when the individual can no longer communicate or participate in decisions (Sampson et al., 2016).

However, carers themselves often experience distress, moral uncertainty, and exclusion during hospital admissions. Studies show that family members feel overlooked in decision-making processes and unsupported by clinical staff, especially when communication is limited or inconsistent (Etters et al., 2008; Davies et al., 2014). Supporting carers with clear information, emotional support, and involvement in care planning improves both their experience and the quality of care provided to the person with dementia (Xiao et al., 2025).

1.8.4 Structural and Systemic Challenges

From a critical realist perspective, the gap between recommended best practice and actual care delivery is not simply a matter of individual performance. It reflects systemic and institutional mechanisms that constrain or shape care. These include staffing ratios, ward routines, funding priorities, performance metrics, and organisational cultures that favour curative interventions (Porter, 2015; Tadd et al., 2011).

Hospitals are primarily designed for short-term, acute care, not for delivering holistic, relational EoLC. This misalignment leads to difficulties in recognising dying, delays in initiating palliative approaches, and continued use of invasive treatments that may not improve comfort (Gkioka, 2020a; Mitchell et al., 2012). Moreover, hospital policies and risk-management frameworks often discourage the flexibility and moral reflection needed for good EoLC (Goodman et al., 2010).

1.8.5 Bridging the Gap Between Theory and Practice

Although the principles of dementia-specific EoLC are well established, such as preserving personhood, enabling ACP, and supporting families, these ideals are not consistently achieved in hospital settings. Without systemic change, even committed and knowledgeable staff may struggle to provide care that aligns with the person's values (Sampson et al., 2016; Van der Steen et al., 2014).

Bridging this gap requires not only better training and leadership but also changes in how hospitals prioritise, resource, and measure EoLC. Embedding dementia and palliative expertise into acute care teams, investing in staff support, and adapting hospital environments are among the strategies proposed in the literature (Aldridge et al., 2017; NICE, 2019).

In the next section, I explore the specific signs and symptoms that indicate a person with dementia is entering the EoL phase, and how these are recognised (or missed) in practice.

1.9 Symptoms at End-of-Life Stage

Recognising when a person with dementia is entering the final stage of life is critical to ensuring appropriate, compassionate, and timely EoLC. However, the nature of dementia complicates this process. The progression of the condition is typically prolonged and unpredictable, and symptoms of dying can be subtle, misinterpreted, or overlooked, particularly in hospital settings where staff may not be familiar with the individual's baseline behaviour or communication style (Van der Steen et al., 2014; Mitchell et al., 2012).

1.9.1 Recognising End-of-Life in Dementia

Dementia differs from other terminal conditions in its trajectory. Unlike cancer, where decline tends to follow a relatively predictable pattern, dementia-related deterioration may span years and include extended periods of stability punctuated by sudden declines (Sachs et al., 2004). This makes it difficult to determine when someone is actively dying.

Key symptoms that typically indicate the approach of death in people with dementia include:

Declining consciousness and alertness: Individuals may become more withdrawn, lethargic, or non-responsive, often spending more time asleep or disengaged from their surroundings (Van der Steen et al., 2014).

Dysphagia and reduced oral intake: Difficulty swallowing is common in advanced dementia. This can lead to reduced food and fluid intake, weight loss, aspiration, and an increased risk of infections such as pneumonia (Mitchell et al., 2012).

Altered breathing patterns: Cheyne–Stokes respiration (periods of rapid breathing followed by apnoea) or noisy breathing caused by retained secretions are often observed in the final days (Hickman et al., 2012).

Fatigue and immobility: People may become bedbound, unable to maintain posture, and too weak to engage in activity or interaction (Sampson et al., 2016).

Loss of appetite and refusal to eat or drink: While this is a natural part of dying, families may struggle with interpreting it and may feel pressure to intervene, even when artificial feeding provides no clinical or emotional benefit (Sampson et al., 2006; Gillick, 2000).

1.9.2 Implications for Hospital-Based Care

Despite these indicators, hospital staff may not always identify when a person with dementia is entering the final phase of life. This is due in part to the general unpredictability of the condition, but also to institutional and structural limitations. Busy wards, short staff-patient interactions, and a lack of continuity often mean that changes are either missed or misattributed to the underlying dementia (Gkioka, 2020a; Goodman et al., 2010).

Instead of initiating palliative care, staff may continue with investigations, intravenous hydration, antibiotics, or other interventions that do not necessarily contribute to comfort or dignity in the final days (Mitchell et al., 2009). Studies have shown that individuals with dementia are less likely than those with other terminal conditions to receive appropriate EoLC, including anticipatory medications and specialist palliative input (Sampson et al., 2016; Van der Steen et al., 2014).

1.9.3 A Critical Realist Perspective on Systemic Challenges

From a critical realist viewpoint, the difficulty in recognising dying is not only a clinical knowledge issue, it reflects deeper systemic mechanisms. Institutional routines, performance pressures, limited dementia training, and biomedical priorities influence how care is delivered and what is considered the "default" response (Porter, 2015). In many hospitals, dying is conceptualised about cancer trajectories or acute organ failure, rather than neurodegeneration, leading to inappropriate care pathways for people with dementia (Sach et al., 2004).

Additionally, communication barriers, both linguistic and behavioural, may obscure signs of pain or distress. With advanced dementia, people may be unable to verbalise discomfort, and staff must rely on non-verbal cues such as facial expressions, restlessness, or vocalisations (Cunningham et al., 2008). Inadequate use of pain assessment tools for non-verbal individuals further compounds the risk of unmet needs (Husebo et al., 2011).

1.9.4 The Role of Families in Recognising and Responding to Dying

Family carers are often best placed to notice when a person’s condition changes, particularly in ways that may not be apparent to unfamiliar staff. They can provide insight into behavioural patterns, preferences, and values that guide care decisions (Sampson et al., 2016). Involving families in care discussions also helps ensure shared understanding of what to expect and can ease the emotional burden of decision-making during the dying phase (Davies et al., 2014).

However, families themselves may feel unprepared or unsupported. Hospital staff may avoid or delay conversations about prognosis, especially when uncertainty is high. Yet clear, compassionate communication about EoL signs and care options has been shown to reduce distress for carers and improve satisfaction with care (Baile et al., 2000; Gkioka et al., 2020b).

Ultimately, recognising the EoL stage in dementia is not only a medical responsibility; it is also a relational, ethical, and systemic one. A shift in approach from cure to comfort depends on timely identification, effective communication, and systems that support staff and families in delivering compassionate, dignified care.

In the next section, I explore the hospital context in more depth, considering how its structural features, professional practices, and institutional limitations shape the delivery of EoLC for people with dementia.

1.10 The Hospital Context

Hospitals play a central role in the care of individuals with dementia, especially during acute illness and at the end of life. However, hospital environments are often poorly suited to the complex and evolving needs of this population. The design and culture of hospitals, prioritising efficiency, biomedical interventions, and risk management, frequently conflict with the principles of person-centred, relational EoLC that people with dementia require. This section explores the structural and organisational features of hospital settings that influence the quality of EoLC, highlighting both challenges and opportunities for improvement.

1.10.1 Dementia in Hospital Settings

Dementia is a major cause of hospital admission, particularly in the advanced stages of the condition. In the UK, approximately one in four hospital beds is occupied by a person living with dementia (Royal College of Psychiatrists, 2019). These individuals are often admitted for reasons other than dementia itself, such as infections, falls, or comorbid conditions, but dementia significantly complicates their care and recovery (Alzheimer’s Society, 2016).

Many of these hospitalised individuals are nearing the end of life, either due to the progression of dementia or the combined impact of multiple comorbidities. Yet EoLC in hospitals remains inconsistent, and staff may struggle to recognise when a person with dementia is dying (Gkioka, 2020a). Studies have shown that individuals with dementia in hospitals often receive burdensome interventions, inadequate symptom control, and limited palliative input (Sampson et al., 2016; Mitchell et al., 2009).

1.10.2 Environmental and Organisational Barriers

The physical and organisational characteristics of hospital wards can contribute to distress and poor outcomes for people with dementia. Hospitals are typically noisy, unfamiliar, and fast-paced environments that can increase disorientation and agitation in people with cognitive impairment (Aldridge et al., 2017; Tadd et al., 2011). Frequent staff changes, rigid routines, and a lack of continuity in care can further undermine the person's sense of safety and identity.

In addition, hospital staff, particularly in general wards, may lack training in dementia care, communication strategies, or palliative approaches (Sampson et al., 2016). The result is often a task-driven model of care that prioritises biomedical goals (e.g. stabilisation, discharge planning) over comfort, dignity, and emotional support. These pressures are compounded by workforce shortages, time constraints, and performance targets, which leave little room for personalised or relational care (Goodman et al., 2010).

1.10.3 Systemic Structures and the Critical Realist Lens

From a critical realist perspective, these challenges cannot be fully explained by individual knowledge deficits or isolated practice failures. Rather, they are shaped by deeper systemic and institutional mechanisms, such as funding structures, staffing models, hospital hierarchies, and risk-averse governance, that influence what types of care are possible, prioritised, or incentivised (Porter, 2015).

Hospitals often operate under a dominant biomedical paradigm that values diagnosis, intervention, and measurable outcomes over relational care or long-term wellbeing

(Sachs et al., 2004). Within this system, death may be seen as a failure, and staff may feel uncertain or unsupported when shifting from curative to palliative modes of care.

This cultural context influences not only the decisions made by professionals but also the experiences of people with dementia and their families. For example, limited access to quiet spaces, private rooms, or dedicated dementia-friendly wards can prevent families from spending time with their loved ones in meaningful ways during the dying process (Tadd et al., 2011).

1.10.4 Potential for Improvement

Despite these challenges, hospitals remain critical settings for intervention. With appropriate training, environmental adaptations, and policy support, it is possible to deliver high-quality EoLC for people with dementia in acute settings (Van der Steen et al., 2014). Improvements may include:

Integrating dementia and palliative care expertise into general wards.

Offering regular education and support for staff.

Creating dementia-friendly environments with calm lighting, clear signage, and noise reduction strategies.

Involving families more fully in decision-making and care processes.

These strategies require leadership and investment but are essential for aligning hospital care with the principles of compassion, dignity, and personhood.

In the next section, I explore how EoLC for people with dementia is currently managed in hospital settings, including the key practices, systemic limitations, and ethical considerations that shape real-world care delivery.

1.11 Research Justification

Despite growing recognition of the importance of EoLC for individuals with dementia, there remains a significant gap in understanding how this care is experienced and evaluated, particularly within hospital settings. Dementia is now the leading cause of death in the United Kingdom, with over 944,000 people currently living with the condition (Alzheimer's Research UK, 2021). Many of these individuals are admitted to hospital in the advanced stages of illness, and one in four UK hospital beds is occupied by a person with dementia (Royal College of Psychiatrists, 2019). Yet, despite the frequency with which people with dementia die in hospital, the quality of EoLC they receive remains inconsistent and, in many cases, inadequate.

1.11.1 The Need for Context-Specific Understanding

Much of the existing literature on EoLC focuses on residential, hospice, or community-based settings. While these studies offer valuable insights, they do not fully capture the complexities of hospital-based care, where acute medical priorities often take precedence and relational care may be deprioritised (Sampson et al., 2016; Davies et al., 2014). Evidence suggests that hospital environments are frequently ill-suited to meet the cognitive, emotional, and physical needs of individuals with dementia, especially during the final phase of life (Gkioka, 2020a).

Research has also largely focused on symptom management, prognosis, or the physiological aspects of decline, rather than exploring what constitutes "quality" EoLC from the perspectives of those most directly involved, family carers. This omission is significant because carers often act as surrogate decision-makers, advocates, and witnesses to the care process, particularly when individuals with dementia lose the ability to speak for themselves (Sampson et al., 2016). Understanding their experiences is essential to identifying where care aligns, or fails to align with the values and preferences of the person dying.

1.11.2 Limitations in Existing Evidence

Chapter 2 of this thesis presents a systematic review of the literature on dementia EoLC, which confirms the fragmented nature of current research. While there is increasing interest in this area, few studies offer detailed accounts of how EoLC is enacted in hospital wards, or how carers experience and interpret the care their loved ones receive. Most research either adopts a clinical focus, such as on feeding, medication, or pain management, or addresses the emotional burden and coping strategies of carers without analysing the care environment itself (Davies et al., 2014).

Chapter 3 further explores these gaps through a critical realist review (CRR), demonstrating that while some mechanisms of poor care are acknowledged (e.g. time pressures, lack of training), they are rarely theorised or linked to deeper structural issues. Few studies explicitly address the generative mechanisms, such as institutional cultures, funding priorities, or normative assumptions about dying, that shape how EoLC is delivered in hospitals. Without this explanatory depth, it is difficult to design better interventions or reform strategies.

1.11.3 Why This Study Matters

This study addresses a crucial gap by examining the quality of hospital-based EoLC for people with dementia through the perspectives of family carers. By focusing on carers' experiences, the study brings forward voices that are often marginalised in policy and practice, yet which hold deep insight into the realities of care delivery. Carers not only witness the care their relatives receive but often participate in decision-making, advocate for the person's preferences, and provide emotional and practical support during the dying process (Etters et al., 2008).

What sets this study apart is its use of a critical realist methodology, which moves beyond description to explanation. This approach allows for an exploration of both surface-level practices (what happens) and the underlying mechanisms (why it happens) that influence care delivery. By identifying structural, cultural, and institutional factors that constrain or enable compassionate care, the study seeks to provide recommendations that are not only context-sensitive but also system-aware (Porter, 2015).

The findings of this study aim to inform:

Practice: by highlighting the relational and emotional needs of people with dementia and their carers at the end of life.

Policy: by exposing system-level gaps that undermine quality care in hospital settings.

Research: by offering a theoretical model of care quality grounded in the real-world experiences of carers.

Ultimately, the study contributes to a more holistic and critical understanding of EoLC for people with dementia. It shifts the focus from what should happen in theory to what actually happens in practice, and why.

In the next section, I outline the structure of the thesis and explain how each chapter builds towards this aim.

1.12 Structure of the Thesis

This thesis is organised into seven chapters, each building upon the previous to form a coherent exploration of EoLC for people with dementia in hospital settings. The structure reflects the logic of a critical realist inquiry, progressing from description to explanation and culminating in theory-informed recommendations for practice and policy.

Chapter 1: Introduction
This introductory chapter sets the scene for the study, outlining the significance of dementia as a global and national challenge, the complexities of delivering EoLC in hospitals, and the rationale for focusing on family carers' perspectives. It also introduces the critical realist lens underpinning the study and provides justification for its focus.

Chapter 2: Systematic Literature Review
This chapter reviews existing literature on EoLC for people with dementia, with a focus on care quality and the experiences of carers. It identifies major gaps in the evidence base, particularly relating to hospital-based care, and justifies the need for further research.

Chapter 3: Critical Realist Review
Building on the findings of the systematic review, this chapter applies a critical realist approach to interpret how care is conceptualised, delivered, and experienced. It explores underlying mechanisms, contextual conditions, and constraints that shape EoLC, and refines the study’s focus and questions.

Chapter 4: Methodology and Methods
This chapter outlines the philosophical foundations of the study, including the rationale for adopting CR. It details the research design, ethical considerations, participant recruitment, data collection, and analytic strategies used to generate and interpret findings.

Chapter 5: Stage One: Initial Programme Theories

This chapter presents data from the first phase of fieldwork, focusing on the perspectives of staff and bereaved carers. It introduces initial programme theories that emerged through analysis and reflects on their implications for care delivery in hospitals.

Chapter 6: Phase Two Findings and Theory Refinement
Drawing on further data collection and deeper engagement with the evidence, this chapter refines the programme theories developed in Chapter 5. It explores how different contextual factors influence the delivery of quality EoLC and presents a more developed explanatory framework.

Chapter 7: General Discussion and Conclusions
The final chapter situates the findings within broader academic and policy debates. It discusses the study's theoretical, methodological, and practical contributions, offers recommendations for improving EoLC in hospitals, reflects on limitations, and identifies directions for future research.

Together, these chapters provide a layered understanding of the factors shaping EoLC for people with dementia in hospital settings, one that is grounded in the lived experiences of carers and informed by critical realist theory.

1.13 Chapter Summary

This chapter has introduced the background, rationale, and theoretical framing of this study, which explores EoLC for people with dementia in hospital settings. Dementia is a growing global health concern, with a rising number of individuals living with the condition and an increasing proportion of deaths occurring in hospitals. Despite this, the quality of EoLC for people with dementia remains inconsistent, particularly in acute hospital contexts where environmental and systemic constraints often undermine person-centred, dignified care.

The chapter began by defining dementia and outlining its symptoms, subtypes, and progression. It explored the global and UK-specific prevalence of the condition, highlighting the additional challenges posed by comorbidities such as diabetes, cardiovascular disease, and depression. The symptoms of dementia, including cognitive, physical, behavioural, and psychological changes, were examined in relation to the complexities they introduce in hospital-based EoLC.

Concepts of death, dying, and quality of life were discussed through cultural, ethical, and spiritual lenses, emphasising how individuals and families experience the end of life in different ways. This was followed by a critical discussion of EoLC principles and their application to dementia care, including personhood, ACP, and family involvement. The challenges of recognising dying in dementia were outlined, alongside the structural barriers that influence how symptoms are interpreted and addressed.

The chapter then examined the hospital context as a primary site of care, identifying organisational factors, such as staffing, training, institutional norms, and biomedical priorities, that shape how EoLC is delivered. Drawing on a critical realist perspective, it was argued that many of the limitations in current practice are linked to deeper systemic mechanisms rather than individual failings.

Finally, the chapter justified the focus of this study by identifying significant gaps in the literature, particularly the lack of research examining how family carers perceive and evaluate hospital-based EoLC for people with dementia. The chapter concluded with an overview of the thesis structure, which reflects the layered, explanatory approach of CR.

In the next chapter, I present a systematic review of the literature on EoLC for people with dementia. This review explores what is currently known about the quality of care and the experiences of family carers and identifies key areas for further inquiry.

Chapter 2 Systematic Review

2.1 Introduction

In this chapter, I present a systematic review of the existing literature evaluating interventions aimed at improving EoLC for hospital inpatients with dementia. The review was conducted to establish a comprehensive understanding of the available interventions and their reported associated outcomes.

Throughout this chapter, I define EoLC as the active support and medical management offered during the final months or year of life, aiming to ensure that individuals live as comfortably and meaningfully as possible until death, while also supporting their families (NICE, 2015; Leadership Alliance for the Care of Dying People, 2014). In the context of dementia, EoLC must address the unique challenges posed by cognitive decline, communication difficulties, and uncertain disease trajectories, which differentiate it from EoLC for patients with conditions such as cancer (Mitchell et al., 2009).

People living with dementia often experience extended hospital stays and are at higher risk of hospital readmission and death in hospital settings (CHKS, 2013). Despite policy initiatives aimed at improving EoLC across the UK, research has consistently indicated that people with dementia receive suboptimal EoL support compared to individuals with other terminal illnesses (Goodman et al., 2010). Common issues include the late or absent recognition of the terminal phase of dementia, the underutilisation of EoLC approaches, and the persistence of aggressive, burdensome interventions at the EoL.

At the time I conducted this review, no published systematic review had comprehensively examined interventions specifically designed to improve EoLC for hospitalised people with dementia. Existing reviews had either focused on EoLC in care homes or covered broader aspects of hospital dementia care without specific attention to the end of life, or conflated EoLC with general dementia care (Spacey et al., 2018). Given the unique needs of this population and the complexity of the hospital environment, there was a pressing need to evaluate interventions specifically situated within hospital settings.

The aim of this systematic review was therefore to critically assess and synthesise the evidence regarding interventions designed to enhance EoLC for people with dementia within hospitals. I sought not only to summarise the findings of the included studies but also to explore the ways in which outcomes were conceptualised and measured and identify gaps in the existing evidence. In keeping with a critical approach, I have integrated quality appraisal findings into the narrative discussion, highlighting where methodological limitations may impact the trustworthiness of the conclusions drawn.

The chapter is structured as follows:

- I begin by outlining the methodological approach used to conduct the review, including the search strategy, inclusion and exclusion criteria, and appraisal processes.
- I then present the findings of the included studies, providing a descriptive overview followed by a critical analysis.
- The chapter concludes with a discussion of the implications of the findings for practice, policy, and future research, as well as the limitations of the review itself.

Through this systematic review, I aimed to contribute to a more nuanced understanding of what constitutes good outcomes in EoLC for hospitalised people with dementia, and to inform the design of future interventions to address the gaps identified.

2.2 Systematic Reviews

Systematic reviews of the literature are based on a clearly formulated question, identify relevant studies, appraise their quality, and summarise the evidence of a particular topic (Webb & Roe 2007). Currently, there is no comprehensive overview of the current interventions to provide EoLC for people with dementia in hospitals. Understanding current knowledge about the interventions provided for people with dementia in hospitals at their EoL was essential at this stage of this PhD project. This knowledge helped the me identify the current clinical practice in hospitals while caring for people with dementia at their EoL stage and consequently influenced the later work in the following stages.

In comparison with a traditional review, a systematic review is more effective. A traditional review involves three key activities: identifying, describing, and summarising relevant research. However, a systematic review adds critical appraisal research methods and brings the findings together in a deep synthesis process (Gough et al., 2012). In other words, systematic reviews provide higher quality and rigour to the study design and methods identified and a critical and analytical evaluation of the explored literature rather than only providing a summary of the selected previously published research. A summary enables the reader to be confident that a thorough search has been carried out and that the results and conclusions are reliable (Aveyard, 2023).

Single studies may not provide a sufficient number or range of participants, which is avoided in systematic reviews due to combining and analysing many studies in one review (Webb & Roe 2007). Thus, systematic literature reviews are important to place new research, which is designed and implemented in an appropriate way (Clarke, 2004).

2.3. The Review

Formulating a protocol is the first stage of undertaking a systematic review (Webb & Roe, 2007). This review protocol was developed and registered in PROSPERO (International prospective register of systematic reviews) (Alhatamleh et al, 2020) CRD42020169037.

2.3.1. Review Aim

To evaluate the interventions designed to improve EoLC for hospital inpatients with dementia?

Main outcomes

1. For quantitative data: Measurement of whether EoLC interventions for patients with dementia work as intended.
2. For qualitative data: Understanding of staff and patients' close others' perceptions of whether EoLC interventions for patients with dementia achieve their intended outcomes.

2.3.2. Search Process

Search strategies for identifying relevant work should be explicit and included in the methods (Smith et al. 1992; Yoshii et al. 2009). Data were collected from the following electronic databases; CINAHL, MEDLINE, ScienceDirect, and Scopus. These databases are relevant because they focus on healthcare research, for instance, the Cumulative Index of Nursing and Allied Health Literature (CINAHL) (see Table 2-1). PEO (Population, Exposure, Outcome) is used in systematic reviews to help formulate clear and focused research questions, particularly in qualitative studies and evidence synthesis, as it aids in identifying the key elements necessary for an in-depth understanding of the exposure and its effects on a specific population (Bettany-Saltikov, 2012). In this review PEO was as the following:

Population – people with dementia
Exposure – EoLC in acute settings
Outcome – whether care or interventions achieved their intended outcomes.

Moher et al. (2009) suggested a flow diagram (PRISMA) document and summarise the search and study selection process clearly. Accordingly, I adopted the PRISMA flow diagram as, in this research, as it was considered an easy mode to let the reader understand the process easily (see Figure 2-1).

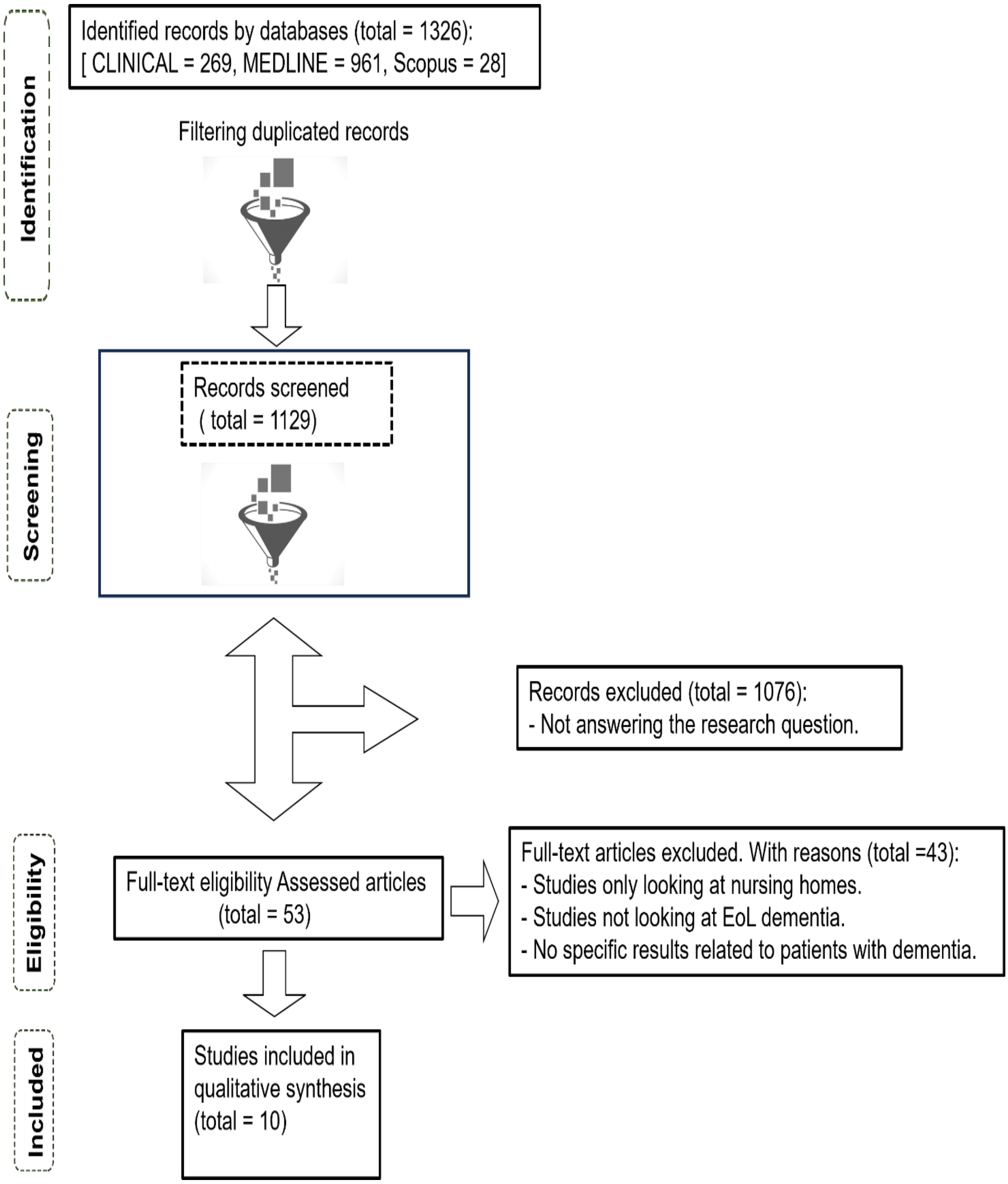


Figure 2-1 PRISMA 2009 Flow Diagram

Table 2-1 Search strategy.

Database	Search Strategy	Number of records
Scopus	Dementia AND "end of life" or "EoL" or "end-of-life" or terminal or "last day*" AND "acute setting*" or hospital* or ward*	28
ScienceDirect	Dementia AND "end of life" or "EoL" or "end-of-life" or terminal or "last day*" AND "acute setting*" or hospital* or ward*	13
CINAHL	(((dementia or Alzheimer) OR (MH "Dementia+”)) AND (("end of life" or "EoL" or "end-of-life" or terminal or "last day*”) OR (MH "Terminal Care+)) AND (("acute setting*" or hospital* or ward*) OR (MH "Hospitals+")))	369
MEDLINE	(((dementia or Alzheimer) OR (MH "Dementia+”)) AND (("end of life" or "EoL" or "end-of-life" or terminal or "last day*”) OR (MH "Terminal Care+)) AND (("acute setting*" or hospital* or ward*) OR (MH "Hospitals+")))	961

Boolean operators

Boolean operators formulate the basis of mathematical sets and database logic. Using Booleans while searching in databases helps connect search words to either narrow the set of results or broaden it. The three leading Boolean operators are OR, AND, and NOT. Boolean operators are used to focus the search, especially when the search topic has many terms. Moreover, they connect several pieces of information to find the needed data accurately (Aveyard, 2023). In this review, Boolean operators have been utilised in the search process, especially And and Or. For example, when using the electronic databases for dementia And (palliative Or end-of-life care) were searched for (see Table 2-2).

Table 2-2 Boolean operators.

Boolean	Definition	Use in the research process
OR	It is used for searching for documents containing either of the words.	Dementia or Alzheimer's "end of life" or "EoL" or "end-of-life" or terminal or "last day*." "acute setting*" or hospital* or ward*
AND	Is used for searching for documents containing both words	Dementia AND "end of life" or "EoL" or "end-of-life" or terminal or "last day*" AND "acute setting*" or hospital* or ward*

2.3.3. Eligibility Criteria

Following the Centre for Research and Dissemination (CRD, 2009) guidelines and after completing a database search, the literature was searched. The data was initially screened based on the title and abstract. Then, full-text screening of potentially relevant articles occurred. The search was conducted on 18/11/2019 with inclusion/exclusion criteria applied (see Table 2-3).

A range of methods and study designs were explored to examine whether current EoLC interventions delivered in hospitals for people with dementia achieve their intended outcomes. The Critical-Appraisal-Skills- Programme (CASP) tools were utilised to assess and appraise the studies critically (CASP 2018).

Table 2-3 Inclusion and exclusion criteria.

Criterion	Inclusion	Exclusion
Participants	1. Patient with dementia 2. Family & close others of patients with dementia 3. Healthcare staff who work/worked with hospital inpatients with dementia	Patient with diseases other than dementia. 2. Family & close others of patients with diseases other than dementia. 3. Healthcare staff who never worked with hospital inpatients with dementia
Stage of the disease	End-of-life stage.	Early stages.
Setting	Hospitals and acute settings.	Homes or residential settings (e.g. care/nursing homes)
Publication	Academic Journals	
Ethics	Articles achieved ethical principles	Articles have not achieved ethical principles
Country of the study	Any country	None
Study design	Qualitative and qualitative studies	Editorials, commentaries, and letters.
Publication date	2009-2019	-Any date before 2009. -Any date after 2019.
Language of publication	English	Any language other than English

2.3.4. Literature Appraisal and Data Extraction

The methodology's evaluation by critical appraisal is an important process while conducting literature-based studies as it evaluates the trustworthiness and the value of a piece of research. Critical appraisal is a structured process of examining a piece of research by determining its strengths and limitations (Aveyard 2023). Fossey et al. (2002) discuss that the criteria used in evaluating the research need to walk side by side with the philosophy and the methodology of the research. This research uses the criteria of CASP appraisal tool for both qualitative and quantitative research to address the relevance of the included studies to the systematic review. CASP was initially developed by the Public Health Resource Unit in England in 2006. Likewise, the critical appraisal process for qualitative studies and mixed-method studies needs to address the same concerns, including the appropriateness of methods and analysis, credibility and relevance, or "generalisability." The reason for choosing the CASP tool was that it has individual checklists for different methodologies. I graded the screening questions numerically (0=No 1=Partly 2=Yes). A maximum score of 20 can be achieved for qualitative studies and reviews and 22 for quantitative (see Table 3-4).

Although the studies were critically appraised, the score achieved was not a condition to include or exclude the articles due to the limited number of the included articles. Data extraction is 'the process by which researchers obtain the necessary information about study characteristics and findings from the included studies' (CRD, 2009).

Data extraction must be developed and carried out systematically (Webb & Roe, 2007). I extracted data from the methodology, design, participants, sample information, interventions, and results. Then, two of the supervisors reviewed the data independently, and the reviewers reached an agreement.

Table 2-4 Summary of Selected Studies: Table of Included Articles and CASP Scores (Systematic review).

Authors	Country	Design	Aim	Intervention(s)	Sample	CASP Score	CASP Exceptions / Quality Notes
Afzal et al., 2010	Ireland	Retrospective clinical case note review	Examine the quality of EoLC for patients with & without dementia during final hospitalisation.	Cognitive status via MMSE; LCP Programme recommendations	75 notes (aged ≥65)	15	Retrospective design; lacks patient/family voice; uncertain causal direction
Campbell et al., 2011	USA	Quasi-experimental retrospective review	Assess impact of education-consultation on PEG tube use in EoLC dementia.	TRIP educational intervention	81 (71 control, 10 intervention)	11	Small intervention group; low statistical power; no qualitative insight
Chen et al., 2017	Taiwan	Case-control analysis	Compare EoLC between dementia and cancer patients.	Life-sustaining interventions	908 dementia vs. 1816	16	Quantitative only; lacks contextual detail or intervention outcomes

					cancer (NHI database)		
Durepos et al., 2019	Canada	Semi-structured interviews	Explore benefits of psychoeducation for dementia caregivers at EoL.	Psychoeducation programme	15 caregivers (10 regular attendees)	19	Small scale; caregiver-only perspective; subjective data
Ernecoff et al., 2018	USA	Computerised screening	Develop EHR phenotype to identify EoL dementia cases.	Electronic Health Record-based phenotype	Reviewed 604 records; 370 final	13	No intervention tested; screening validation unclear
Hanson et al., 2019	USA	Pilot RCT	Test dementia-specific EoLC triggered by hospitalisation.	Specialist EoLC + follow-up support	62 dyads (30 intervention, 32 control)	16	Pilot nature; low generalisability; limited power

O'Shea et al., 2015	Ireland	Retrospective cohort study	Evaluate antipsychotic use and EoLC assessments in dementia.	Multidisciplinary assessment	660 case notes (76 EoL cases)	15	Retrospective; lacks forward-looking planning analysis
Ouchi et al., 2014	USA	Mixed methods	Assess ED palliative consultations post-education intervention.	Educational intervention for ED physicians	18 people with dementia	13	Short-term; small sample; intervention poorly assessed
Sampson et al., 2011	UK	RCT + qualitative	Test ACP + EoLC consultation for advanced dementia.	ACP discussions + consultations	33 (22 intervention, 11 control)	14	Low recruitment; feasibility focus limits conclusions
St John and Koffman 2017	UK	Semi-structured interviews	Evaluate Namaste care in hospital for advanced dementia.	Namaste care programme	8 staff interviews	16	Very small sample; lacks direct patient/family feedback

2.3.5. Mixed-methods Systematic Review Synthesis

Synthesis is 'the product of activity where some sets or parts are combined or integrated into a whole. It involves some degree of conceptual innovation, or employment of concepts not found in the characteristics of the parts and a means of creating the whole' (Strike & Posner, 1983, p.346).

My goal in using the mixed methods approach to research is to draw from the strengths and minimise the weaknesses of the quantitative and qualitative research approaches (Johnson & Onwuegbuzie, 2004). The quantitative research methods approach and the qualitative methods are very interrelated, complementary, and compatible with the mixed methods approach. (Johnson & Onwuegbuzie, 2004, pp.14-26). In this research, there is an interest in both cases by integrating numerical data with people's experiences to enable designing an original research study that responds to both simple and complex questions. Therefore, this review utilised a mixed method systematic review of research to deal with the heterogeneity and diversity of research methods in the included articles and direct the results to future research and practice.

In this review, an integrated mixed methods analysis was chosen. In an integrated design, the studies in a targeted domain are grouped for synthesis not by methods but by findings that are viewed as answering the same question or addressing the same aspects (Sandelowski et al., 2006). Here, the findings addressing the same aspects of care or the same type of EoL were grouped and synthesised. By investigating both qualitative and quantitative viewpoints inside investigations, mixed method synthesis can improve practice significance and utility (Sandelowski et al. 2006). The differences between the studies included for this review were not significant enough to separate a qualitative and quantitative analysis (Sandelowski et al., 2006).

1. This systematic review uses Braun and Clarke's (2006) theme analysis to identify, analyse, and summarise qualitative data patterns.
Step 1: First, read and reread the data and write down my comments. Reviewing all qualitative and quantitative data to determine depth and breadth introduces mixed methods data.
Step 2: the review codes all intriguing data aspects into meaningful categories. This entails identifying and classifying study codes like text fragments or quantitative data

patterns that support or contradict qualitative conclusions.

Step 3: Collection of coded data into themes gathers all essential information. The goal is to find dataset-wide meaning patterns. This stage involves building themes from linked codes and comparing qualitative and quantitative outcomes.

Step 4: This thematic map compares themes to coded extracts and the complete dataset. This verifies themes match the data, check their coherence, distinctiveness, and appropriateness, and appropriately portray the dataset.

Step 5: Each theme is well-defined and named. This requires defining each theme's essence and relevance and writing titles that convey them.

2. For quantitative data, each study's results is used independently to quantify intervention efficacy using their own measures (e.g., mean).

3. Use Sandelowski et al. (2006) to compare qualitative and quantitative data on associated themes or treatments to synthesise them.

2.4. Results

2.4.1 Study Selection

A total of 1326 records were retrieved through initial database searches (Figure 2-1). A total of 197 records were excluded at stage 1 through duplication. A further 1076 records were excluded based on title/abstract screening as they did not focus on the interventions of EoLC for people with dementia in hospitals. The remaining 53 full-text papers were then assessed against the inclusion and exclusion criteria (Table 2-3), resulting in 43 papers being excluded. Finally, a total of 10 papers were selected for review (Figure 2-1).

2.4.2 Study Characteristics

A total of 10 studies were included: two qualitative, two mixed method designs, and six quantitative studies. Participants for the qualitative, quantitative studies, and mixed methods studies included hospital inpatients with dementia, records of people who died in hospitals and were diagnosed with EoL stage dementia, healthcare staff , bereaved family and close others of people with dementia, family and close others of current patients. All the studies were undertaken in acute hospitals in different countries. Four were conducted in the United States of America, two in the United Kingdom, two in Ireland, one in Canada, and one in Taiwan. All the included studies had descriptive elements that described EoLC's nature and the interventions for providing quality care for patients with dementia in hospitals. Most of the selected literature explored healthcare staff's perspectives about the interventions, or their interventions were applied to healthcare staff (40%). Three studies were conducted on patients' notes/records, and three had either family of the patients or both patients and their families as participants. The total number of people with dementia at their EoL stage reported in the studies included was 1120 patients. The majority of people with dementia were female in studies conducted in Ireland and the USA (61.6%), but it was not the case in Taiwan (42.6%); the mean age of participants varied between 77 and 85-year-old. See Figure 1 for a summary of the selection stages. The six papers which included quantitative studies (Afzal et al. 2010; Campbell et al. 2011; O'Shea et al. 2015; Chen et al. 2017; Ernecoff et al., 2018; Hanson et al. 2019) used the designs of retrospective clinical case note review, quasi-experimental comparison from chart review, case-control analysis, computerised screening method, RCT, and retrospective cohort study, respectively. The two qualitative studies used data collection methods of semi-structured interviews (St John & Koffman, 2017; Durepos et al., 2019). The other two studies used mixed methods (Sampson et al. 2011; Ouchi et al. 2014) and utilised questionnaire and thematic analysis, and RCT and structured conversations, respectively.

Following the data extraction procedure described above, thematic analysis following (Braun & Clarke, 2006) was used to synthesise the papers' final selection. Thematic synthesis of identified findings revealed four key themes.

As mentioned above, there was geographical variability in the findings. The studies included were conducted in five different countries. One study was located in Taiwan, an Asian country (Chen et al., 2017). The rest of the studies were located in different western countries in North America and Europe; two studies were applied in Ireland (Afzal et al. 2010; O'Shea et al., 2015), four in the USA (Campbell et al. 2011; Ouchi et al. 2014; Ernecoff et al. 2018; Hanson et al. 2019), two in the UK (Ouchi et al. 2014; St John and Koffman 2017), and one in Canada (Durepos et al. 2019). Different countries might have different contexts, cultures, and policies. These differences might lead to different understanding and recognising the EoL stage.

People with dementia can be found in different clinical locations in hospitals. For instance, Ouchi et al. (2014) intervention was conducted in the emergency department, Chen et al.'s (2017) study was conducted in intensive care units (ICUs), Afzal et al. (2010), O'Shea et al. (2015), St John and Koffman (2017) were applied in acute wards, and Durepos et al. (2019) was conducted in a specialised dementia ward. The variety of places and wards where patients can be found in the hospital and the process of moving patients between the wards was not discussed in the studies included, which indicates a lack of identifying the continuity of care for these patients while transferring between the different hospital settings.

2.4.3 Key Findings

Key themes are:
1. Identifying the EoL stage of dementia.
2. EoL assessments
3. EoLC planning and interventions.
4. Sustainability.

1. Identifying the EoL stage of dementia

This theme explores the identification of the EoL stage in people with dementia, highlighting the methods and challenges involved. Accurate identification is crucial for ensuring appropriate access to EoLC services and interventions, directly impacting the achievement of their intended outcomes.

While all the studies included patients at their EoL stage, they rarely discussed their inclusion criteria or how did the hospital identified them. Correct identification of the EoL stage of dementia facilitates access to the appropriate clinical EoLC services and interventions. Subsequently, acknowledging the Eol stage impacts the achievement of the outcomes of the Eol interventions.

Ernecoff et al. (2018) was the only study that developed an explicitly designed intervention (electronic health record) to identify patients with EoL stage dementia in hospitals. Hanson et al. (2019) used the tool developed by Ernecoff et al. (2018) to identify their participants.

Ernecoff et al. (2018) developed an electronic health record method and compared their results using patients' medical records. Their identification criteria were based on physician-verified late-stage dementia (ICD-9 and ICD-10 diagnosis codes). Starting with all 158 potential ICD-9 and ICD-10 diagnosis codes, they tested how much utility each had in identifying the first 82 patients with late-stage dementia who met eligibility criteria. The first iteration of the EHR method retrieved 604 patients (3/29/16 to 7/13/16), 124 of whom were sent to a palliative care physician, who confirmed that 82 had late-stage dementia. Manual screening of the daily census for two services with higher numbers of dementia cases took an average of 25 minutes per day. From a total of 541 admitted patients, this method identified 236 patients with dementia and 70 with late-stage dementia, yielding positive predictive values of 44% and 13%, respectively. By contrast, using the EHR method followed by more selective manual screening across all hospital services averaged 20 minutes per day. This approach screened 3174 admitted patients to identify 283 with dementia and 91 with late-stage dementia, yielding PPVs of 76.3% and 24.5%, respectively. These results suggest that the EHR method showed success in identifying the EoL stage of dementia compared to manual screening. This success suggests practical benefits, such as timely identification of patients who need EoLC. These results indicate that factors such as specific ICD-9 and ICD-10 diagnosis codes, and physician-verified late-stage dementia criteria, can help identify patients reaching EoL in advance. This early identification can ensure that appropriate EoLC interventions are initiated sooner, potentially improving patient outcomes and reducing unnecessary interventions. It is necessary to implement clear inclusion/exclusion criteria to accurately and efficiently find patients with dementia at their EoL stage for palliative care clinical trials (Ernecoff et al., 2018). All the studies included designed their interventions to target patients with dementia at their EoL stage. However, most of the included studies had no clear explanation of how they identified the EoL stage of dementia to ensure they included the correct participants. Only Hanson et al. (2019) presented clear criteria for identifying patients with dementia at their EoL stage. Their study depended on the EHR method designed by Ernecoff et al. (2018) to identify their sample.

According to Afzal et al. (2010) and O'Shea et al. (2015), the difficulty in predicting the prognosis and the uncertain disease trajectory associated with EoL dementia is a barrier to implementing an enhanced EoLC care approach of care and leads to inappropriate and unnecessary drug prescription and invasive and life-sustaining interventions. Three studies evaluated the prevalence of undertaking life-sustaining interventions for people with dementia in hospitals using a retrospective approach (Afzal et al. 2010; O'Shea et al. 2015; Chen et al. 2017). Using the retrospective approach to examine the data leaves the studies subject to potential observer bias in measuring exposures and interventions' outcomes, because the data was not originally collected with the current research question in mind, and the researchers' knowledge of the outcomes can inadvertently influence how they interpret the exposures or interventions.

O'Shea et al. (2015) evaluated the prevalence of prescribing antipsychotics and life-sustaining interventions. Their total sample consisted of 76 patients who documented receipt of EoLC. In all, 37% had antipsychotic drugs during their admission, and 71% of these received a new prescription in the hospital, most commonly for "agitation" instead of delirium. An inappropriate prescription of antipsychotic medication at EoL was suggested.

Afzal et al. (2010) found that a large majority of the patients received many aggressive life-sustaining interventions. For example, phlebotomy prevalence was 88.9%, arterial blood gases test was undertaken for 83.3%, and a nasogastric tube inserted for 33.3%.

Similar results were found by Chen et al. (2017). For instance, out of 907 patients with dementia at their EoL, tube feeding was undertaken for 67.4%. Mechanical ventilators and high-frequency oscillatory ventilation (HFOV) were inserted in 61.45%, and cardiopulmonary resuscitation (CPR) with defibrillation and temporary pacemaker occurred in 93% of the patients.

The findings from O'Shea et al. (2015), Afzal et al. (2010), and Chen et al. (2017) highlight the consequences of inadequate identification of the EoL stage in people with dementia. These studies underscore the prevalence of inappropriate and aggressive interventions due to the failure to recognise when patients are at their EoL stage. For instance, the high rates of antipsychotic prescriptions, phlebotomy, arterial blood gas tests, tube feeding, mechanical ventilation, and CPR reflect a lack of timely EoL identification. This lack of recognition leads to the continuation of unnecessary, invasive, and potentially harmful treatments instead of appropriate EoLC. The effective use of EHR, as indicated by Ernecoff et al. (2018), could help mitigate these issues by ensuring that patients are identified as being at the EoL stage earlier, allowing for more appropriate and compassionate care interventions.

Summary of the findings

- Lack of clear criteria for identifying EoL stage dementia in most of the included literature was found.
- EHRs were more effective than manual screening in identifying the EoL stage of dementia in a retrospective study. Despite limitations, these studies offer valuable insights for future research. The EHR method (Ernecoff et al., 2018) provided clear inclusion criteria in a clinical trial (Hanson et al., 2019).
- Lack of recognition of EoL stage of dementia might lead to continuation of unnecessary and inappropriate interventions as a consequence (e.g., life-sustaining interventions and inappropriate antipsychotic interventions).

2. End-of-Life assessments

Symptom and needs assessments are critical in diagnosing and providing the appropriate interventions for a patient at their EoL. To provide enhanced EoLC for people with dementia and their families, it is crucial to assess these patients appropriately to enable healthcare staff to provide quality personalised EoLC.

Two articles discussed the prevalence of different EoL assessments (Afzal et al., 2010; O'Shea et al., 2015). One study presented those assessments' results to plan for the patients' care (Sampson et al., 2011).

The intervention developed by Sampson et al. (2010) was multicomponent, involving EoL assessment results and advanced care planning (ACP) consultations. Findings from patients' assessments indicated that 95% of the patients experienced mild to moderate pain levels, and communication was diminished in all patients. Other symptoms, such as lack of mobility, development of pressure sores, need for feeding assistance, and poor dietary intake, deteriorated for most patients. Therefore, according to Sampson et al. (2011), this assessment generated a list of individual-specific issues and needs, which were then discussed with the clinical team to tailor the care plan accordingly. A management plan was formulated and documented in the clinical notes. Findings were used to inform subsequent discussions with the carer and plan appropriately for the care, indicating their understanding of the importance of EoL assessments to provide the patients with dementia at their EoL and their families with good planning.

Many assessments required for dementia EoLC were not conducted at the EoL stage, indicating gaps in essential interventions. Afzal et al. (2010) and O'Shea et al. (2015) highlighted deficiencies in key assessments, such as cognitive, pain, delirium, and mood assessments, during patients' last admissions. For example, cognitive assessment was absent in 33% of the case-notes reviewed (Afzal et al., 2010; O'Shea et al., 2015), and only 54% of patients received cognitive assessments at their last admission (Afzal et al., 2010). Furthermore, 27% of patients did not undergo pain assessment, 68% lacked delirium screening, and 97% were not evaluated for mood or behavioural and psychological symptoms (O'Shea et al., 2015). However, spiritual needs were assessed and addressed for all patients in the studies conducted by Afzal et al. (2010) and Sampson et al. (2011). These findings underscore the need for comprehensive assessments as integral interventions for people with dementia at the EoL stage.

Findings Summary

- Enhanced EoL assessment is essential for developing tailored EoLC that prioritise individual needs. However, inadequate symptom assessment and failure to address individual health needs often impede the delivery of quality care during the EoL stage.
- Evidence suggests that poor EoL assessments were undertaken for people with dementia at their EoL stage.
- The spiritual and religious needs assessment was undertaken in two studies (Afzal et al., 2010; Sampson et al., 2011), and no unmet spiritual needs were identified.

3. EoLC Interventions

This theme presents the EoLC approaches developed and provided for people with dementia and their families at the EoL stage. It explores whether these interventions worked or not and their overall quality, based on how outcomes were measured.

Six studies evaluated four different EoLC interventions (Sampson et al., 2010; Campbell et al., 2011; Ouchi et al., 2014; St Johns & Koffman, 2017; Hanson et al., 2019; Durepos et al., 2019). Five of these studies included an educational component aimed at promoting decision-making through planning and EoLC consultations. Two studies targeted patient–family dyads (Sampson et al., 2010; Hanson et al., 2019), two targeted healthcare staff (Campbell et al., 2011; Ouchi et al., 2014), and one targeted both healthcare staff and family members or close others (Durepos et al., 2019). One intervention employed a different approach involving a multisensory stimulation technique (Namaste care) (St Johns & Koffman, 2017).

All interventions were applied to small samples, ranging from eight participants (St Johns & Koffman, 2017) to eighty-one (Campbell et al., 2011). This small scale may have negatively influenced the certainty of the interventions' outcomes.

3.a. Multicomponent Interventions

Three multicomponent intervention studies implemented more holistic approaches to EoLC, with education being a shared element (Sampson et al., 2010; Hanson et al., 2019; Durepos et al., 2019). These interventions promoted involvement of people with dementia and their families in decision-making and planning, suggesting that the interventions were patient–family-centred and relationship-focused. Each considered physical, psychological, and spiritual aspects of dementia-specific care.

Durepos et al. (2019) aimed to prepare families for the patient’s death by educating them on signs of decline and assessing their psychological readiness. This psychoeducation programme, delivered by two experienced social workers in a specialised dementia care unit, appeared to improve the emotional wellbeing and preparedness of caregivers, which likely translated into better support and care for the patients.

They evaluated the programme through thematic analysis of perceived benefits and challenges. Benefits reported by caregivers included: (i) enhanced emotional wellbeing, (ii) greater preparedness for the EoL stage, and (iii) personal growth through mutual support. At the organisational level, the programme was seen as enhancing relationship-centred care and resource availability. However, challenges included scheduling conflicts, variation in caregiver engagement, and limited staff involvement.

The programme had been in place for 18 months prior to the study and ran weekly for 1.5 hours. Facilitated by experienced programme leaders, sessions used social group work methods with a focus on education and mutual aid. Content included decision-making, medications, and brain function. Ten of fifteen caregivers attended sessions regularly.

Hanson et al. (2019) implemented a dementia-specific EoLC consultation during hospitalisation, followed by transitional care through phone calls. Structured consultations were provided by board-certified EoLC specialists, addressing dementia progression, symptom management, caregiver stress, spiritual and cultural needs, and care goals. Families received a booklet and personalised recommendations, including ACP and follow-up calls post-discharge.

The study measured primary outcomes based on hospital or emergency department visits within 60 days, with secondary outcomes such as patient comfort, family distress, and access to community-based EoLC. Although short-term reductions in ED visits were not observed, the intervention facilitated improved planning and communication, which likely contributed to more appropriate and compassionate EoLC decisions over time.

Sampson et al. (2010) developed a two-part intervention that included EoL assessments and ACP discussions. Thirty-three dyads participated (22 intervention; 11 control). Although only seven carers completed an ACP, the process was well received. Support was provided for six months by an experienced nurse. Reasons for low engagement with ACP were not explored, highlighting an area for future inquiry.

All three interventions shared use of various educational tools and flexible settings. Sampson et al. (2010) used public information sheets and in-person consultations, initially in the hospital and then in the community. Similarly, Hanson et al. (2019) combined in-hospital and phone consultations. Durepos et al. (2019) offered the most diverse educational approach, including printed materials, group discussions, and expert-led sessions. These elements likely enhanced participants’ perceptions of whether the interventions worked or not.

Only Durepos et al. (2019) continued supporting bereaved families. Both Sampson et al. (2010) and Hanson et al. (2019) ended support after the patient’s death. The two randomised controlled trials (RCTs) had similar patient demographics.

Summary of the findings:

- The multicomponent interventions were holistic (considered physical, psychological, and spiritual aspects of care), patient, and family-centred.
- Utilising multi-education tools and an appropriate educational environment seemed to enhance the interventions' outcomes and certainty.
- Targeting different groups of participants (e.g., patient and family or family and healthcare staff) might be a factor that increased the clarity and certainty (as the results are certain whether they are achieving their outcomes or not) of the interventions.
- Supportive interventions for the bereaved family and close others were rarely identified in the literature.

3.b. Healthcare staff only oriented interventions

Unlike the multicomponent interventions that engaged both the person with dementia and their family, the interventions evaluated by Campbell et al. (2011) and Ouchi et al. (2014) were exclusively educational and focused on decision-making processes to support EoLC consultations delivered by healthcare staff. These educational studies were short-term in nature (see sustainability section), each comprising only one or two sessions.

Campbell et al. (2011) provided education to attending physicians about the lack of benefit associated with percutaneous endoscopic gastrostomy (PEG) for people with dementia at the EoL stage. Meanwhile, Ouchi et al. (2014) delivered an educational session about initiating EoLC consultations from the emergency department , which was delivered during monthly faculty meetings. Neither study reported providing a suitable or quiet environment for the sessions, nor did they offer appropriate timing.

Additionally, both relied solely on verbal teaching without the inclusion of printed, evidence-based educational materials. These limitations likely contributed to reduced impact in terms of whether the interventions worked or not. The absence of varied educational tools and appropriate delivery settings limited the knowledge transfer potential in both cases.

Campbell et al. (2011) designed an intervention to discourage the recommendation of PEG tubes for people with dementia at the EoL stage. The intervention group (n=10) received targeted consultations from educated physicians, and the control group (n=71) received usual care. Although none of the patients in the intervention group had PEG tubes placed, compared to four in the control group, this difference was not statistically significant (p=0.44). This rendered the outcomes of the intervention uncertain, especially due to the small size of the intervention group. Furthermore, the study did not explore influencing factors such as family beliefs, cultural considerations, or clinicians' prior attitudes toward PEG use.

Ouchi et al. (2014) assessed the rate of EoLC consultation initiation in the ED following an educational session for ED physicians. Of the 51 patients assessed, only 18 received EoLC consultations during their ED visit or subsequent hospital stay. Of these, only four consultations were initiated in the ED. This indicates that the educational intervention did not lead to a noticeable increase in consultation rates. Physicians' pre-existing beliefs, attitudes, and knowledge were cited as barriers to initiating EoLC discussions.

Regarding the involvement of multidisciplinary teams, Campbell et al. (2011) included EoLC consultants, dietitians, speech and language therapists, gastroenterologists, and surgeons. However, due to the limited scale and statistical insignificance of the outcomes, it is unclear whether this multidisciplinary involvement contributed to the intervention's outcome. In contrast, Durepos et al. (2019) involved nurses in various roles, and their intervention was perceived to have both benefits and challenges. Ouchi et al. (2014), on the other hand, targeted only ED physicians, and their intervention did not appear to work as intended. Consequently, a firm conclusion about the relationship between multidisciplinary involvement and intervention outcomes cannot be drawn from the current evidence.

Summary of the Findings:

- Educational interventions that targeted only healthcare staff did not appear to work or had uncertain outcomes (i.e., the difference between the intervention and control group was not significant).
- Inadequate educational settings and the absence of multiple educational tools may have hindered whether these interventions worked or not.
- Interventions targeting only one group (e.g. healthcare staff) may result in limited outcomes, whereas involving family and/or people with dementia may enhance intervention clarity and outcomes.
- Small sample sizes further contributed to the uncertainty of findings, possibly due to challenges in timely EoL identification.
- The role of multidisciplinary healthcare staff in shaping the outcome of EoLC interventions remains unclear due to varying study results.
- Initiating EoLC interventions immediately upon hospital admission was attempted in one study only. However, as the intervention did not work as intended, the value of early initiation remains inconclusive

3.c. Multisensory intervention

Namaste care, as explored by St. John and Koffman (2017), was the only intervention in this review that did not focus on supporting decision-making processes. Namaste care is a multisensory programme specifically developed for people with advanced dementia at the EoL stage. It aims to support those who are socially withdrawn, unable to participate in group activities, severely cognitively impaired, predominantly non-verbal, and entirely dependent on others for daily care. The programme integrates meaningful activity and sensory stimulation, such as massage, aromatherapy, touch, music, colour, tastes, and scents, with nursing care, person-centred practices, and reminiscence. Additionally, the intervention supports carers by offering education and extending emotional support to family members and loved ones.

St. John and Koffman (2017) conducted a pilot study to assess whether Namaste care was appropriate for use in acute hospital wards for people with advanced dementia. Semi-structured interviews were conducted with eight members of the multidisciplinary healthcare team, and the data were analysed using a framework approach. The study identified two overarching themes: (1) the difficulty of establishing relationships with patients with dementia in hospital settings, and (2) the potential benefits of Namaste care in this context. Subthemes under the first theme included time pressures, resource limitations, and staff anxiety or lack of confidence. Subthemes under the second theme included observed reductions in agitation, enhanced communication through sensory engagement, and demonstrations of value and care toward patients.

Namaste care was perceived as supporting symptom control in areas such as distress, agitation, communication, and psychological wellbeing. However, the intervention's outcomes were not measured in a comprehensive way. The study did not explore its impact on physical health or symptom relief more broadly. Moreover, challenges posed by the acute hospital setting, particularly a lack of time and resources, were seen to hinder the intervention’s delivery. These limitations made it difficult to fully assess whether the intervention worked or not in this context.

Summary of the findings:

- Although Namaste care was perceived as beneficial, its outcomes could not be properly assessed within the acute hospital setting.
- Challenges such as poor staff–patient relationships, resource constraints, and time limitations affected its delivery.
- The intervention supported symptom control in areas like agitation, communication, and psychological care, but did not assess outcomes related to physical wellbeing.

4. Sustainability and longevity of interventions:

The outcomes of an EoLC intervention can be evaluated across different timeframes, short-term, medium-term, and long-term. For this reason, it is important to clearly justify the point at which an outcome is assessed, whether during or after the completion of the intervention. A sustainable intervention goes beyond measuring immediate outcomes and includes long-term assessments (e.g. measuring whether participants continue to benefit after an educational programme has ended). In this review, sustainability refers to outcomes related to healthcare staff and managers’ ability to deliver compassionate and dignified EoLC, and/or whether people with dementia and their families receive appropriate support and comfort at the EoL stage.

Most of the studies measured outcomes either during the intervention or immediately afterward (Sampson et al., 2010; Campbell et al., 2011; Ouchi et al., 2014; Hanson et al., 2019). Only Durepos et al. (2019) planned to evaluate outcomes beyond the immediate post-intervention period. As a result, the long-term sustainability of these interventions remains largely unclear.

The shortest interventions were seen in Campbell et al. (2011) and Ouchi et al. (2014), who each provided brief, time-limited educational sessions. In Campbell et al. (2011), education was delivered during a consultation and outcomes were measured immediately following PEG tube discussions. Ouchi et al. (2014) conducted two one-hour meetings and evaluated outcomes immediately after delivery. No long-term follow-up was undertaken in either case. The absence of longer-term evaluation limits our ability to determine whether these interventions led to sustained behavioural or cultural change. It is possible that staff were not given enough time or support to adjust their practices, which could explain why the interventions did not work as intended.

In the case of Namaste care, St. John and Koffman (2017) conducted one-hour group sessions and 20–30-minute one-to-one sessions per patient, per week. However, the study did not clearly specify when outcomes were assessed or whether the intervention was ongoing or completed at the time of data collection. As a result, no firm conclusions can be drawn regarding whether the intervention’s duration or assessment timing influenced its outcomes.

By contrast, Durepos et al. (2017) implemented a psychoeducation programme that had been running for 18 months prior to evaluation. It involved weekly 1.5-hour onsite sessions for caregivers and healthcare professionals. Importantly, this study clearly identified multiple time points for outcome measurement: short-term (learning outcomes), medium-term (action outcomes), and long-term (condition outcomes, to be evaluated in the future). This approach reflected a more rigorous attempt to assess the sustainability of the intervention over time.

However, the study still had limitations. It did not fully explain how the outcomes were measured, such as how knowledge retention or changes in caregiving behaviour were evaluated. The study focused primarily on caregivers’ perceptions and did not include observational tools or independent assessments of patient outcomes such as comfort, distress, or agitation. Including such measures would have provided a more objective evaluation of whether the intervention worked over time. Furthermore, incorporating direct feedback from patients (or proxies where appropriate) would have helped ensure a more complete picture of intervention outcomes.

Summary of the findings:

- Interventions were typically assessed during or immediately after implementation, making it difficult to judge their long-term impact.
- Whether an intervention works or not may be closely tied to its duration and when outcomes are measured.
- Few studies included long-term follow-up or explained why specific evaluation time points were chosen.
- Only Durepos et al. (2019) planned long-term assessment, indicating a more sustainable approach.
- Other studies lacked clarity on how and when outcomes were measured, and failed to use objective measures such as observational tools or proxy assessments.

2.5 Discussion

This comprehensive review provides an overview of interventions designed to improve care for people with dementia at their EoL stage in hospitals and acute settings worldwide. The focus of this review is on identifying the EoL stage of dementia, assessing EoL needs, and implementing EoLC interventions. In this context, EoLC interventions refer to measures aimed at relieving symptoms and distress associated with a serious illness, with the aim of enhancing the quality of life for both the patient and their family. The review highlights several core areas and concerns related to these interventions, specifically, whether they work or not, their quality, and their sustainability, and how these factors influence the standard of care provided to people with dementia nearing the end of life.

The limited number of studies included reflects a lack of research evaluating EoLC interventions for people with dementia in hospitals. Most of the included studies were conducted in North America and two European countries (the UK and Ireland), with one study emerging from East Asia (Taiwan). However, the transferability of such interventions across international contexts must be considered with caution, as the success or limitations of an intervention are often contingent on specific contextual factors (Tennant, 2012). For example, significant cultural and structural differences exist between Western and Asian health systems. In Japan, physicians tend to favour aggressive life-sustaining treatments, whereas their Western counterparts more commonly opt to withdraw such interventions and initiate EoLC approaches (Yaguchi et al., 2005). Furthermore, in several Asian societies, including Japan, China, and Indonesia, dementia is not consistently perceived as a terminal illness, and life preservation is often prioritised (Yaguchi et al., 2005).

EoLC was delivered to people with dementia across a variety of hospital settings, including emergency departments, intensive care units, acute medical wards, and dementia-specialist wards. This variation in care environments may suggest an attempt to provide continuity of care within the hospital. However, such an assumption remains unsubstantiated, as the literature included in this review did not examine whether care across these settings was integrated or coordinated in a manner that benefited patients.

None of the studies explored how differences between care settings might influence the quality or outcomes of EoLC interventions. Important factors, such as the ward’s speciality, interdepartmental culture, or the degree of cooperation between medical teams, could significantly shape patient experiences but were not addressed in the current evidence base. Cornwell et al. (2012) reported that older patients with complex health conditions often experience fragmented care in hospitals, a concern highly relevant to people with dementia at the EoL stage who tend to have longer admissions and complex, evolving needs. Tadd et al. (2011) similarly noted that some wards deliver unacceptably poor standards of care for older patients, highlighting the importance of understanding contextual factors that may affect the success or failure of EoLC interventions.

A range of structural and organisational barriers to continuity of care were noted in the broader literature, although these were not explored in the studies included in this review. For instance, Cornwell et al. (2012) identified that obstacles such as high staff workload, rigid institutional routines, cultural differences across care teams, and varying staff competencies can significantly affect the continuity of care. Moreover, the engagement of senior staff and healthcare board members with frontline teams, patients, and carers plays a pivotal role in improving care experiences. Yet, this review found that the continuity of care for terminally ill people with dementia in hospital settings was not explicitly addressed, indicating a key gap in the evidence base.

Another core issue highlighted in this review is the limited clarity in identifying the EoL stage for people with dementia. Most studies did not offer specific or standardised criteria for determining when a patient had entered this phase. Only one study, by Ernecoff et al. (2018), developed a method using electronic health records to support the identification of the EoL stage in dementia. This intervention was also employed in Hanson et al.'s (2019) study to help determine eligibility for an EoLC programme. The use of EHR allowed for earlier and more accurate identification of patients entering the final stages of dementia compared to traditional manual screening. When applied within a clinical trial, this approach enabled the timely inclusion of participants and provided clarity in planning care, which suggests that tools for identifying the EoL stage may support the provision of more appropriate EoLC interventions.

In clinical practice, the implications of these findings point to the need for consistent and reliable tools that enable earlier identification of the EoL stage in people with dementia. I suggest that implementing standardised assessment frameworks, such as the EHR-based model developed by Ernecoff et al. (2018), can help clinicians recognise when a person with dementia is approaching the EoL. This would facilitate timely discussions about care preferences and ensure that people with dementia, their families, and care teams have adequate time to plan for EoLC.

However, despite the potential of such tools, the studies included in this review did not offer sufficient detail about the indicators used to signal the EoL stage. The unpredictable and often extended progression of dementia makes it difficult to forecast when someone is entering the final stages. Unlike cancer, where prognosis may be clearer, the fluctuating trajectory of dementia means that patients can live with severe impairment for prolonged periods, complicating decisions around when to initiate EoLC. I believe that early recognition remains essential to achieving better outcomes for both patients and their carers. This can be accomplished through repeated assessments, staff education, and clear communication with families throughout the care journey.

2.6. Limitations

Ultimately, this review is limited by the small number of studies published within this field to draw conclusions. This review included international studies exploring the interventions providing EoLC for people with dementia. This means that potential contextual, cultural, and structural differences between these countries might affect the interventions' outcomes. However, when conducting this review, no systematic review reported the interventions designed to improve EoLC for people with dementia in a hospital context existed. Thus, this review reported the effectiveness of the existing interventions and provided an understanding of the gap between the current and needed EoLC.

2.7. Conclusion and Chapter Summary

At the time of conducting this review, a limited number of intervention studies were oriented towards people with dementia at their EoL stage in the hospital context. Moreover, there was no comprehensive overview exploring their outcomes. This review found that some of the current interventions proved or perceived to be beneficial by the participants in the included studies in providing quality EoLC. However, they also had challenges and were suboptimal or perceived as suboptimal, although many actual or perceived benefits were reported. Therefore, there was a clear need to understand the factors that enhance or inhibit quality EoL care interventions. A CRR was chosen as it is able to identify and evaluate key process information, enabling it to explain outcomes

(Pawson et al., 2005; Wong et al., 2013). The following chapter details the reasons behind this choice in more depth and presents a CRR of interventions designed to improve EoL care for people with dementia in hospitals.

Chapter 3 Critical Realist Review

3.1. Introduction

This chapter presents a Critical Realist Evaluation (CRE) of interventions designed to improve EoLC for hospital inpatients with dementia. Following the systematic review presented in Chapter 2, this chapter aims to explore why and how certain interventions achieve their outcomes, moving beyond identifying what outcomes were observed.

The systematic mixed-methods review in Chapter 2 provided an overview of intervention outcomes and captured stakeholder experiences. While valuable for identifying interventions, their outcomes and understanding participant perspectives, it did not examine the underlying causal mechanisms or contextual influences that explain why specific interventions succeeded or failed.

To date, there is no comprehensive review specifically applying CRE to explore these underlying factors influencing EoLC interventions for people with dementia in hospitals. This chapter addresses this gap by employing a critical realist lens, examining not only intervention components but also the experiences and responses of individuals involved, healthcare professionals, patients, and families, and the contexts within which interventions were implemented.

A CRR investigates mechanisms driving outcomes within complex systems, examining their interaction with contextual factors. This method suits the multifaceted nature of EoLC for dementia, where healthcare staff attitudes, organisational culture, resource availability, and patient and family preferences significantly influence interventions' outcomes.

3.1.1 Justification for Dual Reviews

In this thesis, I conducted both a mixed-methods systematic review (Chapter 2) and a CRR (Chapter 3) to generate complementary insights into interventions aimed at improving EoLC for people with dementia in hospital settings. While the systematic review focused on mapping intervention types, reported outcomes, and stakeholder experiences, the critical CRR extended this by examining how and why these outcomes were produced through the activation of specific mechanisms within particular contexts and in relation to the agency of staff, patients, and families.

This dual-review approach is not a generic methodological choice but is rooted in the logic of CRE. A systematic review identifies what outcomes have been achieved, whereas a CRR explores the generative mechanisms and contextual conditions that produce these outcomes. CRE places emphasis on causation that is non-linear, emergent, and context-dependent, features particularly relevant to EoLC in hospitals, which involves complex clinical, ethical, and interpersonal dynamics (Porter, 2015; Bhaskar, 2008). The systematic review sits within the CRE model by providing a foundation of outcome-based evidence, while the CRR interrogates these patterns to understand why some interventions succeed or fail in different settings.

This approach also addresses known limitations of realist evaluations. A common critique is that realist reviews tend to privilege processes over measurable outcomes, thereby weakening claims of impact (Marchal et al., 2012). Integrating a systematic review strengthens the empirical basis of this thesis, while the CRR ensures that analysis remains theoretically informed and sensitive to the layered realities of hospital care (Pawson et al., 2004; Wong et al., 2013).

Together, these two reviews provide both breadth and depth: the systematic review identified and synthesised existing evidence on EoLC interventions and their outcomes, while the CRR deepened this understanding by theorising how interventions work (or fail to work) in relation to contextual mechanisms and human agency. This integration has shaped the design of the next stages of this study, informing the development of the interview and focus group topic guides and contributing directly to the formulation of programme theories to guide future interventions.

3.2. Critical Realist Reviews

Underpinned by Critical realist methodology, this review is a CRR following the guidelines for conducting a systematic literature review which are explained in detail in Chapter Two (see section 2.2). CRR is a literature-based on methodological approach to critical analysis of health care studies (or any discipline charged with social interventions) that is robust, insightful and essential for the complexities of twenty-first-century evidence-based health and social care.

CRRs produce original conceptual developments beyond those expected in a traditional systematic review (Grant & Booth, 2009). They provide an opportunity to evaluate what is valuable from the previous literature on the topic of interest (Edgley et al., 2016). A CRR can become a primary source of data. This is because it brings literature on the topic of interest and critically synthesises its concepts to build a theory (Edgley et al., 2016).

The systematic CRR methodology was chosen to achieve the aim of this review, to evaluate the factors affecting the effectiveness of the interventions designed to improve EoLC for people with dementia in hospitals. The critical realist methodology is designed to capture how and why context, mechanisms, and stakeholders' experiences may influence outcomes. Using CRE to evaluate these areas increases the proposed interventions' transferability, feasibility, and procedural recommendations. Originally, Pawson and Tilley (1997) formula Context + Mechanism = Outcome (C + M = O) is used in realist evaluation. Porter (2015) argued that Pawson and Tilley (1997) included human agency in the social mechanism, which must be distinguished clearly. Porter revised the evaluation formula to take the form of Contextual Mechanisms + Intervention Mechanisms + Agency = Outcome (CM + IM + A = O).

From the discussion above, I adopt a critical realist approach using Porter (2015) model to identify intervention and contextual mechanisms, actors' interpretations and experiences (human agency), and how these affect outcomes. This help form the basis of developing theories. This approach can be summarised in the formula of "Intervention Mechanisms + Internal Contextual Mechanisms + External Contextual Mechanisms + Agency =Outcome (IM + ICM + ECM + A = O). Indicating that the evaluative process should involve the generation and testing of hypotheses about the mechanisms embedded in the extant social and organisational context (Internal Contextual Mechanism), or beyond the extant context of the organisation but still affecting it (External Contextual Mechanism); a similar process to identify the mechanisms embedded in the intervention designed to countervail against what are identified as problem mechanisms in the social context (Internal Contextual Mechanism), and an examination of how agents interpret and respond to these mechanisms (Agency)". The researcher's focus on outcomes (Outcome) should move beyond the enumeration and explanation of changes in rates and also examine the consequences of interventions for the lives of those affected by them." (Porter 2015).

3.3 The Review

3.3.1 Review Aim

The aim of this review is to describe and explain the effectiveness of interventions designed to support EoLC for people with dementia in hospitals within the global context.

Main objectives

1. To identify mechanisms which operate in interventions to support EoL care for in-hospital people with dementia (Intervention mechanisms) in the literature.
2. To identify the influence of the hospital context on the interventions (contextual mechanisms)
3. To identify stakeholders' responses towards the interventions in the hospital context (Human agency).
4. To identify the outcomes of the interventions.

3.3.2 Search Process

Data were collected from the following electronic databases; CINAHL, MEDLINE, SocIndex, PsychInfo, and Scopus (see Table 3-1). The search strategy used in this critical review was the same of the one used in the systematic review with a few differences regarding the time limit of the search, as well as the aim and methods and methodology used.

Table 3-1 Search strategy.

Database	Search Strategy	Number of records
Scopus	Dementia AND	982

	"end of life" or "EoL" or "end-of-life" or terminal or "last day*" AND "acute setting*" or hospital* or ward*	
PsychInfo	Dementia AND "end of life" or "EoL" or "end-of-life" or terminal or "last day*" AND "acute setting*" or hospital* or ward*	995
CINAHL	(((dementia or Alzheimer) OR (MH "Dementia+”)) AND (("end of life" or "EoL" or "end-of-life" or terminal or "last day*”) OR (MH "Terminal Care+)) AND (("acute setting*" or hospital* or ward*) OR (MH "Hospitals+")))	795
MEDLINE	(((dementia or Alzheimer) OR (MH "Dementia+”)) AND (("end of life" or "EoL" or "end-of-life" or terminal or "last day*”) OR (MH "Terminal Care+)) AND (("acute setting*" or hospital* or ward*) OR (MH "Hospitals+")))	2465
SocIndex		148

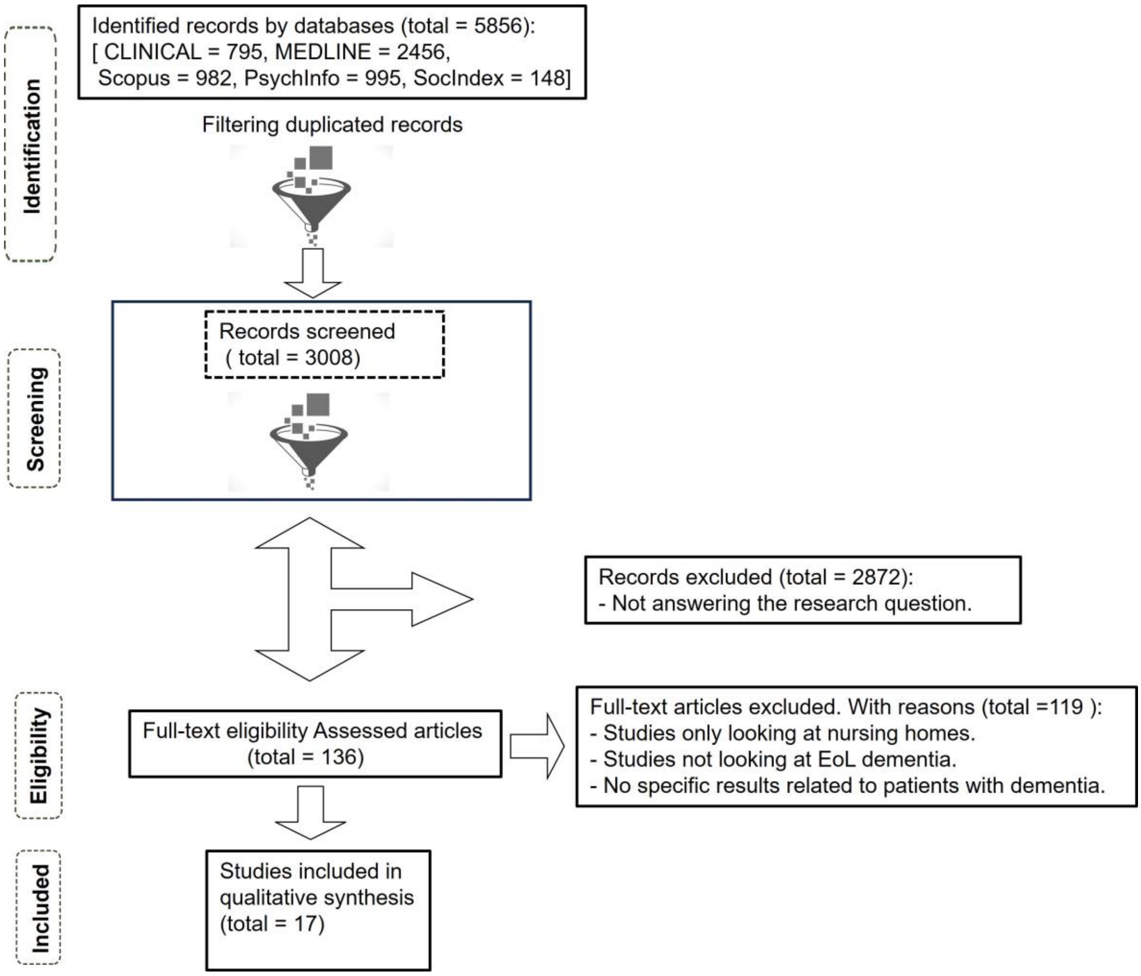


Figure 3-1 PRISMA 2009 Flow Diagram.

Boolean operators

In this review, Boolean operators have been utilised in the search process, especially And and Or. For example, when using the electronic databases for dementia And (palliative Or end-of-life care) was searched for (see Table 3-2).

Table 3-2 Boolean operators.

Boolean	Definition	Use in the research process
OR	It is used for searching for documents containing either of the words.	Dementia or Alzheimer's "end of life" or "EoL" or "end-of-life" or terminal or "last day*."

		"acute setting*" or hospital* or ward*
AND	Is used for searching for documents containing both words.	Dementia AND "end of life" or "EoL" or "end-of-life" or terminal or "last day*" AND "acute setting*" or hospital* or ward*

3.3.3 Eligibility Criteria

Following CRD (2009) guidelines and after completing databases search, the literature was searched, followed by an initial screening of the data based on the title and abstract. Then, full text screening of potentially relevant articles occurred. The search was conducted on 30/07/2021 with inclusion/exclusion criteria applied (see Table 3-3). A range of methods and study types were explored to review the effectiveness of current EoL care interventions delivered in hospitals for people with dementia.

The Critical-Appraisal-Skills- Programme (CASP) tools were utilised to assess and appraise the studies (CASP 2018) critically.

Table 3-3 Inclusion and exclusion criteria.

	Inclusion	Exclusion
Participants	1. Patient with dementia 2. Family & close others of patients with dementia 3. Healthcare staff who work/worked with hospital inpatients with dementia	Patient with diseases other than dementia. 2. Family & close others of patients with diseases other than dementia. 3. Healthcare staff who never worked with hospital inpatients with dementia

Stage of the disease	End-of-life stage or Advanced stage	Early stages.
Setting	Hospitals and acute settings.	Homes or residential settings (e.g. care/nursing homes)
Publication	Academic Journals	
Ethics	Articles achieved ethical principles	Articles have not achieved ethical principles
Country of the study	Any country	None
Study design	Qualitative and qualitative studies	Editorials, commentaries, and letters.
Publication date	Any date prior to August 2021	Any date after July 2021
Language of publication	English	Any language other than English

3.3.4. Literature Appraisal and Data Extraction

The methodology's evaluation by critical appraisal is an important process while conducting literature-based studies as it evaluates the trustworthiness and the value of a piece of research. Critical appraisal is a structured process of examining a piece of research by determining its strengths and limitations (Aveyard, 2023). Fossey et al. (2002) discuss that the criteria used in evaluating the research need to walk side by side with the philosophy and the methodology of the research. This research uses the criteria of the Critical Appraisal Skills Programme (henceforth CASP) appraisal tool for both qualitative and quantitative research to address the relevance of the included studies to the systematic review. CASP was initially developed by the Public Health Resource Unit in England in 2006. Likewise, the critical appraisal process for qualitative studies and mixed-method studies needs to address the same concerns, including the appropriateness of methods and analysis, credibility, and relevance, or "generalisability." The reason for choosing the CASP tool was that it has individual checklists for different methodologies. I graded the screening questions numerically (similar to chapter two) (see Table 3-4).

Although the studies were critically appraised, the score achieved was not a condition to include or exclude the articles due to the limited number of the included articles.

Data extraction is 'the process by which researchers obtain the necessary information about study characteristics and findings from the included studies' (CRD, 2009).

Data extraction must be developed and carried out systematically (Webb & Roe, 2007).

I extracted data from the methodology, design, participants, sample information, interventions, and results. Then, two of the supervisors reviewed the data independently, and the reviewers reached an agreement.

Table 3-4 Summary of Selected Studies: Table of included Articles and CASP Scores (Critical Realist Review).

Authors	Country of Origin	Design	Aim	Intervention(s)	Sample	Quality	Exceptions to CASP
Afzal et al., 2010	Ireland	Retrospective clinical case note review	To examine the quality of EoL care for patients with & without dementia during their final hospitalisation.	-Cognitive status using MMSE score -measuring frequency of Invasive procedures after (Morrison et. al.) -LCP Programme recommendations to examine quality EoL	75 multidisciplinary clinical notes of patients aged >=65 in acute wards within 6 months period in a general hospital	15	Retrospective design with limited information on intervention implementation
Campbell et al., 2011	USA	Quasi-experimental comparison	To determine the impact of multidisciplinary	Translation of Research into Practice (TRIP) to	Advanced dementia with no PEG at	11	Small intervention group size limiting statistical power

		from retrospective chart review	education-consultation intervention in reducing percutaneous endoscopic gastrostomy (PEG) tube placement in patients with EoL dementia in urban hospital.	reduce PEG tube placement (educational intervention).	admission were 81 patients; 71 patients had no intervention while 10 patients received the intervention.		
Chen et al., 2017	Taiwan	Case-control analysis	Compare EoL care patterns between people with dementia and patients with cancer.	Life sustaining interventions.	Data of 908 people with dementia compared to 1816 patients with cancer from	16	Secondary database limiting control over data accuracy

					NHI Taiwan database		
Durepos et al., 2019	Canada	Semi-structured interviews	Explore perceived benefits of psychoeducation programme for caregivers of people with dementia at EoL.	Psychoeducation programme for caregivers	15 caregivers attended the programme, 10 regularly.	19	Limited generalisability due to small and selective sample
Ernecoff et al., 2018	USA	Computerised screening method	Develop EHR method to identify people with dementia at EoL for clinical trial enrolment.	Electronic Health Record Phenotype	604 patients initially reviewed, final refinement 370 records.	13	Computerised identification prone to coding errors

Hanson et al., 2019	USA	Pilot RCT	Test dementia-specific palliative care triggered by hospitalisation.	Dementia-specific specialty palliative care	62 patient-decision-maker dyads, 30 intervention, 32 control.	16	Small pilot sample limiting generalisability
O'Shea et al., 2015	Ireland	Retrospective cohort study	Evaluate antipsychotic prescribing and multidisciplinary assessment at EoL dementia admissions.	Multidisciplinary assessment	660 case notes reviewed, 76 were EoL dementia.	15	Retrospective analysis limiting control over clinical variables
Ouchi et al., 2014	USA	Mixed methods	Assess ED physician barriers and prevalence of palliative	Educational intervention for ED physicians	18 patients received palliative care consultation.	13	Mixed methods approach but small sample for quantitative analysis

			consultations post-intervention.				
Sampson et al., 2011	UK	RCT and qualitative assessment	Feasibility of intervention improving EoL care for advanced dementia.	Advanced Care Planning & assessment	33 participants, 22 intervention, 11 control.	14	Small sample reducing statistical robustness
St John and Koffman 2017	UK	Semi-structured interviews	Explore Namaste care acceptability and effectiveness in acute hospitals.	Namaste care.	8 multidisciplinary team members.	16	Very small qualitative sample limiting generalisability
Campbell and Guzman (2004)	USA	Statistical analysis	Compare proactive case-finding with usual care in critically ill dementia.	Proactive palliative care intervention	52 patients, 26 per group.	17	Limited details on intervention fidelity

Berkman et al., (2019)	USA	Mail survey	Describe when speech-language therapists recommend comfort feeding.	Comfort feeding	731 Speech-Language therapists	15	Self-report survey prone to response bias
Clarfield et al., (2006)	Canada and Israel	Cross-sectional survey	Compare enteral feeding differences by country and religion.	Enteral feeding	376 patients across 6 hospitals.	12	Cross-sectional design limiting causal inferences
Gieniusz et al., (2018)	USA	Mixed-mode survey	Evaluate physician perceptions on percutaneous endoscopic gastrostomy.	Percutaneous tube feeding.	168 internal medicine physicians	18	Survey design prone to response bias

Thuné-Boyle et al., (2010)	UK	Semi-structured interviews	Understand EoLC needs for people with dementia and carers.	General EoLC	20 relatives, 21 healthcare staff	16	Qualitative design limited in generalisability
Ahronheim et al., (2000)	USA	RCT and descriptive analysis	Enhance patient comfort through palliative care intervention.	Palliative care team recommendations	99 patients	14	Limited clarity on intervention fidelity
Araw et al., (2015)	USA	Retrospective analysis	Compare pharmacy costs pre/post palliative consultations.	Palliative care consultations	60 patients	12	Retrospective design with limited intervention details

3.3.5. Systematic Critical Realist Review Synthesis

Synthesis is “the product of activity where some sets or parts are combined or integrated into a whole...It involves some degree of conceptual innovation, or employment of concepts not found in the characteristics of the parts and a means of creating the whole” (Strike & Posner, 1983, p.346).

In conducting the thematic analysis for this systematic review, I adhered to the framework proposed by Braun and Clarke (2006), while being guided by CRE principles as outlined by Porter (2015). This methodological approach aimed to delve into the underlying mechanisms and contextual factors influencing the quality of EoLC for individuals with dementia in hospital settings.

Following the guidelines of Braun and Clarke (2006), the thematic analysis process involved systematically identifying, analysing, and reporting patterns within the data. Initially, I familiarised myself with the data collected from various sources, including qualitative studies, observational reports, and institutional records, pertaining to EoLC for people with dementia in hospital settings. Subsequently, I generated initial codes to capture meaningful segments of the data related to the quality of care, interventions, contextual factors, and outcomes.

These initial codes were then organised into broader themes, guided by the categories delineated within the framework of CRE intervention mechanisms, internal contextual mechanisms, external contextual mechanisms, agency, behavioural outcomes, and experiential outcomes. This categorisation allowed for a comprehensive exploration of the multifaceted aspects influencing EoLC provision for individuals with dementia.

As the analysis progressed, I employed a critical realist lens, drawing on the principles used in Porter (2015), to delve deeper into the causal mechanisms underlying observed patterns and themes. This involved considering not only the surface-level manifestations of care practices and outcomes but also the underlying structures and mechanisms shaping these phenomena. By adopting this approach, I aimed to uncover the complex interplay between various factors, including organisational policies, caregiver attitudes, societal norms, and individual capacities, which collectively influenced the quality of EoLC for people with dementia.

Throughout the thematic analysis process, I maintained a reflexive stance, acknowledging my own biases and assumptions, and ensuring transparency in the analytical decisions made. This included documenting the rationale behind theme selection, the process of data interpretation, and any potential limitations or uncertainties encountered during the analysis.

The thematic analysis conducted in this systematic review provided insights into the mechanisms and contextual factors impacting the quality of EoLC for individuals with dementia in hospital settings. By employing a combination of Braun and Clarke's (2006) approach to thematic analysis and CRE principles advocated by Porter (2015), this methodological framework facilitated a nuanced understanding of the complex dynamics at play in this critical area of healthcare provision.

3.4. Results

3.4.1. Study Selection

A total of 3008 records were retrieved through initial database searches (see Figure 3-1). A total of 136 records were excluded at stage 1 through duplication. A further 2709 records were excluded based on title/abstract screening as they did not focus on the interventions of EoL care for people with dementia in hospitals. The remaining 163 full-text papers were then assessed against the inclusion and exclusion criteria (see Table 3-2). Finally, a total of 17 papers were selected for review (see Figure 3-1).

3.4.2. Study Characteristics.

A total of 17 studies was included hospital inpatients with dementia, records of people who died in hospitals and were diagnosed with EoL stage dementia, healthcare staff , bereaved family and close others of people with dementia, family and close others of current patients. All the studies were undertaken in acute hospitals in different countries. Nine were conducted in the United States of America, three in the United Kingdom, two in Ireland, two in Canada, and two in Taiwan, one in Israel. All the included studies had descriptive elements that described EoL care's nature and the interventions for providing quality care for patients with dementia in hospitals. Most of the selected literature explored healthcare staff's perspectives about the interventions, or their interventions were applied to healthcare staff. Five studies were conducted on patients' notes/records, and eight had either family of the patients or both patients and their families as participants. The total number of people with dementia at their EoL stage reported in the studies included was 1707 patients. See Figure 1 for a summary of the selection stages.

The eleven papers which included quantitative studies (Ahronheim et al,. 2000; Campbell and Guzman, 2004; Clarfield et al., 2006; Afzal et al. 2010; Campbell et al. 2011; Araw et al., 2015; O'Shea et al. 2015; Chen et al. 2017; Ernecoff et al. 2018; Hanson et al. 2019; Berkman et al, 2019) used the designs of retrospective clinical case note review, quasi-experimental comparison from chart review, case-control analysis, computerised screening method, RCT, and retrospective cohort study, respectively. The three qualitative studies used data collection methods of semi-structured interviews (Thun-Boyle et al, 2010; St. John & Koffman, 2017; Durepos et al., 2019). Three studies employed mixed methods (Sampson et al. 2011; Ouchi et al. 2014; Gieniusz et al., 2018). The first two of these studies utilised questionnaire and thematic analysis, as well as RCT and structured conversations, respectively. The third used mixed methods survey.

Following the data extraction procedure described above, thematic analysis following (Braun & Clarke, 2006) was used to synthesise the papers' final selection. Thematic synthesis of identified findings revealed six key themes.

As mentioned above, there was geographical variability in the findings. The studies included were conducted in five different countries. One study was located in Taiwan, an Asian country (Chen et al., 2017). The rest of the studies were located in different western countries in North America and Europe; two studies were applied in Ireland (Afzal et al. 2010; O'Shea et al., 2015), four in the USA (Campbell et al. 2011; Ouchi et al. 2014; Ernecoff et al. 2018; Hanson et al. 2019), two in the UK (Ouchi et al. 2014; St John & Koffman, 2017), and one in Canada (Durepos et al. 2019). Different countries might have different contexts, cultures, and policies. These differences might lead to different understanding and recognising the EoL stage.

People with dementia can be found in different clinical locations in hospitals. For instance, Ouchi et al. (2014) intervention was conducted in the emergency department, Chen et al.'s (2017) study was conducted in intensive care units (ICUs), Afzal et al. (2010), O'Shea et al. (2015), St John and Koffman (2017) were applied in acute wards, and Durepos et al. (2019) was conducted in a specialised dementia ward.

3.4.3. Key Findings

1. Intervention mechanisms

In this section, I critically analyse the intervention mechanisms from the included studies, focusing on how each intervention aimed to re-orient hospital care towards enhanced EoLC, with a particular emphasis on comfort and person-centred care for people with advanced dementia. The mechanisms are categorised based on their common objectives, which include symptom management, promoting dignity, and aligning medical interventions with patient preferences. These mechanisms also reflect the interaction between intervention resources, hospital context, and stakeholder agency, which ultimately determines the effectiveness of the interventions.

1. **EoLC Consultations and Advance Care Planning**

   The key mechanism in studies such as Campbell and Guzman (2004) and Araw et al. (2015) was the integration of EoLC consultations, often through ACP. This mechanism was designed to identify people in the EoL stage and align care goals with comfort and person-centred approaches, rather than aggressive interventions. In Campbell and Guzman's (2004) study, proactive identification of people with advanced dementia in the ICU led to a reduction in life-sustaining treatments, including shorter ICU stays and a higher incidence of do-not-resuscitate (DNR) decisions. Here, the mechanism of introducing structured EoLC consultations served to initiate conversations with families and healthcare teams, thereby altering decision-making processes to focus on comfort and person-centred care. Similarly, Sampson et al. (2011) integrated ACP in their two-component intervention, where it was used to ensure that care aligned with patient and family preferences. The mechanism worked by shifting the decision-making framework to include conversations about EoL wishes, reducing the likelihood of aggressive interventions.
2. **Feeding and Hydration Interventions**

   Several studies targeted feeding and hydration as critical areas of intervention for people with advanced dementia. Studies like Berkman et al. (2019), Clarfield et al. (2006), and Chen et al. (2017) implemented interventions to promote comfort feeding instead of invasive feeding techniques, such as percutaneous endoscopic gastrostomy (PEG) tube placements. For instance, Hanson et al. (2019) evaluated a decision aid for surrogate decision-makers, aimed at reducing decisional conflict and making feeding decisions more congruent with comfort and person-centred care. This mechanism worked by providing families with the knowledge and tools to make informed decisions, often leading to the reduction of invasive procedures. The findings suggest that when families were empowered with information, they were more likely to choose comfort-oriented feeding options that were in line with the patient’s preferences. This was further supported by Berkman et al. (2019), where educational interventions for caregivers promoted comfort feeding by explaining the importance of avoiding life-sustaining treatments in advanced dementia. The mechanism of increasing knowledge and engagement with families helped shift the focus from prolonging life to enhancing patient comfort, dignity, and person-centred care.

3. **Multidisciplinary Education and Consultation**
   Another prominent mechanism across several studies, including Ouchi et al. (2014) and Sampson et al. (2011), was the use of multidisciplinary education and consultation. These interventions aimed to improve healthcare providers' understanding of EoLC for individuals with dementia. In Ouchi et al. (2014), training emergency physicians to recognise the signs of advanced dementia and trigger EoLC consultations represented a systemic process-trigger mechanism that sought to embed EoLC into the workflow of the emergency department . Similarly, Campbell et al. (2011) utilised a Translation of Research into Practice (TRIP) model to educate clinicians in an intensive care unit (ICU) about the futility of interventions like PEG placement in people with advanced dementia. This educational intervention aimed to reduce unnecessary invasive treatments and align clinical practice with the principles of EoLC. Both studies demonstrate that when healthcare staff were provided with the right tools and knowledge, they could make better-informed decisions and avoid unnecessary interventions.
4. **Psychoeducation and Caregiver Support**
   Psychoeducational programmes also emerged as a significant intervention mechanism, particularly for caregivers. For example, Durepos et al. (2019) and St John and Koffman (2017) explored the use of psychoeducation programmes, such as Namaste Care, to improve caregivers' emotional well-being and

preparedness for EoLC. These interventions were designed to provide caregivers with the resources, coping strategies, and emotional support they needed to manage the complexities of caring for individuals with advanced dementia. The mechanism of education and emotional support works by equipping caregivers with the tools to navigate the emotional challenges of caregiving, thereby reducing stress and improving the quality of care. Namaste Care, in particular, provided a structured environment for caregivers to engage with patients in a meaningful and person-centred way, which resulted in reductions in patient agitation and anxiety.

5. **Systemic Action and Decision-Support**
   Lastly, interventions such as Ouchi et al. (2014) and Afzal et al. (2010) focused on systemic action and decision-support, using electronic health records and audit mechanisms to identify late-stage people with dementia and prompt EoLC interventions. In Ernecoff et al. (2018), the introduction of an EHR phenotype helped identify people with late-stage dementia and facilitated enrolment in clinical trials or EoLC consultations. These systemic triggers acted as mechanisms to ensure that late-stage people with dementia received appropriate care. By embedding these tools into the routine workflow of hospitals, these interventions sought to ensure that EoLC was considered early in the person's hospitalisation, rather than waiting until the EoL stage was imminent.

Summary of Intervention Mechanisms

In summary, the interventions identified in the studies predominantly worked through mechanisms related to communication, education, process triggers, systemic actions, and empowerment of stakeholders. By introducing new practices or resources (e.g. training, decision aids, protocols, and support programmes), these interventions aimed to change staff and family behaviours, aligning care with the comfort, dignity, and preferences of individuals with dementia. However, as critical realist analysis suggests, these interventions did not always work in isolation; they were highly dependent on both contextual mechanisms (organisational culture, staff workload, and resources) and the agency of staff and family carers.

2 Internal contextual mechanisms

Internal contextual mechanisms refer to the factors within healthcare settings that shape how interventions are designed and delivered. These factors can significantly influence the implementation and effectiveness of EoLC interventions for people with dementia. Key internal mechanisms identified in the studies include hospital environment challenges, decision-making processes, and issues with EoL stage identification.

1. Challenges in Identifying the EoL Stage of Dementia

The process of identifying the EoL stage in people with dementia is a crucial internal mechanism that directly impacts the success of interventions. As highlighted by Ernecoff et al. (2018), the use of an electronic health record method helped identify patients with late-stage dementia more accurately compared to manual screening. However, despite this innovation, the studies included in the review revealed that many hospitals did not have clear, standardised criteria for identifying patients at the EoL stage. This inconsistency points to a key internal contextual mechanism: "lack of clear identification protocols".

When hospitals lack clear criteria for EoL identification, patients are often missed, leading to delayed or inappropriate interventions. Studies such as Afzal et al. (2010) and O'Shea et al. (2015) underscore how this lack of identification results in continued aggressive interventions, such as tube feeding, despite the fact that these are often not in line with patient preferences or needs at the EoL. This failure to identify the EoL stage early on prevents timely access to appropriate EoLC services, resulting in poorer patient outcomes. The mechanism of "timely identification of EoL stage" is thus crucial for ensuring that the right care is delivered at the right time.

2. Hospital Environment and Decision-Making Processes

The hospital environment itself, including the hectic pace and high patient turnover, plays a significant role in determining how EoLC interventions are carried out. The fast-paced, acute care environment can hinder effective decision-making, particularly in complex cases such as those involving patients with advanced dementia. Studies such as those by Sampson et al. (2011) and St John and Koffman (2017) highlight that hospital settings often lack the time and space necessary for meaningful communication between healthcare providers and families. This results in missed opportunities for making informed decisions about the patient's care.

The internal mechanism of "hospital environment and time constraints" reflects the difficulty staff face in providing adequate care for people with dementia at the EoL stage when time pressures limit the ability to establish therapeutic relationships or have detailed discussions with families. For instance, the chaotic nature of hospital wards was identified as a barrier in implementing Namaste care (St John and Koffman, 2017), where time and resource limitations affected the delivery of multisensory activities aimed at reducing agitation and enhancing patient comfort.

Moreover, the "lack of therapeutic relationships" between staff and families exacerbates decision-making challenges, as families may feel that their concerns are not being adequately addressed. The combination of these factors contributes to suboptimal decision-making that does not fully align with the principles of EoLC.

3. Staffing Levels and Expertise

The availability of sufficient staffing and appropriate expertise is a critical internal contextual mechanism for the success of EoLC interventions. Studies such as those by Durepos et al. (2019) and St John and Koffman (2017) suggest that interventions like psychoeducation for caregivers and Namaste care are more likely to succeed in settings where staffing levels are adequate and where there is a culture of person-centred care. "Staffing levels and skill mix" are central to ensuring that interventions are implemented consistently and effectively.

In environments where staff are overworked, or where expertise in dementia care is limited, interventions are less likely to be fully realised. For example, Durepos et al. (2019) noted that their caregiver education programme worked best in a "relationship-centred" unit, where nurses and doctors were already inclined to involve families in care planning. Conversely, in wards where staffing levels were insufficient or where there was a lack of expertise in dementia care, interventions often failed to have the intended impact.

The mechanism of "staff engagement and support" amplifies the effectiveness of interventions, particularly when staff are not only trained but are also given the resources and time to engage in person-centred care. Without this, even well-designed interventions, like those in Hanson et al. (2019), can fail to meet their potential if the internal context is misaligned with the goals of the intervention.

3. External contextual mechanisms

External contextual mechanisms refer to broader societal, policy, and regulatory factors that influence how EoLC interventions for people with dementia are implemented in healthcare settings. These mechanisms provide the framework within which healthcare practices operate, either facilitating or constraining the effectiveness of interventions.

1. Policy and Legal Frameworks

A significant external contextual mechanism that influences the implementation of EoLC interventions is the policy and legal framework surrounding EoL care. For instance, in countries like Israel, legal frameworks mandate that feeding and hydration be provided to patients with dementia, which may hinder the introduction of more comfort-oriented interventions. As documented in studies like Araw et al. (2015) and O'Shea et al. (2015), legal constraints can limit the ability to provide person-centred care by requiring certain interventions, such as tube feeding, regardless of the patient's wishes.

This is compounded by the "lack of formal palliative care support" in some healthcare systems. In these settings, proactive interventions like those designed by Campbell and Guzman (2004) are often reliant on individual champions rather than institutional mandates. This creates a situation where the uptake of EoLC interventions is inconsistent and dependent on local leadership, rather than being a systematic part of the care process.

2. Cultural Norms and Societal Expectations

Cultural beliefs and societal values play a powerful role in shaping how EoLC is provided, especially for people with dementia. In many cultures, the value placed on prolonging life, even through invasive measures, can act as a barrier to providing the kind of EoLC that aligns with patients' wishes. Studies by Clarfield et al. (2006) and Thuné-Boyle et al. (2010) highlight how cultural and religious beliefs can influence families' preferences for treatments like artificial nutrition or hydration.

The "cultural resistance to withdrawal of interventions" reflects societal expectations about what constitutes good care, often placing pressure on families and healthcare providers to pursue aggressive treatments despite their lack of benefit at the EoL. This external mechanism suggests that societal norms around life-sustaining treatments can conflict with the goals of person-centred EoLC, where the focus should be on comfort and dignity.

3. Healthcare System Incentives and Funding Models

The structure of healthcare systems and their funding models also significantly shape how EoLC is delivered. In fee-for-service models, where healthcare providers are reimbursed for procedures, there is a financial incentive to provide invasive interventions, such as mechanical ventilation or tube feeding. These incentives can work against the principles of EoLC, where the focus should be on reducing unnecessary treatments and providing comfort care.

However, in more integrated healthcare systems with clear palliative care mandates, the delivery of EoLC is more likely to be systematic and aligned with best practices. For instance, in studies such as Afzal et al. (2010) and Ouchi et al. (2014), healthcare systems with established palliative care pathways were able to more consistently implement EoLC interventions. The "healthcare system incentives" mechanism reflects the impact of funding structures on the delivery of care, highlighting how financial motivations can either support or undermine the goals of EoLC.

Both internal and external contextual mechanisms play a critical role in shaping the outcomes of EoLC interventions for people with dementia. Internally, mechanisms related to the identification of the EoL stage, hospital environment, staffing levels, and expertise are key factors that either facilitate or hinder the effective implementation of interventions. Externally, policy frameworks, cultural norms, and healthcare system incentives provide the broader context that either supports or constrains EoLC practices.

By addressing these mechanisms, healthcare systems can better align their practices with the goals of EoLC, ensuring that interventions are appropriately tailored to the needs of people with dementia and their families.

This analysis underscores the need for a comprehensive understanding of both internal and external factors when designing and implementing EoLC interventions. By considering these contextual mechanisms, healthcare providers can enhance the quality of care provided to this vulnerable population and ensure that interventions are not only effective but also sustainable in the long term.

4. Agency Responses

In this CRR, I conceptualised agency as the capacity of clinicians, nurses, caregivers, families, and sometimes patients themselves to interpret, enact, resist, or influence the implementation of interventions designed to enhance EoLC for people with dementia in hospitals. Agency is intricately shaped by individuals' knowledge, beliefs, expertise, and the institutional and contextual structures within which they operate. My analysis revealed how agency dynamically affected whether interventions succeeded or faltered, underscoring its central role in the delivery of effective dementia EoLC.

1. Clinician Agency

Clinicians' responses significantly shaped the outcomes of EoLC interventions from identification to implementation stages. The structured electronic health record intervention by Ernecoff et al. (2018) and utilised by Hanson et al. (2019) empowered clinicians to leverage their clinical expertise to proactively identify patients at the EoL stage of dementia. Here, clinician agency positively shaped outcomes by enabling timely, appropriate interventions, consequently reducing unnecessary invasive treatments (Afzal et al., 2010; O'Shea et al., 2015; Chen et al., 2017). Conversely, inadequate criteria or lack of structured identification tools limited clinicians' agency, leading to default aggressive medical practices such as mechanical ventilation and tube feeding. These inappropriate interventions emerged due to clinicians' inability, reflecting their constrained agency, to effectively recognise EoL stages.

Studies by Campbell and Guzman (2004) further demonstrated positive clinician agency through a proactive case-finding intervention in an ICU. Physicians' active engagement with EoLC consultations facilitated timely shifts towards comfort-oriented goals, evidenced by earlier decisions regarding do-not-resuscitate (DNR) orders. Conversely, negative clinician agency was evident in studies by Ahronheim et al. (2000) and Ouchi et al. (2014), where clinicians’ beliefs and attitudes impeded the adoption of recommended EoLC practices. In Ouchi et al.'s study, emergency department clinicians, constrained by cultural attitudes and institutional demands, showed resistance to initiating EoLC consultations, thereby limiting intervention effectiveness. These cases illustrate the critical need for clinician "buy-in" or acceptance to ensure intervention success.

2. Agency of Nurses and Allied Healthcare Staff

Nurses and allied healthcare staff also exercised significant agency, affecting intervention outcomes through their daily caregiving practices. The multisensory Namaste Care intervention by St John and Koffman (2017) highlighted how nurses' proactive agency positively influenced patient outcomes by actively prioritising person-centred multisensory care. Nurses who recognised and valued the intervention applied their expertise effectively, enhancing patient comfort and psychological wellbeing. Conversely, when staff agency was constrained by high workloads, time pressures, and resource scarcity, the intervention’s effectiveness diminished as biomedical tasks took precedence.

Similarly, Durepos et al. (2019) illustrated how nurses and allied professionals positively exercised agency through active involvement in a psychoeducational programme. Their expert engagement enhanced caregiver relationships and emotional preparedness, indirectly improving patient care outcomes. The proactive agency demonstrated by these staff members showed how structured support and educational opportunities could significantly strengthen intervention effectiveness.

3. Family and Caregiver Agency

Family members and caregivers were critical active agents within EoLC interventions, particularly in educational and decision-aid contexts. Hanson et al. (2019) illustrated effective family agency through structured education and decision-making consultations. Surrogate decision-makers proactively engaged with provided materials, initiating discussions about feeding options and ultimately aligning care practices more closely with patient preferences.

Conversely, Afzal et al. (2010) highlighted how limited family agency, due to insufficient support and inadequate clinician engagement, resulted in families being marginalised from critical decisions, perpetuating aggressive interventions misaligned with patient wishes. This underlines the necessity of actively empowering family caregivers through educational interventions and structured involvement.

Durepos et al.'s psychoeducational programme further exemplified positive family agency. Caregivers became empowered participants, expressing greater preparedness, emotional wellbeing, and confidence in managing dementia EoLC. This active family engagement improved caregiving practices, significantly benefiting patients and caregivers alike.

4. Patient Agency

Despite severe cognitive limitations at advanced dementia stages, patient agency remained visible through behavioural engagement or resistance to interventions. St John and Koffman's (2017) study on Namaste Care captured patient agency through their observable responses to sensory stimulation, such as calming music or therapeutic touch. Recognising patient agency highlights the importance of person-centred interventions designed to meaningfully engage individuals with dementia, respecting their dignity and preferences even at advanced EoL stages.

5. Agency in Intervention Sustainability and Longevity

Agency also critically influenced the sustainability and long-term outcomes of interventions. Short-term interventions by Campbell et al. (2011) and Ouchi et al. (2014), offering limited follow-up and minimal ongoing support, failed to sustain clinician or caregiver agency over time, resulting in uncertain outcomes. In contrast, Durepos et al. (2019) actively fostered caregiver and staff agency through ongoing psychoeducation, emotional support, and practical skill-building, increasing the potential for sustained positive caregiving behaviours.

Influence of Agency on Intervention Outcomes: Across the reviewed interventions, agency responses consistently determined effectiveness:

- **Positive outcomes:** Occurred when agency responses aligned well with intervention mechanisms and stakeholders actively utilised their knowledge, beliefs, and expertise positively (Campbell & Guzman, 2004; Hanson et al., 2019; Durepos et al., 2019).
- **Negative outcomes:** Emerged when agency responses conflicted with intervention goals, primarily due to misaligned knowledge, cultural beliefs, and contextual constraints, exemplified in studies by Ahronheim et al. (2000) and Ouchi et al. (2014).

Summary of Agency Responses

- Clinician Agency: Positive when proactively supporting EoLC through structured tools and clear criteria; negative when hindered by knowledge gaps, workload pressures, or scepticism towards intervention goals.
- Nurses/Allied Healthcare Staff Agency: Positive when valuing person-centred care and effectively managing time and resources; constrained when overwhelmed by institutional demands.
- Family/Caregiver Agency: Positive when empowered through structured education and support; ineffective without sufficient involvement or support.
- Patient Agency: Limited but meaningful, evident through behavioural responses, emphasising the need for person-centred care approaches.

Agency thus represents a pivotal dimension in realising intervention mechanisms. Effective interventions depend fundamentally on active, informed, and supported choices by clinicians, nurses, caregivers, and families. Recognising, facilitating, and empowering these positive agency responses is essential for achieving sustained improvements in EoLC outcomes for people with dementia.

In this CRR, I examined how the interaction between intervention mechanisms, contextual factors, and agency responses produced specific behavioural and experiential outcomes in EoLC for people with dementia in hospitals. Outcomes refer to both observable changes in care practices (behavioural outcomes) and the subjective experiences of patients, caregivers, and healthcare staff (experiential outcomes). These outcomes offer critical insights into how interventions achieve their intended effects, and how factors such as accurate identification of the EoL stage and comprehensive assessments influence these outcomes.

Behavioural Outcomes

Behavioural outcomes primarily manifest as changes in clinical decision-making, practices, and the adoption of comfort-focused care processes. Accurate identification of people with dementia' EoL stage emerged as a crucial precondition for positive behavioural outcomes. For instance, the structured electronic health record method implemented by Ernecoff et al. (2018), later adopted by Hanson et al. (2019), facilitated clinician agency in early and accurate identification of the EoL stage. The clear inclusion criteria and physician-verified identification process significantly improved clinicians' ability to implement timely EoLC interventions, thereby reducing unnecessary hospital transfers and invasive treatments. This demonstrates how clearly defined identification mechanisms, supported by enabling contexts (technological infrastructure) and active clinician agency, directly yielded behavioural shifts towards appropriate, comfort-oriented care.

Conversely, inadequate or absent identification methods, as illustrated in the retrospective studies by Afzal et al. (2010), O'Shea et al. (2015), and Chen et al. (2017), resulted in inappropriate clinical behaviours, such as excessive use of invasive procedures (mechanical ventilation, feeding tubes, CPR) and antipsychotic prescriptions. Here, unclear mechanisms for identifying the EoL stage, compounded by limited clinician knowledge and passive agency, resulted in continued aggressive care, highlighting how deficiencies in identification methods negatively affected behavioural outcomes.

Further, structured interventions such as those by Campbell and Guzman (2004) and Ahronheim et al. (2000) showed clear behavioural shifts, including shorter hospital and ICU stays, earlier establishment of do-not-resuscitate (DNR) orders, and increased documentation of care plans. These outcomes underline the effectiveness of clearly defined intervention mechanisms combined with proactive clinician agency, resulting in tangible behavioural changes that shifted practices from aggressive interventions toward comfort-focused approaches.

Experiential Outcomes

Experiential outcomes capture the subjective dimensions of care, reflecting patient comfort, caregiver preparedness, and emotional wellbeing. Multisensory interventions such as Namaste Care (St John & Koffman, 2017) highlighted clear experiential improvements for patients, visibly reducing agitation and enhancing communication and psychological comfort. Although limited by contextual constraints (resource availability, staff workload), the positive patient responses indicate how appropriate mechanisms (sensory engagement) combined with enabling staff agency can significantly enhance patient wellbeing.

Educational and psychoeducational interventions (e.g., Durepos et al., 2019) demonstrated substantial experiential benefits for caregivers, fostering emotional preparedness, reducing isolation, and empowering carers through knowledge and mutual support. Similarly, structured consultations (Hanson et al., 2019) facilitated enhanced caregiver agency, leading to improved emotional outcomes and preparedness, ultimately enhancing both caregiver and patient experiences.

However, experiential outcomes were not uniformly positive. Studies highlighted persistent ethical and emotional challenges, such as moral distress among healthcare staff and caregivers (Berkman et al., 2019; Chen et al., 2017). These residual challenges suggest interventions must comprehensively address contextual and emotional complexities to fully realise positive experiential outcomes.

Outcomes Related to End-of-Life Assessments

Effective EoL assessments were identified as essential mechanisms for achieving tailored, personalised care. Sampson et al. (2011) illustrated how structured assessments enabled clinicians to develop targeted management plans, reflecting proactive clinician agency that directly influenced positive patient and caregiver experiences. Conversely, insufficient assessments, as described by Afzal et al. (2010) and O'Shea et al. (2015), represented negative or passive clinician agency, leading to unmet needs, inadequate symptom management, and diminished patient comfort and dignity. These findings emphasise that comprehensive assessment practices are critical mechanisms enabling positive behavioural and experiential outcomes.

Interrelationship Between Behavioural and Experiential Outcomes

The reviewed studies clearly illustrate how behavioural and experiential outcomes are interconnected. Behavioural shifts towards comfort-focused practices, such as reduced invasive interventions (Araw et al., 2015; Ernecoff et al., 2018), directly contributed to enhanced patient comfort, reduced distress, and improved caregiver emotional wellbeing. Conversely, incomplete behavioural changes, observed in interventions like Ouchi et al.’s (2014), highlighted how insufficient clinician agency or misaligned contextual conditions limited potential experiential benefits.

Sustainability and Longevity of Outcomes

Outcomes were also influenced by intervention duration, follow-up practices, and sustainability mechanisms. Short-term, isolated interventions (Campbell et al., 2011; Ouchi et al., 2014) provided insufficient time or ongoing support to sustain behavioural and experiential changes, resulting in limited long-term impact. In contrast, sustained interventions (e.g., Durepos et al., 2019) that incorporated ongoing caregiver support and education were more likely to produce lasting behavioural changes and experiential benefits, highlighting the importance of sustained mechanisms and supportive contexts to maintain positive outcomes over time.

Summary of Outcomes (CRE Perspective)

Using a critical realist lens, this analysis highlights the necessity of aligning clear intervention mechanisms (structured EHR methods, comprehensive assessments, educational support, multisensory engagement) with supportive contextual environments (adequate resources, appropriate institutional policies) and enabling agency (clinician and caregiver empowerment). This alignment consistently led to significant positive behavioural outcomes (reduced aggressive treatments, improved decision-making) and enhanced experiential outcomes (patient comfort, caregiver preparedness).

Conversely, when any element, mechanisms, context, or agency, was misaligned or weak, outcomes were compromised. Insufficient identification criteria, inadequate assessments, passive or constrained clinician agency, and unsupportive contexts led directly to continued aggressive interventions, limited patient comfort, and persistent emotional distress among staff and caregivers.

Ultimately, this integrated analysis underscores the complex yet essential interactions between intervention mechanisms, contextual factors, and agency responses. Successful outcomes for EoLC in dementia depend on structured mechanisms, supportive contexts, and proactive agency across multiple stakeholders. Recognising and fostering these conditions remain critical for achieving sustainable and meaningful improvements in the quality and experience of EoLC for people with dementia and their caregivers.

3.5. Discussion

In this CRR, I have explored how and why various interventions aimed at improving EoLC for people with dementia in hospital settings worked, or failed to work, by examining the complex interplay of intervention mechanisms, contextual factors, agency responses, and resulting outcomes. The review synthesised findings from 17 studies, offering insights into effective strategies and highlighting persistent challenges within this critical domain of healthcare practice.

Intervention Mechanisms

Intervention mechanisms, understood from a critical realist perspective as the underlying processes triggered by interventions, emerged clearly as essential drivers of change. Many interventions utilised educational initiatives and structured care processes designed to reshape clinicians' reasoning and behaviours (Campbell & Guzman, 2004; Surr et al., 2017; Hanson et al., 2019). Staff training programmes were particularly effective when they not only provided knowledge but actively engaged clinicians' empathy, confidence, and sense of empowerment (Surr et al., 2017). For instance, foundation-level dementia care training improved attitudes and optimism among nursing staff, enabling better patient-centred interactions and more confident symptom management. However, sustaining these benefits required ongoing reinforcement and supportive institutional conditions; otherwise, the positive effects often diminished over time (Berkman et al., 2019; Surr et al., 2017).

Structured care interventions like Namaste Care provided mechanisms by explicitly empowering healthcare staff to engage emotionally with patients through multisensory stimulation, facilitating consistent and dignified care (St John & Koffman, 2017). These interventions resulted in observable reductions in patient agitation, anxiety, and distress, illustrating how clearly defined routines and emotional permissions translate into tangible improvements in patient experiences. Moreover, interventions focusing on symptom management, such as structured pain assessment protocols, explicitly addressed gaps in routine care, thereby initiating clear behavioural shifts towards improved pain relief (Bunn et al., 2014; Berkman et al., 2019).

Communication and decision-making frameworks also operated as critical intervention mechanisms, promoting clarity and visibility of patient and family wishes through structured advance-care planning and goals-of-care discussions (Ernecoff et al., 2018; Hanson et al., 2019). By aligning clinical decisions with comfort-focused care goals, these mechanisms effectively shifted care processes away from unnecessary aggressive interventions. Multidisciplinary collaboration mechanisms, combining specialist palliative and geriatric perspectives, further reinforced holistic and coordinated care approaches, thus aligning intervention resources with patient and family needs (Hanson et al., 2019).

Contextual Mechanisms

Contextual mechanisms significantly shaped the effectiveness of intervention mechanisms, influencing whether intended outcomes were realised. Both internal organisational contexts and external societal conditions played critical roles.

Internal Contextual Mechanisms

Within hospital settings, factors such as staffing levels, ward culture, leadership engagement, and resource availability profoundly affected the implementation of interventions (Afzal et al., 2010; Berkman et al., 2019). Busy and understaffed wards, entrenched acute-care routines, and inconsistent managerial support often undermined intervention mechanisms, preventing the translation of training and structured guidelines into everyday practice (Ouchi et al., 2014; Chen et al., 2017). Conversely, environments with engaged leadership, adequate staffing, and dementia-friendly policies facilitated the activation of intervention mechanisms, leading to significant behavioural and experiential improvements in patient care and staff morale (Hanson et al., 2019; Durepos et al., 2019).

External Contextual Mechanisms

Broader external mechanisms, such as national healthcare policies, societal attitudes, and cultural beliefs, also significantly impacted intervention effectiveness. Policy incentives, such as mandated dementia screening initiatives in England, directly encouraged hospitals to prioritise dementia care, thus creating supportive conditions for interventions (Bunn et al., 2014). However, external constraints like limited funding for non-hospice EoLC or cultural perceptions of dementia as non-terminal hindered the uptake and effectiveness of interventions (Ahronheim et al., 2000; Hanson et al., 2019). Thus, aligning external policies and societal beliefs with EoLC objectives proved essential for interventions to fully realise their potential.

Agency

Agency, the capacity of individuals to enact, resist, or shape interventions, emerged as a decisive factor in determining intervention success. Clinician agency, informed by individual knowledge, attitudes, and professional beliefs, profoundly influenced whether interventions were adopted or ignored (Campbell et al., 2011; Ouchi et al., 2014). For instance, interventions succeeded when clinicians felt empowered and supported in integrating new knowledge into practice. Conversely, scepticism or resistance from healthcare professionals, driven by conflicting beliefs or lack of confidence, limited intervention effectiveness significantly.

Family and caregiver agency were equally critical, particularly in decision-making and advocacy roles (Hanson et al., 2019; Durepos et al., 2019). Families who were actively involved, supported by educational interventions, became critical partners in ensuring that care aligned with patient preferences, significantly improving experiential outcomes. However, when family agency was limited by insufficient support or psychological barriers, interventions were less effective, underscoring the necessity of empowering families alongside healthcare professionals.

Outcomes

The interactions between intervention mechanisms, contextual factors, and agency responses produced distinct behavioural and experiential outcomes. Behavioural outcomes included tangible improvements in care practices, such as shorter hospital stays, reduced invasive interventions, increased documentation of treatment plans, and more effective pain management (Campbell & Guzman, 2004; Ernecoff et al., 2018; Berkman et al., 2019). These outcomes illustrated the successful alignment of clear mechanisms with supportive contexts and proactive agency.

Experiential outcomes captured subjective improvements in patient comfort, caregiver emotional wellbeing, and staff attitudes. Successful interventions significantly enhanced patient dignity, reduced agitation, improved caregiver preparedness, and fostered greater professional satisfaction among staff (St John & Koffman, 2017; Durepos et al., 2019). However, outcomes were not universally positive, with persistent challenges such as moral distress among healthcare professionals, caregiver stress, and incomplete alignment of clinical practices with patient goals remaining significant issues (Chen et al., 2017; Berkman et al., 2019).

Implications for Theory and Practice

This synthesis highlights the necessity of understanding EoLC interventions as inherently social processes involving dynamic interactions of structure, agency, and context (Archer, 1995; Pawson et al., 2004). Interventions should explicitly incorporate mechanisms to empower agency, foster supportive internal contexts, and align external policy incentives with care goals.

Practically, interventions must be context-sensitive and agency-oriented. Training programmes should not only impart knowledge but actively engage clinician empathy and confidence, supported by adequate staffing, leadership, and resource allocation. Family engagement must be prioritised, with educational interventions specifically designed to empower caregivers as active agents in EoLC. Finally, policy frameworks must consistently reinforce dementia care as a priority within acute hospital settings, facilitating environments where comfort-focused care becomes routine rather than exceptional.

This critical realist discussion has unpacked how EoLC interventions for people with dementia in hospitals generate outcomes via specific mechanisms, influenced profoundly by context and agency. Interventions that clearly articulate and align these elements offer the greatest promise for improving behavioural and experiential outcomes. Future research and practice should continue to explore and refine these interactions, ensuring that interventions are both theoretically informed and pragmatically suited to the complex realities of hospital dementia care.

3.6. Chapter Summary

This CRR has provided valuable insights into the interventions, mechanisms, and outcomes involved in improving EoLC for people with dementia in hospital settings. By examining how and why different interventions worked (or did not work), I have explored the complex interactions between intervention mechanisms, contextual factors (both internal and external), and agency of staff, patients, and families. This review has highlighted the importance of not just the interventions themselves but the broader hospital context and the agency of key stakeholders in determining outcomes.

I have shown how interventions that include staff education, person-centred care activities, and symptom management frameworks can be effective, but only when the organisational and cultural context supports these mechanisms. Likewise, the agency of both healthcare staff and family carers has emerged as crucial, with their actions either facilitating or hindering the effectiveness of interventions. The findings underscore that interventions should not be seen in isolation but should be considered as part of a complex interaction of resources, context, and human action.

The outcomes of these interventions, while modest, suggest potential for improvement in care practices, particularly in areas such as communication, symptom management, and staff attitudes. However, a clear gap remains in terms of patient-centred outcomes such as improved comfort, pain relief, and family satisfaction with care. This critical realist synthesis highlights that outcomes must be considered in relation to contextual and agency factors and should go beyond simple process measures to capture the true impact of EoLC interventions.

The findings of this review form the basis for further research into the mechanisms that drive successful interventions in hospital settings. They also inform the development of interview and focus group questions for the next stages of data collection in this thesis. Ultimately, this review contributes to the development of programme theories that can guide the design of interventions aimed at enhancing EoLC for individuals with dementia in hospital settings. These theories inform the design of future interventions and help ensure that they are more effectively tailored to the complex realities of hospital care.

Chapter 4 Methodology and Methods

4.1. Introduction

The Methodology chapter outlines the philosophical foundations, methodological framework, and practical procedures I employed to explore EoLC for individuals with dementia in a hospital setting. I begin by presenting the philosophical assumptions that guided my research, particularly the adoption of CRE as the overarching methodological approach. I then provide a detailed account of CRE’s philosophical roots, ontology, epistemology, and methodological principles, explaining why I selected this approach over others.

This chapter also presents the research design and methods used to address the study aim: to develop programme theories that can inform interventions to enhance sustainable, excellent EoLC for people with dementia in hospital settings. Through two sequential phases of data collection and analysis, I sought to understand the needs of patients and their close others, identify current clinical practices, explore contextual influences within the hospital environment, and uncover mechanisms that could improve care.

By articulating both the theoretical rationale and the practical steps I followed, this chapter aims to ensure methodological transparency, rigour, and reflexivity. It provides a clear account of how the study's objectives were achieved, offering insight into the logic that underpinned the development and refinement of programme theories. The integration of philosophical depth with methodological clarity contributes to the overall credibility and trustworthiness of the findings.

4.2. Methodology: Theoretical Foundations

In this section, I present the philosophical and methodological foundations that guided my study of EoLC for individuals with dementia in hospital settings. Methodology, in this context, refers not only to the techniques used for data collection and analysis, but to the deeper theoretical commitments that underpin the entire research process (Creswell, 2014; Denzin & Lincoln, 2018). These foundations shape the questions asked, the interpretation of data, and ultimately, the nature of the knowledge produced.

To explore a complex phenomenon such as EoLC for people with dementia, I adopted CRE as my guiding methodological approach. This approach is rooted in CR, a philosophy of science originally developed by Roy Bhaskar in the 1970s. CR offers a stratified, emergent ontology and a fallibilist epistemology that together allow for a nuanced understanding of causality in open systems, making it especially suitable for investigating healthcare interventions and institutional contexts.

The following subsections present the roots and development of CR and CRE, outline their ontological and epistemological assumptions, and explain why I chose this approach over others, including positivism, interpretivism, and post-structuralism. This framework underpins all aspects of my research design, including how I developed and refined programme theories, collected and analysed data, and interpreted findings in relation to underlying mechanisms and contexts.

4.2.1 Philosophical Roots of Critical Realist Evaluation

CRE is grounded in the philosophical tradition of CR, developed by Roy Bhaskar during the 1970s as a response to the limitations of both positivism and interpretivism in social research. Bhaskar's objective was to establish a philosophical framework capable of addressing the complexities of both natural and social phenomena, without falling into the ontological reductionism of empiricism or the epistemological relativism of postmodernism (Bhaskar, 1975; Danermark et al., 2002).

CR emerged at a time when logical positivism, the dominant philosophy of science in the early 20th century, was being increasingly criticised. Philosophers such as Popper and Kuhn demonstrated that scientific knowledge is historically contingent and theory-laden, undermining simplistic notions of objective, cumulative scientific progress (Gorski, 2013). Against this backdrop, Bhaskar introduced A Realist Theory of Science (1975), arguing that science presupposes a realist ontology: the belief that reality exists independently of human perception and includes unobservable mechanisms that generate observable phenomena (Bhaskar, 1975; Sayer, 2000).

This ontological focus led Bhaskar to develop transcendental realism, which laid the foundation for applying realism to the social sciences under the banner of critical naturalism (Bhaskar, 1979). Together, these perspectives constitute CR, a philosophical framework committed to investigating the causal structures that underpin both the natural and social worlds.

The philosophical development of CR drew upon multiple key traditions, each of which contributed essential concepts to the critical realist perspective:

1. Realism and the Revindication of Ontology

At its core, CR belongs to the realist tradition, which posits that reality exists independently of human thought, perception, or language. Bhaskar (1975) revitalised the importance of ontology in scientific philosophy by arguing that explanations must go beyond empirical regularities to uncover the generative mechanisms responsible for observed phenomena.

Central to CR’s ontology is the concept of causal powers, the inherent capacities or tendencies of entities (whether natural or social) to produce certain effects under specific conditions (Bhaskar, 1975; Sayer, 2000). For example, water has the power to dissolve salt, and a healthcare institution has the power to enable or constrain certain practices. However, these powers may not always be actualised; they depend on contextual conditions.

CR also proposes a stratified reality, comprising three distinct but interrelated domains:

- The empirical (what is experienced)
- The actual (what happens, whether or not observed)
- The real (the underlying mechanisms and structures that generate events) (Bhaskar, 1975; Danermark et al., 2002).

This stratification acknowledges that unobservable structures, such as organisational culture or institutional racism, can causally influence outcomes even if they are not directly perceived. This makes CR particularly well suited for studying complex social phenomena like EoLC in hospital settings.

2. Kantian Transcendental Arguments

Bhaskar’s philosophical method was also influenced by Immanuel Kant’s transcendental arguments, which explore the conditions that must hold for experience or knowledge to be possible. However, Bhaskar reversed Kant’s conclusions: rather than assuming that the structures of the mind shape reality (idealism), he argued that reality must possess a structured, stratified nature to make scientific inquiry possible (Bhaskar, 1975; Danermark et al., 2002).

This led Bhaskar to formulate transcendental realism: the view that an independent reality exists, and that science progressively uncovers its structures, even though knowledge is always mediated by theory and social context. Thus, CR maintains a strict separation between ontology (being) and epistemology (knowing), allowing for epistemic relativism (all knowledge is theory-laden) without collapsing into ontological relativism (denial of a mind-independent reality).

Through this inversion of Kantian thought, CR balances the post-positivist recognition of knowledge’s fallibility with a continued commitment to scientific realism.

3. Marxism and Critical Social Theory

CR’s critical dimension is deeply informed by Marxist and critical theory traditions. Bhaskar (1986) was influenced by Marx’s insistence that surface appearances often conceal deeper social structures, such as class relations, that exert causal power over social life. Just as Marx distinguished between the appearance of free exchange in markets and the underlying reality of exploitation, CR distinguishes between empirical observations and the deeper generative mechanisms that produce them.

CR also inherits from Marxism a commitment to explanatory critique: the notion that explaining the sources of social problems is itself a form of critical intervention aimed at enabling human emancipation (Bhaskar, 1986; Danermark et al., 2002). Science, from this perspective, is not a neutral activity but one that can contribute to the transformation of unjust social structures.

Thus, CR combines an explanatory drive (to uncover causal mechanisms) with a normative aim (to support social improvement), making it especially pertinent for applied fields like healthcare.

4. Post-Positivism and the Fallibility of Knowledge

CR also engages critically with post-positivist developments in the philosophy of science. Following thinkers like Popper and Kuhn, Bhaskar accepted that all scientific observations are theory-dependent and that knowledge is historically contingent and fallible (Bhaskar, 1975; Bhaskar, 1979; Gorski, 2013).

However, unlike relativism, CR maintains that it is possible to rationally evaluate competing theories based on their explanatory power, a position known as judgemental rationality (Archer et al., 1995). Thus, while acknowledging that knowledge is provisional, CR rejects the idea that all interpretations are equally valid. Some accounts are better because they explain more, predict better, or are more coherent with known mechanisms.

This dual commitment, to epistemic humility and to rational critique, allows CR to steer a middle course between positivist certainty and postmodern relativism, making it an ideal foundation for explanatory social research.

CRE emerged from these philosophical roots as an applied methodology particularly suited to the evaluation of complex interventions. Initially popularised by Pawson and Tilley (1997), realist evaluation introduced the Context–Mechanism–Outcome (CMO) configuration as a way to understand not just whether an intervention works, but how, for whom, and under what circumstances. However, CRE, as developed in the work of Porter and others, builds more explicitly on the philosophical principles of CR by further differentiating between types of mechanisms and embedding a critical stance that considers the normative and ethical implications of outcomes (Porter, 2015).

CRE is therefore not only explanatory but also evaluative: it examines whether outcomes are desirable, just, or emancipatory. This makes it particularly suitable for studying healthcare interventions, such as EoLC for people with dementia, where complex institutional, interpersonal, and ethical factors intersect. CRE encourages the development of programme theories that identify intervention mechanisms, contextual enablers or constraints, and the agency of those involved, resulting in a layered understanding of how outcomes emerge (Marchal et al., 2012; Porter, 2015).

I chose CRE for this study because it aligns closely with the research aim of developing programme theories to inform sustainable interventions in hospital-based EoLC for people with dementia. CRE allows me to move beyond surface-level descriptions and instead identify the deeper generative mechanisms, both structural and agential, that shape care practices. Its focus on context, stratified causation, and moral evaluation makes it uniquely suited to addressing the complexities and value-laden nature of dementia care in hospital settings.

4.2.2. Ontology and Epistemology of This Study

The ontological position underpinning this study is that a structured, layered reality exists independently of human perceptions and discourses. This reality is stratified into three domains: the real (generative mechanisms and causal powers), the actual (events and outcomes), and the empirical (experiences and observations) (Bhaskar, 1975; Danermark et al., 2002). In the context of EoLC for individuals with dementia in hospitals, this means that institutional practices, professional behaviours, and patient experiences are shaped by deeper social, organisational, and cultural structures that exist whether or not they are immediately observable.

The study’s epistemological stance is one of epistemic relativism combined with judgemental rationality. I recognise that all knowledge is historically and socially conditioned, shaped by researchers' assumptions, values, and theoretical frameworks. However, this does not imply that all interpretations are equally valid. By employing CRE, I aim to use retroductive reasoning to infer the most plausible underlying mechanisms influencing observed patterns of care. Through systematic empirical inquiry, theory refinement, and reflexive engagement, I seek to produce provisional but robust explanations of how sustainable, enhanced EoLC can be achieved for people with dementia in hospital settings.

This ontological and epistemological positioning allows for a deeper, explanatory analysis of the interplay between context, agency, and intervention, rather than a purely descriptive account of surface-level phenomena.

4.2.3 Why Critical Realist Evaluation Was Chosen?

I selected CRE as the methodological approach for this study because of its ability to generate deep, context-sensitive, and explanatory insights into the complex social reality of EoLC for people with dementia in hospital settings. My research aimed to develop programme theories to inform interventions that support excellent and sustainable EoLC, and this required an approach capable of revealing not only what works, but how, for whom, and under what conditions. CRE, as derived from the ontological and epistemological commitments of CR (Bhaskar, 1975; Danermark et al., 2002), offered precisely such a framework.

Unlike methodologies that are primarily descriptive or grounded in empiricist assumptions, CRE allows me to go beyond surface-level observations to investigate the underlying causal mechanisms that influence care delivery. It acknowledges that outcomes are not simply the result of linear cause–effect relationships, but emerge from the dynamic interplay between intervention mechanisms, contextual conditions (both internal and external), and the agency of human actors (Porter, 2015). This aligns closely with my study’s objectives: to explore the needs of patients and their close others, identify how hospitals currently respond to these needs, and determine the mechanisms that can bridge the gap between care needs and care provision.

In practice, CRE has enabled me to address all five objectives of the study. By identifying contextual enablers and constraints at both system and ward levels, I could examine what supports or inhibits good practice. By exploring staff and family perspectives on care needs and delivery, I could interrogate the generative mechanisms that shape experiences and outcomes. In doing so, I was able to construct and refine programme theories that account for both agency and structure, and that reflect the real-world complexity of hospital-based EoLC for people with dementia.

CRE is also suited to ethically grounded research. Its philosophical foundation encourages evaluators to assess not only whether an outcome is produced, but whether that outcome is desirable or just (Porter, 2015; Archer et al., 1995). This is crucial in my study context, where questions of dignity, personhood, and humanity are central to understanding care at the end of life. CRE supports this ethical reflexivity while offering analytical tools to systematically interrogate how care practices are shaped and how they might be improved.

Another strength of CRE is its accommodation of multiple layers of analysis and methods. Because it rests on the assumption that reality is stratified and emergent, CRE permits the use of qualitative methods to examine meaning and experience (at the empirical level) while also theorising about causal mechanisms (at the real level). This allowed me to develop an analytic framework that captured both behavioural and experiential outcomes, two domains critical to evaluating the effectiveness of interventions in EoLC settings.

In sum, I chose CRE over other approaches because it provides a comprehensive and theoretically coherent means of understanding complex social phenomena such as EoLC in hospitals. It enabled me to develop context-sensitive and mechanism-based explanations, grounded in real-world practice, that are both explanatory and evaluative. This methodological choice supports the development of robust programme theories that can guide interventions to improve care for people with dementia and their families in hospital settings.

4.2.4 From Theory to Evaluation: Critical Realist Evaluation in Practice

Having selected CRE as the methodological foundation of this study, I now explain how it has been practically applied to the investigation of EoLC for people with dementia in hospital settings. This section outlines how CRE supports the development of context-sensitive programme theories and illustrates its value in evaluating complex care interventions.

CRE is grounded in the philosophical principles of CR, particularly its ontological commitment to real, stratified, and emergent structures and its epistemological stance of explanatory critique. Building on this foundation, CRE enables evaluators to move beyond measuring outcomes to uncover how, why, for whom, and under what circumstances interventions produce particular effects. This makes it well-suited for exploring care processes in hospital-based dementia care, where outcomes are shaped by layered interactions between interventions, institutional structures, and the actions of those involved.

Realist evaluation initially emerged as a response to the limitations of experimental approaches that failed to explain variation across settings or account for the influence of context (Pawson and Tilley, 1997). CRE builds on this tradition by integrating a stronger ontological grounding and a more explicit differentiation between social structures and human agency (Bhaskar, 1989; Danermark et al., 2002). It places particular emphasis on uncovering generative mechanisms – the causal processes that lie behind observed outcomes – and understanding how they operate within specific social and organisational contexts.

In CRE, outcomes are understood to emerge through the dynamic interplay between three elements: the intervention itself (and the mechanisms it activates), the context in which it is introduced, and the agency of individuals who interpret and act upon it (Marchal et al., 2012). Rather than seeing outcomes as the direct result of interventions, CRE frames them as emergent phenomena arising from complex causal relationships within open systems.

To operationalise CRE in this study, I applied a structured analytic model tailored to the investigation of EoLC in hospitals. This approach supported the development of programme theories that explain not just whether an intervention works, but how and why it does so in particular contexts.

The key analytical components of this model – intervention mechanisms, internal and external contextual mechanisms, human agency, and both behavioural and experiential outcomes – are introduced here but are explained in full in the next section (see section 4.2.4). That section also presents the adapted CRE framework used in this research and discusses how it reflects my critical realist ontology and supports theory-building across phases of data collection and analysis.

4.2.5 Components and Logic of Critical Realist Evaluation in This Study

The application of CRE in this study is guided by a structured analytical framework grounded in the ontological, epistemological, and methodological principles of CR, as previously discussed. By acknowledging a stratified reality composed of generative mechanisms, contextual conditions, and human agency, this approach enables me to explore how interventions operate in the complex, open system of hospital-based EoLC for people with dementia.

Informed by the foundational CRE formula – *Intervention Mechanisms + Contextual Mechanisms + Agency = Outcomes* – I adapted this model to suit the specific conditions of the hospital environment by distinguishing between internal and external contextual mechanisms. This resulted in a modified equation:

Intervention Mechanisms + Internal Contextual Mechanisms + External Contextual Mechanisms + Agency = Behavioural Outcomes + Experiential Outcomes

This nuanced version reflects my epistemological stance that social reality is stratified, context-dependent, and mediated through individual and collective agency. It also aligns with the study's aim to develop explanatory programme theories that address both the practical and experiential dimensions of EoLC.

Intervention Mechanisms

Intervention mechanisms refer to the internal logics or causal powers within specific care practices or strategies that aim to produce change. These are not the interventions themselves (such as a new communication protocol or palliative training initiative), but rather the processes triggered by these interventions that influence behaviour or perception. In this study, intervention mechanisms include efforts to improve multidisciplinary collaboration, enhance staff confidence in managing dying with dementia, or increase shared decision-making. Their success depends on the alignment between the intervention, the context in which it is introduced, and the actions of those engaging with it (Pawson & Tilley, 1997; Wong et al., 2013).

Internal Contextual Mechanisms

Internal contextual mechanisms comprise the organisational conditions within the hospital that either constrain or enable the activation of intervention mechanisms. These include resource availability, leadership practices, care routines, institutional norms, staff roles, and local culture. As part of a stratified ontology, these mechanisms represent structures that possess causal power, even if not always visible. My understanding of these internal dynamics draws on CR’s anti-reductionist stance, which holds that higher-level properties such as culture or hierarchy cannot be reduced to individual actions (Bhaskar, 1979; Danermark et al., 2002).

External Contextual Mechanisms

External contextual mechanisms refer to influences originating outside the immediate organisational setting, such as health policies, professional standards, public attitudes, media narratives about dementia, and funding frameworks. These broader structures impact how internal mechanisms function and shape the environment in which interventions are received. In line with CR’s emphasis on emergence and open systems, I conceptualised these external influences as part of the wider social ecology that interacts with internal mechanisms and agency to shape outcomes (Marchal et al., 2012; Bonell et al., 2012).

Human Agency

Agency captures the capacity of individuals – whether healthcare professionals, patients, or family members – to interpret, assess, and respond to the mechanisms at play. From a critical realist perspective, agency is irreducible to structure but always situated within it. Actors may reproduce, resist, or transform contextual conditions through their actions (Archer, 1995). In this study, agency includes staff decisions to initiate ACP, relatives' advocacy for loved ones, or ward managers adapting care protocols. These actions are shaped by professional identities, experiences, moral beliefs, and relational dynamics.

Outcomes: Behavioural and Experiential

This framework distinguishes between behavioural outcomes – observable changes in care practices, staff behaviour, or system processes – and experiential outcomes – the lived experiences, meanings, and emotional responses of patients, families, and staff. Behavioural outcomes might include increased documentation of treatment escalation plans or earlier recognition of dying. Experiential outcomes might involve feelings of being heard, respected, or supported at the end of life. This dual outcome lens reflects CR's layered ontology and my commitment to evaluating not just what happens, but how it is experienced (Pawson & Tilley, 1997; Wong et al., 2013).

Application to Theory Development

By tracing how intervention mechanisms are influenced by internal and external contexts, and mediated through human agency, I was able to build detailed programme theories that explain how and why certain outcomes emerge in specific settings. These theories were refined across two empirical phases: the first aimed at generating initial explanations, and the second at testing and elaborating them based on participant feedback. This process aligns with the logic of retroduction, a hallmark of CR methodology, through which explanatory theories are iteratively developed by reasoning from observed effects to potential causal structures (Bhaskar, 1975; Danermark et al., 2002).

In sum, this framework allowed me to examine the causal interplay between structure and agency, context and intervention, and observable and experiential consequences. It also provided the basis for evaluating whether current practices in EoLC for people with dementia promote or inhibit core values such as dignity, autonomy, and compassion – outcomes that are central to both policy aims and patient-centred care.

Having established the philosophical and methodological foundations underpinning this study, the next section outlines the research design and approach adopted to address the study's aim and objectives, detailing the sequential phases of data collection and analysis.

4.3. Research Design and Approach

A research design is a comprehensive plan that outlines a study's overall structure and methodology, providing a systematic framework for researchers to address their research questions or objectives (Leedy & Ormrod, 2014; Creswell & Creswell, 2017). It encompasses selecting appropriate data collection methods, sampling strategies, and data analysis techniques. A research design aims to ensure the study's rigour, validity, and reliability by guiding researchers in conducting their research systematically and logically. It helps to minimise bias, control extraneous variables, and establish the feasibility of the study (Polit & Beck, 2017). A well-designed research design enhances the quality and credibility of the study's findings, contributing to advancing knowledge in the field.

This research project follows a sequential multistage qualitative model to develop programme theories, using CRE to support quality and sustainable EoL for people with dementia in hospitals. The two main phases are developing programme theories and refining programme theories.

4.3.1. Research Aim and Objectives

Research aim

To develop programme theories to inform programme/interventions that enable hospitals to provide quality EoLC for people with dementia.

Objectives

1. To identify the needs of this group of patients.
2. To identify the needs of patients' close others.
3. To identify current clinical practice in response to these needs.
4. To examine the hospital context to identify factors that may support or inhibit good practice.
5. To identify the mechanisms required to narrow the gap between needs and the provision of care.
6. To develop programme theories to support quality EoLC for people with dementia in hospitals incorporating identified mechanisms, taking contextual factors and agency (stakeholders) into account.

4.3.2. Study Setting

Staff, managers, and bereaved relatives and close others were recruited from a District Hospital in England. The research was conducted in an acute hospital boasting a total of 345 beds and serving a diverse population of approximately 185,000 individuals, primarily hailing from south Somerset, North and West Dorset, and parts of Mendip. This healthcare facility is equipped to offer a comprehensive array of clinical services, encompassing general medicine, cardiology, general surgery, orthopaedic surgery, trauma, and paediatrics. On an annual basis, the hospital handles a substantial volume of cases, witnessing approximately 20,000 emergency admissions and 18,000-day cases. The accident and emergency department of the hospital accommodates more than 40,000 visitors each year, while the intensive care unit provides specialised care to numerous individuals. The diverse and extensive nature of services offered by this hospital serves as a rich backdrop for the study, providing valuable insights into a dynamic healthcare environment.

4.3.3. Sample and Recruitment

Anonymity

To ensure privacy protection, all participants' identities were anonymised. Personal identifiable information was removed, and participants were assigned nominal pseudonyms. Anonymity measures were applied uniformly to all project participants, as follows:

- Nominal pseudonyms were used to conceal participants' identities (e.g., staff member 'James' identified as 'S1', Focus group 1 staff member ‘Jane’ identified as ‘FG1P1’, Family member ‘John’ identified as ‘F1’).
- Only me had access to personal contact details.
- If contact details were known, they were stored separately on a secure, password-protected computer at Bournemouth University and deleted at the study's conclusion.

Participants had the freedom to withdraw from the study at any point. For individual interviews, participants could request that their data be withheld or destroyed until the anonymisation point. In the case of focus group discussions, participants were informed beforehand that once the discussions commenced, their data could not be withheld or destroyed.

Inclusion and exclusion criteria

The following eligibility criteria were established to fulfil the objectives and aims of the study:

1) Staff working in the District Hospital must have had experience in delivering EoLC for people with dementia or regular direct contact with such individuals. The participants encompassed healthcare staff from diverse professions and ancillary staff to capture varied perspectives and obtain richer data.

2) Bereaved relatives of individuals who died with terminal stage dementia within the last few weeks and were admitted to or died in the District Hospital.

Exclusion criteria

1) Staff working in the District Hospital with no experience or direct contact with inpatients with dementia.

2) Bereaved relatives of individuals who died from terminal non-dementia-related diseases.

3) Bereaved relatives who were not actively involved in the care of people with dementia during their EoL stage.

4) Bereaved relatives lacking mental capacity to consent.

5) Bereaved relatives under 18 years old.

6) Bereaved relatives who could not communicate in English.

4.3.4. Sampling and Size of Sample

Recruitment was conducted using stratified sampling, a subset of purposive sampling (Robinson, 2013). Purposive sampling involves selecting participants based on known characteristics and the study's aim (Tongco, 2007). Therefore, individuals who met the study's aim and selection criteria were invited to participate. Stratified sampling involved categorising participants into three groups: staff, managers, and bereaved relatives. Each group had its own inclusion criteria and participants were selected accordingly.

Given that a qualitative approach prioritises depth and richness of data over quantity (Tongco, 2007), a small number of participants were involved in the study. This approach ensured manageability within the study's timeframe and accounted for the amount of data generated. Mason's (2010) survey of over 500 PhD projects revealed that a sample size between 10 to 40 was common for qualitative interviews. In this study, it was anticipated that starting with a minimum size of 5 participants per group in each phase, potentially doubling that size, would be sufficient for individual interviews. For focus groups, it was expected that starting with a minimum of three participants per group, with two focus groups per group in each phase, and a maximum of eight, would be adequate. The total minimum expected number of participants in this study was around 40.

4.3.5. Recruitment and Consent

The recruitment and consent process for this study was carefully designed in alignment with Health Research Authority (HRA, 2019) guidance. Participation was entirely voluntary. All participants were fully informed about the study and provided written consent prior to data collection. Recruitment and consent procedures were carried out across two stages of the study, involving three groups: bereaved relatives, healthcare staff (interview participants), and healthcare staff (focus group participants).

1. Phase One: Recruitment and Consent

Bereaved Relatives – Semi-Structured Interviews

Bereaved relatives were recruited from an acute hospital in England via the Bereavement Team, who acted as gatekeepers. Flyers with my contact details were also posted on hospital notice boards in waiting areas and wards. Around one to two weeks after bereavement, gatekeepers contacted potential participants by phone. I had no access to any personal information until individuals gave oral consent to be approached.

Once interest was expressed, I provided the Participant Information Sheet (PIS) (Appendix 2), consent form (Appendix 5), and interview schedule (Appendix 6). Several participants used the information provided in the Participant Information Sheet to clarify logistical details, such as the expected duration of the interview, the type of questions they would be asked, and the location of the session. Interviews were arranged at a time and location chosen by the participant, with the option to delay participation for up to six months post-bereavement. Written consent was obtained prior to the interview. Follow-up contact was made the week of the interview to confirm attendance and answer any final questions.

Bereaved relatives were not included in focus groups due to the sensitive and private nature of their experiences, the emotional vulnerability often present in grief, and the risk of retraumatisation through group discussion. Individual interviews were deemed more appropriate to provide a safe, confidential space for open reflection.

Healthcare Staff – Semi-Structured Interviews

I recruited healthcare staff directly from the wards to ensure open access and avoid gatekeeper selection bias. Staff were approached during informal conversations and invited to express interest independently. Flyers were displayed in common staff areas, and interested staff were provided with the PIS (Appendix 4), consent form (Appendix 5), and interview schedule (Appendix 8) Several staff members used the Participant Information Sheet to ask clarifying questions about the expected duration of the interview, the nature of the discussion, and scheduling logistics.

Interviews were scheduled based on staff availability, often during quiet periods on shift or before/after work. Written informed consent was obtained before interviews, and participants were reminded of their right to withdraw at any time. In total, [insert number] staff members participated in individual interviews during phase one.

Healthcare Staff – Focus Groups

Focus group recruitment for staff was conducted through ward announcements, informal briefings, email invitations, and flyers. Staff were invited to express interest and suggest availability for proposed group sessions. While many expressed enthusiasm about participating, coordinating availability proved challenging. The nature of shift work and unpredictable clinical demands limited the number of staff able to attend at the same time.

Those who expressed interest were provided with the PIS (Appendix 3), consent form (Appendix 5), and schedule (Appendix 7). Some participants used the PIS to clarify practical aspects such as the timing and structure of the session and whether attendance could occur during working hours**.** Several participants had to withdraw on the day of the scheduled focus group due to unforeseen work commitments. Despite these challenges, [10] staff participated in two focus groups (5 in each). Consent was reconfirmed prior to participation.

2. Phase Two: Recruitment and Consent

Following the analysis of phase one data and the development of initial programme theories, phase two commenced. The aim was to validate, refine, or challenge the initial theories through additional data collection involving the same three participant groups.

Bereaved Relatives – Follow-Up and New Interviews

Previous participants were re-contacted to assess their interest in phase two and reconfirm consent. New bereaved relatives were also recruited through the same procedure as in phase one, using the Bereavement Team and hospital flyers. All were given updated study documents (PIS, consent form, interview guide), and informed consent was re-confirmed before interviews**.** As with phase one, several participants referred to the PIS to clarify expectations regarding timing, format, and the nature of questions to be asked. As before, only individual interviews were conducted with bereaved relatives due to the emotional and ethical sensitivities of group discussions.

Healthcare Staff – Follow-Up and New Interviews

Staff who had participated in phase one were invited to contribute to phase two. New staff participants were also recruited using the same direct and voluntary approach. Updated PIS, consent forms, and interview guides were provided**.** Some participants used these materials to confirm practical details such as duration, format, and their role in responding to the theories**.**

Interviews were arranged based on availability, and informed consent was obtained and reconfirmed.

Healthcare Staff – Focus Groups

Staff focus groups in phase two followed the same recruitment strategy as in phase one, with continued challenges related to availability and shift patterns. Efforts were made to provide flexible scheduling options. Participants were again given the PIS, consent form, and focus group guide**.** Several participants used the information sheet to clarify expectations around group size, length of discussion, and confidentiality. Despite persistent scheduling issues and occasional last-minute withdrawals due to clinical demands, [insert number] staff participated in phase two focus groups.

Participation levels and withdrawal patterns mirrored those in phase one, highlighting ongoing operational pressures in the healthcare environment.

3. Gatekeepers management**.**

The palliative and EoLC team, the dementia team, and the bereavement team served as gatekeepers. The gatekeepers, especially for the bereaved relatives, were first contacted through written invitations that explained the project and the expected involvement. The invitations provided relevant contact information for the research team, allowing gatekeepers to reach out with any inquiries.

Effectively managing gatekeepers was a crucial aspect of ensuring the success of participant recruitment in this study. As the principal investigator, I recognised that gatekeepers, particularly clinical staff and team leads, played a central role in enabling access to potential participants, especially bereaved relatives and frontline healthcare professionals. I prioritised establishing early and clear communication by outlining the study’s aims, ethical safeguards, and practical expectations. Several gatekeepers were involved from the planning stage, which helped foster a sense of ownership and trust. For example, I held three planning meetings with the palliative care team lead, where I shared a draft of my recruitment strategy and invited feedback. One key suggestion was to approach bereaved relatives earlier in the process, provided the bereaved relatives gave consent. I considered this input seriously, searched the literature to explore its feasibility, and subsequently amended my protocol in line with the suggestion. Throughout, I aimed to create a collaborative relationship by maintaining transparency and showing genuine appreciation for their involvement.

To support gatekeepers in their role, I provided accessible materials such as PIS, copies of the research protocol, and invitation letters. I also made myself available for questions by sharing both my email address and mobile number. In addition to informal conversations, I organised routine follow-up meetings to discuss progress, clarify roles, and address any concerns. When one gatekeeper stepped back from their role due to workload and logistical pressures, I adapted my strategy by updating the list of gatekeepers and amending my HRA protocol accordingly. Roles and responsibilities were clearly defined from the outset, particularly for bereaved relatives, where the gatekeeper's, basically the bereavedment team, sole task was to offer a brief introduction to the study, provide the PIS, and obtain verbal consent for me to make further contact. I consistently aimed to recognise the efforts of gatekeepers, and as a gesture of appreciation, I gave each of them a personalised thank-you card and a small token (such as a chocolate gift box). These actions, alongside ongoing support and ethical diligence helped build a trusting, cooperative environment that facilitated the recruitment process in a respectful and professional manner.

4.3.6. Data Collection

1. Phase One of Data Collection

This research project's recruitment and consent process were carefully considered and aligned with the HRA consent and participation guidance (HRA, 2019). Participation in the study was entirely voluntary, and potential participants were informed about the research objectives, their rights, and the confidentiality and anonymity of their data. Phase One of data collection aimed to explore the experiences, needs, and challenges associated with EoLC for people with dementia in a hospital setting. This stage provided the foundation for developing initial programme theories, consistent with the principles of CRE.

The participants for Phase One of the study included bereaved families and close others of patients who had passed away with dementia in hospitals, as well as hospital managers and healthcare/non-professional staff. Two primary data collection methods were employed: focus group discussions and individual semi-structured interviews. The interviews took place either at the hospital, over the phone, or through teleconferencing applications. For bereaved relatives, HER

Focus group discussions were conducted exclusively in the hospital setting, while individual interviews were held in a suitable room provided by the hospital. The designated room ensured privacy, minimal background noise, and reduced disruptions, creating an environment conducive to participants sharing their experiences. The interviews lasted approximately 40 minutes, while focus group discussions were limited to a maximum duration of one hour. The number of participants in the focus groups varied between 3 and 8 individuals.

To facilitate the recruitment process, I provided a verbal introduction to the staff. At the same time, gatekeepers, the bereavement team, orally introduced the study to bereaved relatives. The contact details of potential participants were obtained from the Bereavement team, and flyers with the my contact information were posted on advertising boards. Interested individuals were encouraged to contact me or provide permission to the gatekeepers, allowing arrangements for in-person, email, or postal visits to deliver information and obtain informed consent.

During the data collection process, oral and written informed consent was obtained from participants. Interviews and focus group discussions were audio-recorded with participants' permission to ensure accurate transcription. Confidentiality was encouraged throughout the research, and participants were requested to respect the confidential nature of shared content. Ground rules were established to prevent over-disclosure and ensure that participants were aware of the boundaries of the discussions. Transcripts of the recorded data were anonymised by removing any personal identifiable information. Nominal codes were assigned to protect participant identities, such as S1 for staff participant 1, and F1 for bereaved family 1. The anonymised transcripts are securely stored in a locked and secure location within Bournemouth University for up to 30 months, in accordance with Bhaskar and Hartwing, 2016 and Bournemouth University's Code of Practice for research (2023). After data collection, participants were thanked for participating and offered a summary of the findings if requested. They were also allowed to ask any questions. Participants were assured that their personal information would be kept confidential, and the data would only be accessible to me and discussed with the supervisory team for the purpose of the study. Personal data, including contact information, would be securely stored in a password-protected Bournemouth University account and deleted once the study was completed. If any participants became upset during the interviews or focus group discussions, data collection was paused or stopped, and they were signposted to relevant support services and charities. The presence of a second researcher in focus group discussions provided additional support to participants. If necessary, the focus group could be restarted or postponed to a later date to ensure the well-being of participants. Throughout the research, participants were free to withdraw their participation at any point. For individual interviews, participants could request that their data be withheld or destroyed until the point of anonymisation. However, for focus group discussions, participants were made aware that their withdrawal would be challenging due to the nature of the data collection method. The data collection process employed a combination of semi-structured interviews and focus groups to gather a comprehensive understanding of patients' and close others' needs, current approaches to EoLC in hospitals, and potential barriers or opportunities for the provision of appropriate care. Semi-structured interviews allowed in-depth exploration of participants’ perspectives and meanings (Patton, 1990; Kvale, 2007). This method was particularly suitable for bereaved relatives, who may be more comfortable sharing their experiences on a one-to-one basis.

On the other hand, focus groups provided a platform for participants to engage in group discussions, allowing for diverse perspectives and interactive exchanges (Bloor et al., 2001). However, focus groups required careful management due to the involvement of multiple participants and the potential challenges associated with participant dynamics (Van Teijlingen & Pitchforth, 2006). It was necessary to ensure both talkative and quiet participants had the opportunity to contribute, facilitated by a skilled moderator and facilitator (Williams et al., 2005; Van Teijlingen & Pitchforth, 2006).

Despite the benefits of focus groups, some limitations were acknowledged. Familiarity among participants could potentially inhibit open discussions on sensitive topics or lead to the phenomenon of ‘groupthink,’ where one dominant member’s opinion influences the rest of the group (Van Teijlingen & Pitchforth, 2006; Boateng, 2012). Considering the sensitivity of discussing the death of a family member, bereaved relatives and close others were allowed to participate only in semi-structured interviews to ensure their comfort and willingness to share their experiences. The questions asked during both the interviews and focus groups were open-ended, allowing participants to provide detailed responses and enabling me to explore various aspects related to understanding palliative care, the needs of patients and their close others, and the factors that support or inhibit good practice. The questions were carefully designed based on insights from two literature reviews, a systematic review and a CRR, to ensure relevance and alignment with existing knowledge (Patton, 1990; Kvale, 2007).

2. Phase Two Data Collection

After developing the initial programme theories through thematic analysis in Phase One, I proceeded with Phase Two to further validate and refine the theories. This phase involved engaging stakeholders in semi-structured interviews and focus groups to gather their feedback, insights, and experiences.

Semi-structured Interviews

During the semi-structured interviews, individual stakeholders, including healthcare staff, managers, and bereaved relatives, were invited to participate. The interviews allowed the me to explore and delve deeper into each participant's perspective, providing rich and detailed insights. The interview questions were open-ended and designed to align with the research objectives, exploring themes related to EoLC for people with dementia and identifying barriers and facilitators.

Focus Groups

In addition to semi-structured interviews, focus groups were conducted separately for staff. Focus groups provided a platform for participants to engage in group discussions, enabling interactive exchanges and capturing diverse viewpoints. I acted as a moderator and facilitator, ensuring that all participants had the opportunity to contribute and that the discussions remained focused on the research objectives.

Consistency in Data Collection Process

The data collection process for Phase Two followed a similar approach to Phase One. I approached potential participants with a verbal introduction to the study. Participants provided informed consent, and both the interviews and focus group discussions were audio-recorded with their permission.

4.3.7 Data Analysis

4.3.7.1. Compatibility of Thematic Analysis with Critical Realist Evaluation

In this study, I adopted thematic analysis as the principal approach to data analysis during both phases of primary data collection. I selected this method because of its conceptual flexibility and its alignment with the philosophical underpinnings of CRE.

Thematic analysis, as outlined by Braun and Clarke (2006), provides a structured yet adaptable method for identifying, analysing, and interpreting patterns of meaning across qualitative data. Importantly, it allows for both inductive and deductive approaches and is not tied to any one theoretical orientation. This made it particularly suitable for my research, where the objective was to understand the mechanisms, contexts, and agency shaping EoLC for people with dementia in hospital settings.

The compatibility of thematic analysis with CRE rests on their shared commitment to investigating both the observable and the underlying structures of social phenomena. While CRE seeks to explain how and why interventions generate particular outcomes in specific contexts by identifying underlying mechanisms (Porter, 2015), thematic analysis offers a systematic approach to surfacing those mechanisms from empirical data. In line with Bhaskar’s (2008) stratified ontology, thematic analysis allowed me to explore experiences and practices at the empirical level while also identifying patterns indicative of deeper causal tendencies at the actual and real levels. This was particularly important in a complex care environment like hospital-based dementia care, where much of what influences practice is not directly visible but rather embedded in institutional, relational, and emotional structures.

In Phase One, I used thematic analysis inductively to generate themes from interviews and focus groups without relying on any pre-existing coding framework. I began with a topic guide shaped by the findings of two preceding literature reviews, one systematic and one critical realist. These reviews informed the questions I asked but did not impose any theoretical categories upon the data. As I engaged with the transcripts, I applied open coding to identify recurring ideas, concerns, and meanings expressed by participants. This approach allowed the data to guide the emergence of potential explanatory patterns.

Within the critical realist tradition, knowledge is always mediated by social and conceptual structures; however, reality exists independently of our perceptions of it (Bhaskar & Hartwing, 2016). Thematic analysis enabled me to trace this interplay between meaning and structure. Through the iterative process of coding, categorising, and developing themes, I was able to move beyond descriptive accounts to identify latent patterns that suggested the presence of deeper generative mechanisms. These mechanisms, such as institutional norms, communication dynamics, or workforce constraints, were not always directly articulated by participants but could be inferred from their accounts of actions, routines, and outcomes.

Moreover, thematic analysis supports the CRE goal of building and refining programme theories. In my study, the themes derived from participants' accounts of EoLC were used to map out early configurations of context–mechanism–outcome relationships. For instance, participants' references to restricted visiting policies, staff shortages, or emotional labour were not simply grouped as thematic categories; rather, they were examined for their potential role as contextual mechanisms or constraints on agency. This analytical movement from theme to explanatory structure reflects the abductive and retroductive logic central to CRE (Fletcher, 2017).

I also found that the reflexive and transparent nature of thematic analysis helped maintain rigour in the analytic process. I documented decisions made during coding and theming, regularly discussed interpretations with my supervisory team, and engaged in critical reflection on how my own background and positionality might shape the lens through which I viewed the data. This reflexive practice was essential to ensure that themes were not only grounded in participants' accounts but also capable of contributing to theory development within the critical realist paradigm.

In summary, thematic analysis proved to be a robust and philosophically compatible method for analysing qualitative data within a CRE framework. It enabled me to move from empirical accounts to theoretically meaningful insights, aligning with the broader aim of this study: to uncover the complex, context-sensitive mechanisms that shape EoLC for people with dementia in hospitals.

4.3.7.2. Phase One of Data Analysis

Developing Questions for the First Stage

At the outset of this study, I did not begin with predefined programme theories. Instead, I adopted an exploratory stance, drawing on the findings of two prior literature reviews, one systematic and one critical realist, to guide the development of my interview schedule. These reviews provided a foundational understanding of existing interventions, policy-practice gaps, and the challenges and enablers of EoLC for people with dementia in hospital settings. Rather than using these findings to formulate theoretical propositions, I used them to shape a flexible and responsive set of open-ended questions.

The purpose of this initial phase was to generate a context-sensitive understanding of how EoLC is delivered to people with dementia in hospitals and to surface the needs, experiences, and challenges faced by staff and bereaved relatives. This approach aligns with the methodological principles of CRE, which seeks to identify underlying mechanisms, contextual conditions, and human agency that shape outcomes (Porter, 2015).

My interview schedule was structured around three broad domains identified through the reviews: (1) understandings of EoLC and palliative care; (2) the needs of patients and their close others; and (3) barriers and facilitators to enhanced care. For instance, one recurrent issue in the literature was the limited involvement of families in decision-making at the end of life. This directly informed the inclusion of questions such as: *"How do you feel about initiating conversations about end-of-life within the team or with the patients and their close others?"* and *"What do you feel as a professional about the need for those conversations?"* These questions aimed to explore how communication, timing, and cultural factors shaped collaborative care planning.

Importantly, the questions were designed as guides rather than rigid prompts. I approached each interview with a topic schedule that ensured coverage of key areas, while allowing participants the space to speak freely, follow their own lines of thought, and reflect on personal or organisational experiences. This flexible approach was particularly effective in revealing nuanced insights, for example, around the emotional labour involved in delivering EoLC, and the tensions between policy expectations and real-world constraints.

This process reflects what Bhaskar (2008) describes as "epistemic relativism" within a realist ontology, acknowledging that our understanding of causality is partial and situated, and that meaningful theories must be grounded in the lived experience of those embedded in practice. My aim was therefore not to test hypotheses, but to elicit rich data from which to begin theorising, inductively, about the mechanisms and contextual factors influencing care delivery.

Rather than framing the data collection process through pre-existing logic models or theory-driven questions, I used findings from the literature as a sensitising framework to inform a grounded, participant-led inquiry. The initial programme theories were subsequently developed not from assumptions, but from patterns and explanations emerging from the narratives of staff and bereaved relatives.

Coding Strategy

In line with the methodological underpinnings of CRE, I adopted a hybrid approach to coding that combined both inductive and deductive strategies. This dual approach enabled me to remain open to novel insights emerging from participants' accounts while also drawing on the conceptual foundations laid by the earlier stages of the study, including the systematic and CRRs.

Inductive Coding

Inductive coding was used to allow themes to emerge directly from participants' narratives, without being constrained by pre-existing theoretical frameworks. I immersed myself in the transcripts by reading and re-reading them, paying close attention to the language used, metaphors, and emotionally charged expressions. I highlighted significant statements, patterns of meaning, and recurring experiences relevant to how EoLC was provided to people with dementia in hospital settings. This open-ended engagement allowed for the identification of themes that were grounded in participants’ lived experiences, such as uncertainty around prognosis, relational care practices, and the emotional labour of providing compassionate care.

Deductive Coding

In parallel, I used a deductive strategy to sensitise my analysis to themes that reflected key concepts identified in my prior literature reviews. These included, for example, EoLC needs (spiritual, emotional, and physical), systemic or organisational barriers to good care (e.g., time constraints, staff training), and enabling factors (e.g., family involvement, team communication). While these sensitising concepts were not imposed onto the data, they guided the development of my coding framework and helped ensure that relevant aspects of the participants’ accounts were systematically explored.

For instance, codes such as "relational care," "barriers to family involvement," and "staff communication gaps" were derived deductively, while codes such as "being human with patients" and "learning from international colleagues" emerged inductively. The dual strategy supported the identification of both expected and unanticipated mechanisms influencing the provision of EoLC.

Iterative Theme Development

The coding process was iterative and recursive. Initial coding was followed by grouping related codes into tentative categories, which were then refined into preliminary themes. These themes were discussed with my supervisory team in regular analysis meetings. Through these discussions, I reflected critically on the codes and considered alternative interpretations. Some codes were split into sub-themes; others were collapsed into broader categories when their scope became clearer.

As I moved through the transcripts, I continuously returned to earlier coded data to refine my analysis, check for consistency, and remain responsive to new insights. This iterative process allowed me to gradually move from detailed descriptive codes to more abstract and explanatory themes that could underpin the development of initial programme theories.

In keeping with the critical realist commitment to identifying generative mechanisms, I sought to understand not only what was happening but also why and under what conditions particular patterns of care or responses emerged. This layered approach helped link the data to the broader evaluative aim of explaining how EoLC interventions might work, for whom, and in what contexts.

Coding and Theming Process

Following the combined inductive and deductive coding strategy, I used Braun and Clarke’s (2006) six-phase framework for thematic analysis to develop and refine themes across the dataset. These phases were not treated as strictly linear; rather, the process was iterative and reflexive, enabling repeated movement back and forth across phases to better understand and reframe developing insights.

Phase 1: Familiarisation with the Data

I immersed myself in the data by reading and re-reading the transcripts of interviews and focus groups, listening to recordings, and taking observational notes. This enabled me to identify early patterns of meaning and pay close attention to verbal and emotional cues that pointed to participants' assumptions, concerns, and priorities related to EoLC for people with dementia.

Phase 2: Generating Initial Codes

Coding was carried out manually using Word and Excel documents. In this phase, I generated initial inductive codes closely tied to participants' own language. These were descriptive and low-level, capturing features of interest across the dataset without attempting to interpret their broader significance prematurely. For example:

- The segment: "*I think education helps in making sure starting with ward staff, HCAs and nurses, able to understand dementia better and how end-stage dementia presents" (S8)* was initially coded as: importance of education, understanding end-stage dementia, need for HCA/nurse knowledge.
- Another excerpt: "*I participated in a simulation exercise... the consultant assessed my performance and provided feedback" (S14)* was coded as: simulation training, communication practice, feedback from senior staff.

Phase 3: Searching for Themes

These codes were then reviewed and organised into potential themes. I grouped similar codes under broader thematic umbrellas that related both to the mechanisms and contexts shaping EoLC. At this stage, I also began comparing these codes with the concepts and findings from the systematic and CRRs, mapping the data onto the overarching CRE domains: intervention mechanisms, contextual mechanisms (internal/external), agency, and outcomes.

Phase 4: Reviewing Themes

Thematic groupings were iteratively reviewed in collaboration with my supervisory team to ensure that themes were coherent, distinct, and robust. This stage involved comparing themes across different participant groups (e.g. hospital staff vs bereaved relatives) and examining negative cases or contradictions. Reflexive discussions and theoretical memo-writing helped me identify gaps and test the coherence of each candidate theme.

Phase 5: Defining and Naming Themes

Each theme was refined to capture its central organising concept and its relation to the realist formula (intervention mechanisms + contextual mechanisms + agency = outcomes). For instance, a theme initially labelled ‘education’ was later developed as ‘Education and Training’ and positioned as an intervention mechanism because it was described by participants as an action to improve knowledge, confidence, and compassionate care delivery. Similarly, ‘communication across shifts’ and ‘hierarchical decision-making’ were identified as internal contextual mechanisms.

Phase 6: Producing the Report

Themes were finalised and structured to form the results in Chapter 5, organised into eleven themes across the five critical realist categories. Data extracts were carefully selected to illustrate the mechanisms and their interaction with context and agency. These examples were chosen to highlight the generative mechanisms at play and how they shaped EoLC outcomes.

Throughout this process, I engaged reflexively by keeping a research diary to note my assumptions, shifts in interpretation, and critical reflections on my position as an outsider to the NHS system. I also consulted with my supervisors after initial coding to test thematic development, and discussed emerging interpretations, particularly where they related to entrenched medical ideologies or conflicting staff perspectives.

This process ultimately allowed for the development of themes that were grounded in the data but also aligned with the critical realist framework of the study.

Development of Initial Programme Theories

Following the completion of inductive and deductive thematic analysis, the early patterns that emerged from the data were systematically mapped to the components of the CRE heuristic: intervention mechanisms, internal contextual mechanisms, external contextual mechanisms, agency, and outcomes (Porter, 2015). This mapping process enabled me to theorise how and why particular mechanisms influenced care outcomes in specific hospital contexts for people with dementia at the end of life.

Mapping Early Themes to CRE Components

Thematic findings were first clustered into broad categories corresponding with the five components of the CRE formula:

- **Intervention Mechanisms**: These were actions, strategies, or structures perceived to bring about change in EoLC for people with dementia. For instance, staff described simulation-based training and video education (Theme 1: Education and Training) as mechanisms for improving communication and empathy. ACP (Theme 2) and multidisciplinary meetings (Theme 3) were also considered purposeful interventions.
- **Internal Contextual Mechanisms**: These were conditions internal to the hospital that either enabled or constrained the effectiveness of interventions. For example, communication practices between staff (Theme 5), institutional hierarchies, the quality of documentation, and organisational resources (Theme 6) were identified as key internal contextual mechanisms. These factors shaped whether interventions such as care plans or family meetings could be effectively implemented.
- **External Contextual Mechanisms**: These mechanisms existed outside the immediate hospital setting but had a direct impact on care quality. For example, Theme 7 (Communication with Community Services) and Theme 8 (Medical Ideology to Save Lives) illustrated how fragmented communication across community and hospital settings and a culture of aggressive treatment impacted EoLC delivery.

- **Agency**: Agency referred to the capacity of stakeholders, staff and family members, to act within or against contextual constraints. Themes 9 (Culture), 10 (Staff Perceptions), and 11 (Bereaved Relatives' Perceptions) illustrated how actors made sense of their roles, advocated for change, or passively accepted suboptimal care. Overseas nurses learning UK approaches to death and dying, and bereaved relatives reflecting on their involvement in care decisions, were prime examples of agency shaping practice.
- **Outcomes**: These were the changes observed or anticipated as a result of the interaction between intervention mechanisms, contexts, and agency. For example, outcomes of training interventions included increased empathy, better communication, and confidence in delivering EoLC (for more details, see section 5.7).

Informing Initial Programme Theories

Once these thematic elements were categorised using the CRE framework, I began developing a series of initial programme theories. Each theory was built by tracing how a specific intervention mechanism interacted with particular contextual conditions and how different actors responded to these conditions (agency), ultimately shaping the outcomes. For instance:

- **Education and Training Theory**: Simulation training (intervention) was effective in small, cohesive teams (internal context), but challenged by resource limitations (context) and varied levels of staff confidence (agency).
- **Advance Care Planning Theory**: ACP mechanisms succeeded when community planning occurred early (external context), but were undermined by time constraints and medical ideology in acute settings (internal and external context). Family collaboration and staff confidence were essential agentic elements.

These theories were then structured into question sets, which were presented to participants in Phase Two of the study (see Chapter 6), as part of a validation and refinement process. The stakeholder interviews and focus groups in the second phase built upon these initial theories to assess their resonance, accuracy, and completeness within real-world practice.

In summary, the development of initial programme theories was not a linear process but an iterative, abductive exercise. Early themes provided the raw material, which I then analysed using the CRE framework to construct explanatory propositions about how EoLC interventions function within the complex hospital system. These initial theories laid the foundation for their refinement through stakeholder engagement in the second stage of the study.

4.3.7.3. Phase Two Data Analysis

Following the development of initial programme theories in Phase One, the second phase of data analysis aimed to refine these theories by presenting them back to stakeholders for review and critique. This phase was designed in alignment with the principles of CRE, recognising that theory development is iterative, contingent on empirical engagement, and shaped by ongoing interpretive processes (Porter, 2015). As such, I adopted a cyclical approach to data collection and analysis, whereby stakeholder feedback was analysed to test, challenge, and deepen the programme theories originally developed.

Theory Presentation and Engagement

At the outset of each semi-structured interview and focus group, participants, including hospital staff, managers, and bereaved relatives, were provided with a summary of the initial programme theories. These theories had been developed using the formula: **intervention mechanisms + internal contextual mechanisms + external contextual mechanisms + agency = outcomes**. Participants were asked to reflect on each theory and offer comments on whether the configurations made sense, whether anything was missing, and how well the theory reflected their own experiences.

For example, the initial theory regarding education and training proposed that a combination of immersive training, communication development, and culturally sensitive instruction could enhance EoLC delivery. Participants in Phase Two validated key components but also highlighted additional intervention mechanisms, such as the role of dementia education teams and the influence of online learning environments, that were subsequently integrated into the refined theory (see Chapter 6, section 6.3.2).

Thematic Coding and Refinement

Data from stakeholder interviews and focus groups were analysed using a hybrid of deductive and inductive thematic coding**.** The deductive component involved mapping participant responses to the components of the existing theories (e.g. identifying new internal contextual mechanisms like “lack of dedicated space for online training” or new agency factors such as “importance of ward leader engagement”). The inductive component allowed new patterns to emerge that had not been captured in Phase One. For example:

- In the refinement of the ACP theory, participants introduced a new external contextual mechanism: the lack of unified platforms for ACP documentation, which was not part of the original theory (Section 6.4.5).
- Similarly, participants' experiences of collaboration with hospice professionals emerged inductively as an important external mechanism in the education theory (Section 6.3.5).

All coded data were categorised under the CRE framework components: intervention mechanisms, internal/external contextual mechanisms, agency, and outcomes.

Iterative Validation and Synthesis

The refinement process involved iterative synthesis. After initial coding, I returned to the original theories and generated updated logic models that integrated stakeholder perspectives. For instance:

- Theory One (Education and Training) evolved from a generic model of video and simulation-based training to a more nuanced theory that included a two-tier training system**,** staff interest and availability, and dementia champions as critical enabling mechanisms (Section 6.3.8).
- Theory Two (Advance Care Planning) was expanded to reflect cultural barriers**,** legal ambiguities around translation, and the absence of proactive community

engagement, which participants identified as key external contextual mechanisms inhibiting ACP (Sections 6.4.5 and 6.4.6).

In each case, I not only mapped findings to the critical realist formula but used direct quotes to preserve the stakeholder voice and maintain epistemological proximity between data and interpretation. For example, P5’s comment about the mentorship role of hospice staff (“...someone who can give them little, 'Right, if you're really struggling...’”) illustrated the need for embedded, peer-supported learning mechanisms in EoLC education.

4.3.8. Reflexivity and Researcher Positioning

Throughout both phases of data collection and analysis, I engaged in continuous reflexivity to consider how my own background, assumptions, and positioning shaped the interpretation of data. My prior experience as a nurse in intensive care units outside the UK meant that I was familiar with EoLC practices but less so with the institutional frameworks and cultural expectations surrounding dementia care in British hospitals.

This outsider perspective offered both challenges and advantages. In Phase One, unfamiliarity with the local context required deliberate efforts to understand institutional protocols and team dynamics. I mitigated this by reviewing NHS policy documents, engaging in shadowing opportunities, and maintaining openness in interviews. However, this positionality also allowed me to critically observe and question taken-for-granted practices without being embedded in the assumptions of the system.

In Phase Two, reflexivity became even more important. As I returned the theories to participants, I was aware of the power dynamics that might influence how feedback was shared. I made it clear that the theories were provisional and open to change, and I invited participants to critique them candidly. This transparent stance enabled participants to share divergent views and facilitated the co-construction of more grounded and nuanced programme theories. Reflexive memos were maintained throughout this phase to capture my evolving interpretations and reactions to participant feedback.

By maintaining a reflexive stance, I was able to enhance the rigour of both phases of analysis, remain attentive to my influence on the research process, and ensure that the emerging theories were genuinely informed by stakeholder voices

4.3.9 Rigour of the Study

The rigour of this study was ensured through several measures, including transferability, credibility, dependability, and confirmability. These aspects are essential in maintaining the quality and trustworthiness of qualitative research (Lincoln & Guba, 1985; Shenton, 2004).

Transferability

Transferability refers to the extent to which the findings of a study can be applied or generalised to other contexts or settings (Lincoln & Guba, 1985). In this study, efforts were made to provide a detailed description of the research context, data collection process, and the characteristics of the participants. This transparency allows readers to assess the extent to which the findings may be applicable to other similar hospital settings or populations facing EoLC for people with dementia. By including a comprehensive description of the research methodology and the context, the study aimed to enhance the transferability of its findings.

Credibility

Credibility, also known as internal validity, concerns the accuracy and truthfulness of the study’s findings (Shenton, 2004). To enhance credibility, several strategies were employed. First, I engaged in prolonged engagement with the participants, spending sufficient time within the research setting to understand the intricacies of EoLC for people with dementia. This immersion allowed me to gain an in-depth understanding of the participants’ perspectives and experiences, thereby strengthening the credibility of the findings. Moreover, the use of multiple data sources, such as semi-structured interviews and focus groups, allowed for triangulation, ensuring consistency and coherence in the data.

Dependability

Dependability, analogous to reliability, refers to the consistency and stability of the study’s findings over time and under different circumstances (Lincoln & Guba, 1985). In this study, I maintained detailed records of the research process, including data collection, analysis, and interpretations. These records were kept for audit purposes, allowing for verification and reproducibility of the study's findings. Additionally, the use of a systematic and transparent data analysis approach, such as thematic analysis, added to the dependability of the research.

Confirmability

Confirmability relates to the objectivity and neutrality of the research findings, ensuring that they are not influenced by the researcher's biases or preconceptions (Shenton, 2004). To establish confirmability, I engaged in reflexivity throughout the research process, continuously reflecting on my own assumptions and potential biases. By documenting my reflexive thoughts and decision-making processes, I provided transparency and enhanced the confirmability of the study.

Ethics

Before commencing this study, it was reviewed by an independent NHS research ethics committee (REC), Wales REC 6, as part of the IRAS NHS ethics approval process granted on 14/02/2022. Before the project's commencement, approval was sought for the study and all supporting documentation. An annual progress report was submitted to the REC within 30 days of the anniversary of the time the favourable opinion was given and until the study had ended. After completing the project, a final report with the project results was submitted to the REC. In conclusion, this study employed various rigorous strategies, including transferability, credibility, dependability, and confirmability, to ensure the trustworthiness and quality of its findings. These measures were essential in maintaining the integrity of the research and in producing meaningful insights into EoLC for people with dementia in hospital settings.

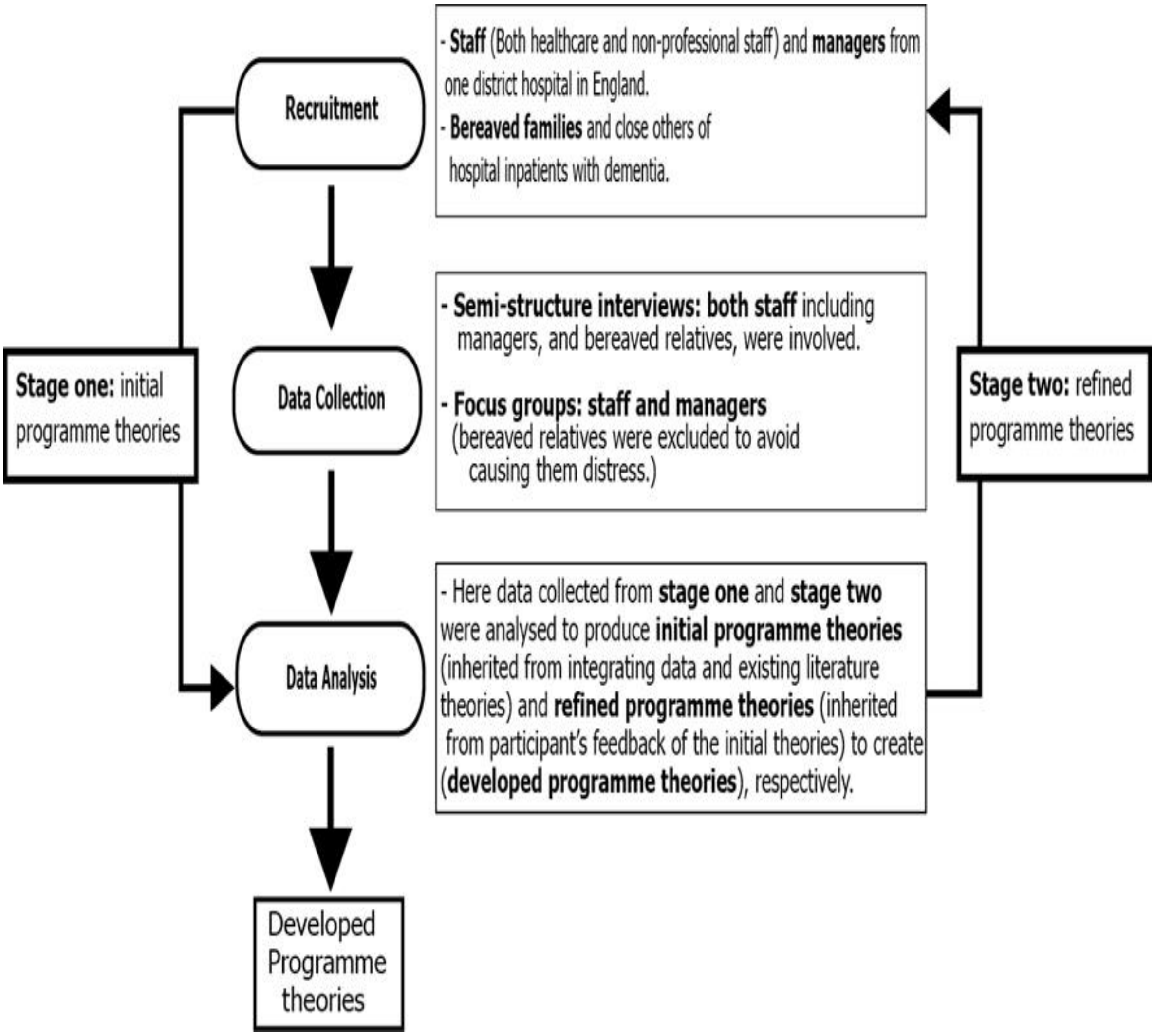


Figure 4-1 Study Flowchart.

Table 4-1 Study sample Numbers.

Summary of the expected participants number for the study Activity	Staff	Bereaved relatives	Duration
Focus groups phase 1	Two groups of 3-8 participants in each.	Nil	1 hour
Semi-structured interview phase 1	5-20	5-10	40 minutes
Focus groups phase 2	One group of 3-8 participants.	Nil	1 hour
Semi-structured interview phase 2	5-20	5-10	40 minutes

4.3.10. Ethical Considerations

Disclosures around the topic of EoLC had the potential to be emotive and evoke emotions. Therefore, the project was managed with sensitivity and awareness of these issues in mind. Furthermore, I am a registered nurse, and in accordance with the Nursing and Midwifery Council (NMC) code of conduct (2018), practised safely and ethically, recognised their vulnerability (physical and emotional) or distress while also providing any support, conveying compassion and sensitivity.

Participation in the project required each participant to be fully informed and consented. Before the project was commenced, it gained Health Research Authority approval and NHS Research Ethics Committee favourable opinion.

It was acknowledged that bereaved relatives and staff might have become upset or experienced emotional trauma while discussing their experiences of EoLC for people with dementia. In such cases, I also signposted the participants to the relevant support services (see PIS, Appendices 4-6).

The bereaved relatives were contacted within the first week or two after bereavement. Bentley (2015) reported that family carers stated that recall would be better earlier in bereavement and felt it might help them talk about their experiences earlier. However, I was aware that the length of the grief period varied for different people. Therefore, the I allowed the bereaved relatives to decide for themselves when to be involved in the interview.

In addition, cultural factors were taken into account, and the interviews and focus group discussions were sensitive to such issues. For example, different nationalities and religions might have had different approaches to talking about death, which needed to be managed as part of the data collection.

A. Assessment and management of risk

Lone working

I was lone working when interviewing bereaved relatives through phone calls. In line with Bournemouth University's policy, I informed the supervisory team about the timing and duration of lone working to manage associated risks effectively (see appendix: 11 for Bournemouth University's lone working policy).

To account for the risks posed during data collection over the phone with bereaved relatives, I conducted risk assessments considering both their own safety and the emotional well-being of participants (bereaved relatives). Risks were posed to both me and the participants, such as uncertainty about others health. Bournemouth University's lone worker policy and risk assessment policy were followed to manage these risks. Furthermore, as I was meeting people who were already potentially vulnerable emotionally, they carefully reflected on coping strategies if they were to become very distressed.

B. Reporting practice

I, being a registered nurse, had a legal, ethical, and professional duty to report any instances of foreseeable risk to the safety of the public, patients, and staff, as well as any unsafe practices (NMC, 2018). Throughout the project's duration, it was possible that malpractice or unsafe practices might be discussed in interviews or focus group discussions. In such cases, I adhered to Yeovil District Hospital policy regarding reporting instances of foreseeable risk. The Participant Information Sheet (mention their numbe) highlighted my duty to report any unsafe practices that may be raised during the study.

C. Emotional distress to the participants

It was acknowledged that the interviews would explore the difficult and potentially distressing subject of EoLC for people with dementia. Therefore, it was possible that some participants might become distressed during the interviews, especially bereaved relatives who had lost a loved one. The interviews were conducted with sensitivity, and the questions asked were carefully designed to consider participants' emotions and well-being. Some procedures were put into consideration in case a bereaved relative became distressed during the interview, it would be paused or stopped, and I considered to offer hospital chaplaincy EoLC or suggest approaching a UK-based charity providing support to individuals who have experienced bereavement.

Regarding staff, they might have experienced emotional trauma while discussing EoLC experiences for people with dementia. All data collection for the staff occurred in a district hospital, which had mechanisms and procedures in place to support staff who might experience emotional trauma during such discussions.

To avoid distress, I explained the nature of the questions briefly to the participants before the start of the interview. Participants were given the opportunity to stop or pause the interview if they became distressed, and they were signposted to relevant support services if necessary. Furthermore, if distress occurred for staff in the hospital, I directed them to the wide range of available resources within the trust accessible online (see PIS sheet, Appendices 4 and 5).

If staff became distressed or upset during focus group discussions, I considered to pause or stop the discussion, and would allow the participant to leave. The clinical supervisor was present at the focus group discussion and was available to offer participants any necessary support.

D. Emotional distress to the researcher

Due to the research project's focus on EoLC for people with dementia and the qualitative nature of exploring emotions and experiences, I have experienced some emotional stress throughout the project. To manage the potential emotional stress, I discussed issues with the supervisory team and also considered contacted Bournemouth University's counselling service.

E. Participant Withdrawal

Participants were free to withdraw from the study at any point. For individual interviews, participants could request that their data be withheld or destroyed until the point of anonymisation. However, due to the nature of focus group discussions, participants were made aware that withdrawal would be challenging.

F. Researcher Bias

Being the researcher of this study, there is a potential for bias to have influenced various stages of my research process. Researcher bias refers to the subjective opinions, beliefs, or preferences of the researcher that can influence the design, data collection, analysis, and interpretation of the study results (Creswell, 2014).

During the data collection phase, my background as a registered nurse and prior experiences in healthcare settings may have influenced how she interacted with participants and the questions she asked during interviews and focus group discussions. This could have led to unintentional framing of questions that aligned with my pre-existing knowledge or assumptions about EoLC for people with dementia. Moreover, my familiarity with the hospital setting and the research topic may have influenced how she selected potential participants or approached gatekeepers for recruitment. This could have led to a biased sample, where certain perspectives or experiences were overrepresented or underrepresented in the study (Babbie, 2016).

During data analysis, my prior knowledge of the literature and theoretical frameworks may have influenced the identification and interpretation of themes. For example, if I had preconceived notions about the importance of certain factors in EoLC, I might have unconsciously emphasised or downplayed certain themes during the thematic analysis process (Braun & Clarke, 2006).

To mitigate researcher bias, I employed several strategies throughout the research process. First, she continuously reflected on my own beliefs and assumptions about EoLC and dementia to remain conscious of their potential influence on the study. Second, I used an iterative approach to data collection and analysis, seeking feedback from the supervisory team by sending discussing them with the supervisors in their meetings and receiving feedback from the clinical supervisor after attending the focus groups to challenge my interpretations and ensure multiple perspectives were considered (Miles et al., 2014).

While every effort was made to minimise researcher bias, it is essential to acknowledge that some degree of subjectivity is inherent in qualitative research. By being transparent about the researcher’s potential biases and employing rigorous research methods, I aimed to enhance the credibility and trustworthiness of the study findings (Creswell, 2014).

4.4. Chapter Summary

In this chapter, I have outlined the theoretical and methodological framework underpinning this research, which explores EoLC for individuals with dementia in a district hospital in England. I began by presenting the philosophical foundations of the study, grounding the research in CR and applying CRE to examine complex social phenomena within healthcare settings. By tracing the roots of CR, including its influences from realism, Kantian philosophy, Marxism, and post-positivist thought, I justified the selection of CRE over other paradigms, highlighting its alignment with the study's aims and objectives.

I then described the research design, setting, sampling strategy, recruitment processes, and the two-phase approach to data collection and analysis. Phase One involved semi-structured interviews and focus groups with staff, managers, and bereaved relatives, applying thematic analysis to identify initial mechanisms, contextual factors, and emerging programme theories. I explained how inductive and deductive coding approaches were combined under the principles of CRE to ensure theoretical depth. Phase Two engaged stakeholders in validating and refining the initial theories through further interviews and focus groups, ensuring that the final programme theories were grounded in both empirical data and stakeholder perspectives.

Throughout the study, I ensured ethical rigour by adhering to NHS and University ethical protocols, safeguarding participant welfare, ensuring informed consent, maintaining confidentiality, and practising reflexivity to critically examine my own assumptions and positionality. I also mapped the research process visually, providing a clear account of how data were transformed into programme theories.

This chapter provides the philosophical, methodological, and ethical foundations upon which the subsequent findings chapters are built, offering a robust and critical framework for understanding and improving EoLC for individuals with dementia through a CRE lens.

Chapter 5 Stage One: Initial Programme Theories

5.1. Introduction

This chapter presents the initial programme theories developed from the first phase of fieldwork. The overall objective of this stage was to explore how and why EoLC for individuals with dementia succeeds or fails in hospital settings, from the perspectives of hospital staff and bereaved relatives. Grounded in a CRE framework, this chapter seeks to explain not only what works but also how, why, for whom, and under what circumstances improvements in care can be achieved.

To meet this objective, qualitative data were collected through semi-structured interviews and focus groups. These involved two primary stakeholder groups:

Hospital staff, anonymised as (S1, Staff) for staff participant number one, anonymised as (S1, Staff) participant number one, (FG1P1, Staff) participant one from focus group one.

Bereaved relatives of individuals who died with dementia in a district general hospital in the UK, anonymised as (F1, Family).

The analysis combined inductive and deductive thematic approaches within the CRE logic model (Intervention Mechanisms + Internal Contextual Mechanisms + External Contextual Mechanisms + Agency = Outcomes), as proposed by Porter (2015). The initial programme theories presented in this chapter emerged from this analytical process.

A total of eleven themes were identified during the first phase of analysis. These themes are structured under the following components of the critical realist framework:

The following section details how these themes were developed and their alignment with the Critical Realist Evaluation framework.

This chapter presents the initial programme theories derived from the first phase of this CRE. The aim was to explore the underlying mechanisms and contextual factors that support or inhibit the delivery of EoLC for people with dementia in an acute hospital setting. To do so, qualitative data were collected through semi-structured interviews with bereaved relatives and focus groups with hospital staff in one district hospital in the UK.

The thematic development followed a combined inductive and deductive approach, guided by the five dimensions of the CRE framework: Intervention Mechanisms, Internal Contextual Mechanisms, External Contextual Mechanisms, Agency, and Outcomes. Transcripts were first explored inductively to allow patterns and categories to emerge naturally from the narratives. This was followed by a second cycle of coding, in which emerging themes were aligned deductively with the CRE framework components.

The process was iterative and reflexive. Themes were initially coded line-by-line and grouped into first-level codes reflecting observable phenomena. These were then reviewed and abstracted into higher-level categories that reflected the generative mechanisms and contextual enablers or barriers influencing EoLC for people with dementia. Codes were validated through memo-writing, researcher triangulation, and cross-comparison of staff and relative transcripts to ensure thematic rigour and data balance (For more details, see 4.3.7.2. Phase One of Data Analysis).

The final eleven themes are presented below, grouped according to their alignment with the CRE framework:

Intervention Mechanisms:
1. Education and Training
2. Advance Care Planning Implementation
3. Multidisciplinary Team Care Approach
4. Family and Person-Centred Approach

Internal Contextual Mechanisms:
5. Communication Within the Organisation
6. Organisational Policies, Resources, and Facilities

External Contextual Mechanisms:
7. Communication with Community Health Services
8. Medical Ideology and the Drive to Save Lives

Agency:
9. Cultural Sensitivity
10. Staff Perceptions About End-of-Life Care
11. Family Perceptions About End-of-Life Care

Intervention mechanisms strategies and resources intended to improve EoLC.

Internal contextual mechanisms: organisational, interpersonal, and cultural factors within the hospital.

External contextual mechanisms: broader structural factors such as policy and funding.

Agency: the actions and interpretations of staff and families within given contexts.

Outcomes: reported or observed effects on EoLC quality and patient-family experience.

Each theme is discussed in relation to its origin in the data, supported by anonymised quotations from both staff and relatives. Care has been taken to balance representation between the two groups, ensuring that the voices of both professional and familial carers are equitably presented where possible. The quotes have also been edited for length where appropriate to improve clarity, while preserving their intended meaning.

5.2. Participants

At this stage of the study, fourteen staff participated in semi-structured interviews, and ten staff were involved in two focus groups and five bereaved relatives of people who died of dementia in one district hospital for semi-structured interviews. For the staff, all the interviews and the focus groups were conducted face-to-face in the hospital. The bereaved relatives were interviewed over the phone. The demographics of the participants are presented in Table 5-1 for the staff and Table 5-2 for the bereaved relatives. The participants were recruited from a district hospital in the UK. For more information about the recruitment process (see Chapter 4). The time since the death of the person with dementia and recruiting their close others ranges between two weeks and 6 months after death.

Table 5-1 Hospital Staff Demographics.

Gender	
Male	4
Female	20
Age Range	
20-29	5
30-39	6
40-49	9
50+	4
Years of experience	
Less than 1	2
1-10	12
11-20	8
+20	2
Post	
Consultant Nurse	5
Registrar	1
Registered Nurse	4
GP Trainee	4
Student Nurse	2
HCA	4
Dietitian	1
Physiotherapist	1
Art Design Coordinator	1
Chaplain	1
Country of origin	0
United Kingdom	15
Oversees	9

Table 5-2 Bereaved Relatives Demographics.

Total interviewed	5
<u>Gender</u>	
Male	2
Female	3
<u>Age range</u>	
40-59	2
60-79	2
80+	1
<u>Next of Ken</u>	
Spouse	1
Adult child	3
Family Friend	1

5.3. Intervention Mechanisms

This section presents the intervention mechanisms identified, and their effect on the outcomes of care in hospitals. Four themes emerged, including education and training, ACP, multidisciplinary team communication, and family and person-centred approach.

Theme one: Education and training

Education and training are foundational intervention mechanisms that underpin the capacity of hospital staff to deliver high-quality EoLC for people with dementia. The data from both staff and family participants highlight that the most effective education operates through a variety of targeted methods, each shaping staff knowledge, attitudes, and behaviours in unique ways.

A core mechanism is the structured induction programme for new staff, which uses video-based education and experiential sessions to foster empathy and encourage a person-centred approach.

> *“I remember we had shown a lovely video of a patient's own experience… The staff should be trained because if the staff doesn't know what's going inside patients’*

> *mind… she's not knowing that this patient is either going for feeling forgetfulness. She may say you don't know this"* (S7, Staff).

This approach helps staff appreciate the lived reality of dementia, establishing a foundation for sensitive and individualised care. However, participants acknowledged that the impact of induction can be short-lived unless continuously reinforced in practice.

Structured education on recognising symptoms specific to EoL dementia emerged as a critical educational need. Misidentifying these symptoms can significantly affect the timeliness and appropriateness of care provided. As one participant described:

> "*I think education helps...teaching staff how to recognise pain in people with dementia, and agitation is another one. Some staff might mistake terminal agitation for normal dementia agitation, leading to delays in appropriate care*" (S8, Staff).

This mechanism is vital because timely recognition of EoL symptoms directly impacts the patient's comfort and overall care experience. Targeted training on symptom recognition ensures staff can distinguish between regular dementia progression and critical indicators of EoL, thus improving care delivery and family confidence.

To build on this foundation, simulation and scenario-based training represent a further intervention mechanism. These sessions allow staff to practise complex communication tasks, such as breaking bad news to families, and receive immediate feedback from experienced trainers.

> *"I participated in a simulation exercise alongside a palliative care team consultant, where we practised breaking bad news to a family member. Following my interaction with one of the daughters, the consultant assessed my performance and provided feedback. It was very helpful, as it made me realise how to phrase things gently and how important my body language is. After the session, I felt much more confident to do this in real life"* (S14, Staff).

Such immersive experiences increase staff confidence and skill in managing emotionally charged situations, supporting more compassionate EoLC.

Ongoing and refresher training were repeatedly emphasised by participants as essential for maintaining competence, particularly in the face of high staff turnover and the emotional complexity of dementia care.

> *"We need more refresher courses… sometimes I forget what I learnt in the last course, especially if I haven't had a dementia patient for a while. The refresher brings it back to the front of my mind"* (S3, Staff).
>
> *"We need more regular training. There's just too few and far between at the moment. Staff turnover is quite high, so we have to keep holding on"* (S13, Staff).

These statements underscore that effective training is not a one-off event, but a continuous process that supports knowledge retention and normalises good practice in a changing workforce.

A critical suggestion to address the persistent gap between dementia and EoLC expertise was the development of dual-specialist roles, capable of bridging both domains.

> *"…perhaps looking at someone who would have that role… So, they would specialise in dementia, but at the end of life, so they would work between us [Dementia and palliative teams]. It would be a sort of personal development, professional development for one of us... I think the problem is educating staff and staying on top of that"* (S13, Staff).

The data suggest that such integrated specialist roles could significantly improve continuity and coherence of care, provided there is sustained organisational commitment to professional development.

Peer learning and the presence of "*dementia champions*" or *"link nurses"* emerged as informal yet powerful mechanisms for disseminating up-to-date knowledge and fostering a culture of best practice. As one staff member explained,

> *“Dementia champions… They get study days. So, they get the up-to-date information if they want to volunteer… and they could actually support the ward if they needed something”* (FG2P3, Staff).

These roles act as real-time resources for colleagues, supporting ongoing learning and modelling best practice within clinical teams.

Written policies, booklets, and regular email communications from the palliative team were also cited as accessible, practical resources that help to standardise care.

> *“For policies related to these patients, we have a separate booklet that contains all the necessary information. We don't have to search everywhere to find what we need to do. The booklet provides us with the guidance we require, so we are familiar with the appropriate actions to take when caring for the patient”* (S14, Staff).

This highlights the importance of integrating written guidance with face-to-face and peer-supported learning.

Many participants recognised that staff who were trained overseas often perceive death and dying differently, reflecting the cultural context in which they originally worked. For example, S7 explained:

> *“Most of us do not come from a background where we have a lot of dementia patients. We are given training… and that helps a lot. Then the experience, asking senior staff who know exactly what to do.”* (S7, Staff)

These staff members gradually gain confidence and adapt to UK practices through experience and the informal support of their colleagues. However, several participants emphasised that relying solely on peer learning is not sufficient or appropriate. Instead, structured, formal education is essential to ensure that all staff, regardless of their background, are equipped to provide high-quality EoLC for people with dementia.

As (S8, Staff) (Palliative Care Specialist Nurse) articulated:

> *“When we have lovely overseas nurses… the cultures are so different… we just don’t spend enough time accessing what it was like in cultures that aren’t English. ...If we give them the appropriate training, yes, and sometimes if we give the training, not once, but twice or repackage it and refresh it. …When you’ve been in a role a long time, it never hurts to go back to the beginning… Sometimes you forget.”* (S8, Staff)

Participants emphasised that, beyond training overseas staff, there is also a significant need for British-trained staff to better understand the diverse cultural backgrounds and expectations of their patients. As one participant explained:

> *"We have patients coming from different cultures and backgrounds, and sometimes we don’t fully understand how they perceive care or death and dying. It would be really helpful if we could have some structured training around understanding different cultural practices and preferences. I think that would make us more sensitive and aware in providing better care"* (S10, Staff).

This highlights a critical educational gap, recognising that culturally sensitive care must extend beyond simply integrating overseas staff. The effectiveness of dementia care and EoLC significantly relies on staff's cultural awareness and their ability to address the nuanced expectations and practices of diverse patient populations. Structured, culturally sensitive education tailored for British staff would enhance the person-centred care model and improve patient and family experiences at critical times.

This highlights that, while experience and peer support are valuable, the key mechanism for enabling overseas-trained staff to deliver compassionate, confident care is a combination of targeted, repeated formal education and a genuine appreciation for their cultural perspectives. By investing in ongoing, structured training and cultural exchange, hospitals can transform perceived barriers into opportunities for learning and improved care.

Participants also highlighted the importance of structured dementia and EoLC training for non-clinical hospital staff. Non-clinical staff frequently serve as the initial point of contact for patients and families, particularly during emotionally charged situations. One healthcare assistant clearly illustrated this:

> "*Even non-clinical staff have daily contact with these patients, and families often talk to them first. They need proper training about dementia and EoL so they can confidently support both patients and families*" (FG1P2, Staff).

Without adequate training, non-clinical staff may feel ill-equipped or uncertain, potentially negatively affecting their interactions with families. By providing structured dementia and EoLC education to non-clinical staff, hospitals can ensure all personnel contribute consistently to compassionate, person-centred care, improving communication, patient experiences, and family interactions.

In summary, education and training mechanisms identified in the hospital context are multi-faceted and intricately connected, each addressing distinct and vital aspects of EoL dementia care. Structured induction programmes employing experiential and video-based methods establish an initial foundation for empathy and understanding, but require ongoing reinforcement through additional training mechanisms such as regular refresher courses and simulation-based exercises. The importance of these regular training sessions was repeatedly highlighted as essential for maintaining staff competence amid high turnover and emotionally challenging care scenarios.

Specialised, dual-competent roles, integrating dementia and palliative care expertise, were proposed as a valuable educational intervention mechanism, bridging existing gaps between specialised teams. Peer learning strategies, including the implementation of dementia champions or link nurses, provide real-time support and ensure continuous dissemination of best practice.

Written guidance materials, including policies, booklets, and regular email updates, further complement practical training sessions, offering accessible, standardised resources for all staff. Crucially, the revised analysis emphasises culturally tailored education not just for overseas-trained staff, who require structured formal training alongside peer support, but also for British-trained staff to deepen their understanding of culturally diverse patient populations. The additional focus on structured dementia and EoLC education for non-clinical staff acknowledges their pivotal role in frontline interactions with patients and families, underscoring the need for comprehensive organisational training.

Collectively, these interconnected educational mechanisms support the ongoing development of compassionate, culturally sensitive, and competent dementia EoLC. This comprehensive training approach ensures that knowledge is not merely delivered but deeply integrated into everyday practices, enhancing the quality of care for patients and their families.

Theme two: Advance Care Planning Implementation

Staff and families highlighted that ACP's main function is to move away from a "one size fits all" approach to truly personalised EoLC. ACP is seen as a tool for capturing each individual's unique wishes, but there was widespread agreement that it ideally should not be created for the first time in the acute hospital setting. Instead, the hospital's role is often to act on an existing ACP or, if none exists, to begin the process as best as possible under time constraints.

> *"ACP is basically a document to enable us to give person-centred care and treat that person as an individual instead of treating everyone the same. And, you know, equality is great, but we need to treat that person."* (S1, Staff)
> *(Shows staff explicitly contrasting ACP with the "one size fits all" approach.)*
>
> *"The ideal would be for ACPs to be started before admission, so we know what the person wants before they come to hospital. But if they arrive without one, we have to start that conversation here."* (S8, Staff)
> (Acknowledges ACP is best created earlier but hospitals are forced to start ACP if one is missing.)
> ACP was sometimes misunderstood as a checklist or confused with DNACPR, though some staff made clear that ACP is broader, encompassing preferences for comfort, setting of care, visitors, and cultural wishes.
>
> *"Sometimes people think ACP is just about DNACPR, but it's actually about everything: where someone wants to be, who should be there, and what sort of care they want."* (S2, Staff)
> *"The DNACPR is part of it, but ACP is a bigger plan about how you want to be looked after at the end of your life."* (F4, Family)

There were mixed views on whether ACP is obligatory, with some staff emphasising that, while ACP is strongly encouraged, it is not legally binding, and families or clinicians sometimes override written wishes in practice.

> *"Even if there's an ACP, it's not always set in stone. Things change, and sometimes we need to make decisions that aren't written down."* (S9, Staff)

> *"ACP isn't something you have to do, but it helps everyone understand what's important for the patient."* (S11, Staff)

This evidence underlines ACP's role in preventing generic, protocol-driven care at EoL. However, both staff and family sometimes see ACP as bureaucratic or symbolic—an "ideal" not always achieved, especially when initiated late. There is also ongoing uncertainty about the status and "obligatoriness" of ACP, which can undermine its influence on actual care decisions.

A thorough, ongoing assessment and screening process is pivotal for effective ACP. This mechanism allows staff to "discover" the person behind the diagnosis, surfacing diverse needs physical, psychological, social, spiritual that generic plans would miss.

> *"…the nursing staff do that assessment and their screening… There's a big variation between what people see as comfortable. Some want to be left alone; some want company. Some want everything done; others don't."* (S4, Staff)

> *"They asked about my mum's favourite music and if there were foods she disliked. It wasn't just medical."* (F5, Family)

Assessment goes beyond "tick-box" forms, requiring skilled conversation and patience. In practice, the quality of assessment varies by staff training, workload, and personal attitudes.

The best assessments include family perspectives, past advance statements, and input from multiple disciplines, not just the admitting doctor or nurse.

When assessment is rushed or superficial, ACP risks reverting to the "one size fits all" default, with the plan reflecting what's convenient for the service not what's meaningful to the person.

> *"Some staff are very good at asking the right questions, but sometimes it's done in a hurry. You end up with the basics, not what matters most."* (F1, Family)

> *"If there's no time, you do what's standard, not what's personal."* (S13**,** Staff**)**

The true strength of ACP as an intervention lies in thorough, sensitive, and repeated assessment. Without this, ACP becomes an empty document. Where assessments are done well, staff can anticipate needs, prevent crises, and deliver genuinely personalised care, as illustrated by the most positive family accounts.

The hospital setting often requires adaptation of ACP documents to account for the complexity of acute care and the unpredictability of EoL trajectories in dementia. This requires both written plans (ACP) and skilled, ongoing dialogue.

> "*Plans need to be flexible. What someone wants might change, especially if things get worse suddenly."* (S6**,** Staff**)**
> *"We use the treatment escalation plan if there's no ACP, but that's more medical. The ACP should be about the whole person."* (S5**,** Staff)

> *"Sometimes the ACP says not to do something, but the family changes their mind or the situation changes. We have to adapt."* (S10, Staff)

Flexibility is an intervention mechanism in its own right: it enables staff to provide care that is both safe and person-centred, even as clinical realities shift. The risk is that too much flexibility can undermine patient autonomy, especially if staff or families are not familiar with the patient's previously expressed wishes.

This analysis demonstrates that ACP's *intervention mechanisms* personalisation, holistic assessment, and flexible application—are essential for delivering meaningful EoLC for people with dementia in hospitals. However, barriers such as time constraints, misunderstanding of ACP's purpose, lack of early planning, and inconsistent applicaion of documents (e.g., TEP, DNACPR) can reduce ACP to a mere formality. The most effective ACP processes are those started early, continually revisited, and embedded in the day-to-day work of hospital teams, always prioritising the person's values over convenience or routine.

Theme three: Multidisciplinary Team Care Approach

The Multidisciplinary Team (MDT) model emerged from staff interviews as a key intervention for enabling high-quality EoLC for people with dementia in hospital settings. MDT functioning works through mechanisms that promote collaborative planning, responsive communication, shared decision-making, and information continuity. While bereaved relatives did not explicitly discuss MDT processes, this likely reflects their "backstage" nature, central to the coordination of care, but not always visible to patients and families.

A core mechanism underpinning MDT functioning was informal, real-time collaboration among professionals. Participants described ad hoc conversations with colleagues, often outside formal meetings, as central to identifying and responding to EoL needs in people with dementia.

> *"I can think of times in the past when I've worked closely with speech and language therapists, for example, and they've been excellent and always communicated their concerns with the medical team or nursing team."* (S1, Staff)

> *"If I notice something, I go straight to the palliative care nurse or the doctor, no need to wait for a meeting. We deal with it as a team there and then."* (S6, Staff)

These informal interactions act as a flexible and rapid communication mechanism, enabling swift care planning and reducing delays, especially in situations where patients deteriorate quickly. Such conversations are often initiated by frontline staff who notice changes in patients' behaviour or status and seek input from colleagues with different expertise.

Regular MDT meetings were identified as a key mechanism for enabling shared care planning, especially in complex cases of dementia where trajectories are uncertain and multiple specialities are involved. These meetings bring together doctors, nurses, allied health professionals, and dementia or palliative care specialists to review each patient's case.

A critical reason for the importance of these meetings in dementia care is the high rate of comorbidities. People with dementia often have multiple long-term conditions, such as heart failure, diabetes, or recurrent infections, that require input from different specialities. As such, EoLC planning for this group cannot be managed by a single clinician or team.

> *"So we have what we call multidisciplinary team meetings. We have them every morning… We get together and discuss the patients' cases. And sometimes, speech and language therapists are there… We even talk about our dying patients, what we need to do. For example, we look at feeding risks"* (S12, Staff).

> *"A lot of dementia patients are under multiple specialities, cardiology, geriatrics, sometimes stroke. It gets confusing if we don't all speak. The meetings help keep everyone on the same page"* (S9, Staff).

These structured meetings act as a coordination mechanism across specialities, preventing fragmented care and allowing teams to discuss treatment escalation, goals of care, and family communication in a unified way. They are particularly useful for reviewing deteriorating patients who may be approaching the end of life, ensuring that all clinical voices are heard and care plans reflect the totality of the patient's condition and preferences.

A third mechanism was in-situ mentoring of junior doctors and less experienced staff by more senior clinicians. This support was critical in helping junior staff recognise signs of EoL in dementia and engage in sensitive discussions with families.

> *"It should be the medical staff's decision that somebody is reaching EoL. I think a lot of junior doctors struggle with decision-making… we [palliative care team] help them out and guide them on communication and signs to look for."* (S11, Staff)

> *"If a junior nurse is unsure, they often come to me or one of the dementia team. We talk them through what to say or how to document something sensitive."* (S13, Staff)

This mechanism promotes knowledge transfer, emotional confidence, and clinical competence. Rather than relying solely on formal training, real-time mentoring helps embed good EoLC practices within daily clinical routines.

A final mechanism was the use of shared documentation across professional boundaries. Participants described the importance of consistent and accessible notes, medical, nursing, and specialist, to ensure everyone involved had a clear picture of the patient's status, preferences, and care plan.

> *"Because there are so many staff, you've got to track care. You've got medical notes, nursing notes… sometimes you have like a hip fracture pathway."* (S13, Staff)

> *"It's the notes that hold it all together. If one person misses something, someone else can catch it later. It's all about staying aligned."* (S5, Staff)

This mechanism supports asynchronous collaboration, especially important in shift-based systems, and ensures that changes in patient needs, EoL decisions, or family conversations are not lost between handovers. Consistent documentation also helps reduce contradictions in care and builds trust among families who receive consistent messages from different professionals.

This theme identified four core intervention mechanisms through which functioning supports high-quality EoLC for people with dementia. Informal interprofessional collaboration enables timely and flexible coordination, particularly in fast-paced hospital environments where rapid responses to changing patient needs are essential. Structured MDT meetings facilitate collective decision-making and early recognition of EoL trajectories, especially important for patients with dementia and multiple comorbidities who are managed across different specialties. Mentorship of junior staff, particularly by experienced palliative care professionals, strengthens the team's capacity by modelling sensitive communication and guiding clinical judgement in complex

EoLC situations. Shared documentation across professions ensures continuity of care, prevents fragmentation, and supports a unified approach by keeping all team members informed of patients' evolving needs and preferences. Although these mechanisms were identified solely through staff interviews, they are crucial for delivering coordinated, person-centred care. Their success depends on organisational commitment to maintaining structured MDT processes, providing protected time for mentoring, and ensuring system-wide access to integrated documentation platforms.

Theme four: Family and Person-Centred Approach

Intervention mechanisms centred around a Family and Person-Centred Approach to EoLC for individuals with dementia in hospitals were perceived as offering comprehensive support to both the person with dementia and their close relatives. These mechanisms encompassed several key elements:

Firstly, the adaptation of care approaches to align with the individual's unique personal needs, preferences, and goals for EoLC.

> *"They really got to know Dad... they treated him like a person, not just a patient."* (F3, Family)
> *"We try to tailor care to what they used to like... some prefer music, others quiet."* (S7, Staff)

Secondly, the active involvement of the patient with dementia in decision-making processes, to the extent feasible given their condition.

> *"Mum wasn't able to say much in the end, but before that, they always asked her preferences when possible."* (F2, Family)
> *"We give them choices in food, activity... even if they're confused, that moment of control matters."* (S9, Staff)

Thirdly, the inclusion of both the patient and their family in care planning and discussions, ensuring that their perspectives and wishes are considered.

> *"The team always included us in decisions. They'd ask what we thought Dad would want."* (F4, Family)
> *"We try to involve the family early... they know the patient best."* (FG2, Staff)

Additionally, efforts were made to modify the physical environment to minimise confusion, enhance comfort, and optimise sensory experiences for individuals with dementia.

> *"The room was quiet, they dimmed the lights... made it less medical."* (F1, Family)
> *"We adjust the lighting, reduce noise, and bring familiar things into the room."* (S6, Staff)

Emotional support was provided to both the person with dementia and their close relatives throughout the entirety of the EoL journey.

> *"One of the nurses sat with me for ages... she didn't have to, but it meant everything."* (F5, Family)
> *"We're not just caring for the patient, the family is part of it too."* (S10, Staff)

Furthermore, measures were taken to ensure continuity of care and facilitate smooth transitions between different care settings, as well as to connect families with additional support services. The emphasis on identifying preferences of both the patient and their family is an essential intervention mechanism. By gathering and proactively utilising this information, healthcare professionals can better meet the needs and preferences of the individuals involved. It was suggested that when clear preferences are known, healthcare providers can effectively address those needs. However, it also raises the question of how frequently proactive sharing of information occurs. By actively seeking and considering the preferences of both the patient and their family, healthcare professionals can ensure a person and family-centred approach, where care decisions and interventions are tailored to the specific desires and values of the individuals involved.

> *"I think having, perhaps having more information about somebody's preferences, I think, when someone has a clear preference, we can meet that need quite a lot. And I am not sure how much the information proactively is*

> *often enough. And this information is about both the patient and the family."* (S2, Staff)

Some participants identified promoting spiritual peace as a person and family-centred intervention mechanism, emphasising the significance of considering different religious needs based on an individual's specific religious affiliation. This intervention mechanism emphasises the importance of identifying and involving the appropriate religious officers for everyone. It ensures that patients and their families have access to the religious support they desire, such as receiving the last rites or engaging in specific religious rituals. By integrating the appropriate officers of religion into the care process, a person and family-centred approach is fostered, allowing individuals to find solace and comfort in their spiritual beliefs during challenging times.

> *"When being asked about the different religious needs a participant answered "It depends on what religion they follow. If they want to see a priest or if they are Muslim, they would see imam. They need someone to come and talk to them if they want the last rights or anything like that."* (S3, Staff)

The challenge of a person with dementia at their EoL to make informed decision, therefore, the family and close others are being trusted to make decisions on their behalf.

> *"I think it's a bit challenging with dementia because obviously we would involve the patient. And if a bit, if a patient has dementia, they can't give consent. But what they would like to responsible for that, if they have a next of kin that has power of attorney in sense, it's a bit better because we have somebody that can vouch for them".* (S6, Staff)

In summary, the intervention mechanisms related to a Family and Person-Centred Approach to EoLC for people with dementia in hospitals focus on providing holistic support to both the individual with dementia and their close family members. These mechanisms include tailoring care approaches to the individual's personal needs, preferences, and goals of EoLC. Involving the patient with dementia in decision-making to the extent possible, as well as engaging the patient and their family in care planning and discussions, are essential components. Emotional support for both the person with dementia and their close family members throughout the EoL journey is crucial. Ensuring continuity of care and facilitating seamless transitions between different care settings also contribute to a person-centred approach. Finally, connecting families with supporting bodies and services, such as chaplains, dementia and palliative care support, and social services, address the spiritual and psychological needs of the patients and their families.

5.4. Internal Contextual Mechanisms

This section presents the contextual mechanisms identified in the hospital context, and their effect on the outcomes of care in hospitals. The two themes that emerged: communication within the organisation, and organisational policies, resources, and facilities.

Theme five: Communication within the organisation

This theme presents the communication mechanisms within the organisation that was identified to enhance or inhibit the quality of MDT collaboration. The identified contextual mechanisms were related to clarity of the documentations, fostering a supportive and open communication organisational culture, regular and in-depth MDT meetings. Barriers perceived to inhibit communication within the hospital are related to the time constraints, hierarchical structure, and lack of resources, lack of communication between shifts.

Maintaining accurate and clear documentation is crucial for effective communication between staff. It was perceived that maintaining quality documentation practice as healthcare staff were required to add adequate and clear details to save the time of the reader.

> *“if I'm reading notes, I will always talk to the doctor looking after the person, because actually what you're reading could be taken completely out of context.”* (S11, Staff)
>
> *“Documentation quality is variable. I think, some people write too much. And if you’ve got two pages, you haven’t time to read all of that. That needs to be more succinct, more bullet points so they are easy to be followed” (*S13, Staff)

Supportive organisational culture that values interdisciplinary collaboration is essential. This includes encouraging open communication, mutual respect among healthcare professionals, and providing resources to facilitate this collaboration to happen.

> *"I quite like the fact that dementia team now have sort of activity coordinators... people whose job it is to try and improve quality of end-of-life for people with dementia... not come to do clinical things... but they've come to spend time and*

> *interact... I think that's really important... we try and kind of demedicalise things... that’s really important."* (S2, Staff)

Some barriers are related to the workload, unnecessary referrals, and prioritising the patients who are acute. This highlights the issue of resource allocation and prioritisation in care, which is crucial for improving EoL care for patients who are not imminently being discharged.

> *“I think for us, probably the main barrier is the volume of work. And we get quite a lot of unnecessary referrals at the moment... And then. If we're not receiving all those referrals, I think we then have more time to spend with patients. I think there's just a lot of, and there's a lot of focus on discharge about patients we can get out quickly, but the patients who aren't going anywhere sometimes are not a priority.”* (S2, Staff)

Another barrier for collaborative approach of care, is the communication breakdowns between staff and between shifts in the same ward. This is perceived to hinder team collaboration and identifying appropriate person-centred approach of care.

> *“I think for us, probably the main barrier is the volume of work... we get quite a lot of unnecessary referrals... If we're not receiving all those, we have more time to spend with patients... there's a lot of focus on discharge... but the patients who aren't going anywhere sometimes are not a priority."* (S2, Staff)

MDT meetings were perceived by some to be not deep enough to identify a collaborative plan.

> *“Some wards have more regular MDTs, and they communicate more. Mostly, they are just basic, no discussions the patient, no one who has a specialist knowledge to be able to interject their opinion. I think, it is more of a handover, it needs to be really robust and in depth”* (S13, Staff)

Hierarchical structure was in inhibitor to providing EoLC. This was seen when many participants identified doctors as being the final decision makers, however, they are coming from a medical background of saving lives.

> *“It should be a medical staff decision that somebody is approaching Eol.”* (S11, Staff)
>
> *“Particularly form a medical point of view from doctors, they are more resistant than nursing staff to acknowledge that a patient is dying”* (S13, Staff)

> *“I think doctors just want to save lives. They are taught that they are hippocratic, you are a medic to save lives. But they have to recognise that time is time, and it is EoL as well”* (S12, Staff)

Being in a small hospital, where staff know each other is identified as a facilitator to MDT communication.

> *"We discuss every patient every morning... nurses, therapists, doctors... Palliative care always make a point of finding us... Sometimes that's just easier getting everyone in one room... the benefit of a slightly smaller hospital... everybody kind of knows each other."* (S12, Staff)

To summarise, improving the standard of care for individuals with dementia at the end of their lives in a hospital necessitates effective internal communication within the organisation. Several contextual factors can either boost or hinder the quality of care provided. This includes ensuring clear documentation, fostering a culture of supportive and open communication, and conducting regular and in-depth MDT meetings. Barriers that impede communication within the hospital are associated with time limitations, hierarchical structure, and insufficient resources. By implementing these contextual factors and addressing the barriers, healthcare organisations can enhance communication and elevate the quality of EoLC for individuals with dementia in a hospital setting.

Theme six: Organisational Policies, Resources, and Facilities

Organisational facilities, resources, and policies exert a profound contextual influence on the intervention mechanisms explored in previous themes, ultimately shaping the delivery and experience of EoLC for people with dementia in hospital. These contextual mechanisms operate in both enabling and constraining ways, often acting as the foundation, or barrier, for the successful implementation of interventions at the level of staff, patients, and families.

Both staff and families described how limited resources, such as staff shortages, high turnover, and overwhelming workloads, undermine the sustainability and effectiveness of key intervention mechanisms including ongoing education, advance ACP, multidisciplinary team (MDT) collaboration, and person-centred care. As one staff member noted,

> *"Nurses often face stress due to the busy ward environment, impacting their ability to provide palliative care effectively"* (S4, Staff).

Another echoed,

> *"Resource shortages, including staff and time constraints, make it challenging to prioritise palliative care within the demands of a busy ward"* (S2, Staff).

For families, these constraints are often experienced as inconsistent communication or delays in symptom management, with one relative observing, *"Sometimes I would have liked a nurse to explain more, but they were always so busy…"* (F2, Family).

The direct impact on person-centred care (Theme 4) and team-based interventions (Theme 3) is clear, as staff have less time for meaningful conversations or collaborative planning, and relatives struggle to feel informed or involved.

The hospital environment, including the physical layout, access to quiet or side rooms, communal gardens, and the use of familiar objects, was consistently cited as essential for enabling person- and family-centred care. However, shortfalls in these environmental resources often became barriers to the intended intervention mechanisms. As one staff participant explained,

> *"We have got a dementia garden here, but it's quite hard to access, particularly for patients who aren't very mobile… even having space where families can come and visit, having enough room, having quiet areas… these are simple things that really need to be changed"* (S5, Staff).

A family member reinforced the need for these supportive spaces:

> "*It was helpful when we could all sit together in a quiet room… But sometimes it was just on the ward, which felt very public and stressful"* (F3, Family).

Environmental factors intersect directly with mechanisms of person-centred care by either supporting or undermining efforts to reduce distress, agitation, and confusion. For example, S2 (a physiotherapist) highlighted that the lack of appropriate equipment prevented them from taking patients outside to the garden for fresh air, thereby limiting activities that could enhance comfort and wellbeing at end of life. Moreover, the importance of using familiar objects, such as a patient's own cup rather than a hospital beaker, was stressed:

> *"Limited resources, like insufficient supportive seating, hinder physiotherapy efforts to provide patients with activities outside their rooms or access to fresh air [while providing EoLC."* (S2, Staff)

> *"And you offer them a cup of tea from a beaker, which they've never had a beaker in my life. Yeah. And they're really confused because they're disorientated because you've just worked in the muffle"* (S4, Staff).

Such small acts of familiarity are not just comforting but serve as vital mechanisms for supporting identity, dignity, and emotional security in the midst of clinical care. By contrast, lack of such personalisation can increase distress and further alienate patients from their environment.

Moving patients repeatedly between wards or failing to provide private spaces at the end of life exacerbates these challenges:

> *"When patients have been moved around the wards all the time… it just exacerbates confusion"* (S4, Staff).

One family member described the emotional toll: *"Dad was moved twice in his last week. Each time he was unsettled, and it made it harder for us to feel we could say goodbye"* (F4, Family).

Organisational policies around staff education, communication, and family inclusion have a powerful contextual impact on key intervention mechanisms, especially education and ACP (Themes 1 and 2). While induction and refresher training are present, their effectiveness is diluted by information overload and insufficient follow-up:

> *"During the induction or refresher course, there is an information overload… It's difficult to remember everything when we are presented with such a large volume of information"* (S6, Staff).

Families echoed that much of what they learned was from others, not from structured hospital education:

> *"I learned more about what to expect from other families in the visitors' room than from any leaflet or poster…"* (F5, Family).

This suggests that formal education and communication policies are often inadequate and that informal peer learning becomes a critical fallback.

Some staff suggested developing clear tools (like booklets) to clarify roles and responsibilities for both staff and families. However, lack of awareness of such resources limited their effectiveness:

> *"I believe we would greatly benefit from a simple booklet that explains people's roles in the hospital. It could serve as a refresher for everyone, and it should be encouraged for people to read it"* (FG1P4, Staff).

From the family perspective, the absence of clear guides increased uncertainty and dependence on chance encounters for information:

> *"I didn't know who to ask for some things, if there was a list or a guide for families, it might have helped"* (F1, Family).

This lack of accessible, visible information resources not only impedes family participation in care planning (Theme 2) but also hinders staff from operating as a truly cohesive, informed MDT (Theme 3). Widening access, visibility, and encouragement to use these tools should be a priority, accompanied by an organisational culture that values ongoing, role-specific learning and open communication.

Staff and family participants pointed to hospital policies that sometimes hinder timely ACP initiation or make discharge processes impersonal and bureaucratic, undermining intervention mechanisms for person-centred care and continuity. Staff noted,

> "We've tried, we've tried and it's really hard. I think…if someone's been unwell in hospital…they want to go home. They want to put it behind them…They don't want to think how near death they might've been" (S8, Staff).

This highlights the limitations of trying to implement ACP in an acute setting, when patients and families are focused on immediate recovery or discharge, not future planning.

From the family side, this policy gap can result in experiences of exclusion from decision-making:

> *"No one talked to us about planning ahead. It all happened very suddenly, and we just followed what we were told"* (F2, Family).

Discharge policies were also widely perceived as insufficiently individualised, affecting smooth transitions and leaving patients and families feeling processed rather than cared for as individuals:

> *"I think, yeah. Like I said, the discharge policy [at the EoL stage of life] is probably my biggest problem with the fact that perhaps it's not as individualised as I would like, would we like to be able to tailor a discharge plan to someone's needs and we don't have enough social work present within the hospital" (S2)*

"We felt like Mum was just being moved along a process, not as a person" (F3, Family*).*

These organisational contextual mechanisms do not operate in isolation. Rather, they actively shape, constrain, or enable the intervention mechanisms previously identified, such as staff education (Theme 1), ACP (Theme 2), MDT collaboration (Theme 3), and person- and family-centred care (Theme 4). For instance, staff shortages and high turnover undermine the sustainability of both formal training and regular MDT meetings; inadequate physical environments limit opportunities for privacy and meaningful family engagement at the end of life; and lack of clear policy on family involvement or communication disrupts delivery of person-centred care. Inflexible discharge procedures and insufficient social work resources can disrupt even the best-laid ACP or MDT plans, negatively impacting continuity and quality of care.

The evidence across staff and family perspectives suggests that organisational investment in accessible physical spaces, clear and visible family information tools, protected staff time for training and communication, and more individualised policy implementation is crucial for optimising the mechanisms described in earlier themes. A critical realist perspective underlines that addressing these contextual barriers and enablers at the organisational level is essential for sustaining improvements in hospital-based EoLC for people with dementia. By recognising the interplay between organisational context and intervention mechanisms, and by drawing on the lived experiences of both staff and families, hospitals can develop more robust, equitable, and person-centred models of EoLC.

5.5. External Contextual Mechanisms

This section presents the contextual mechanisms identified between the hospital and the community. It identifies how the external contextual mechanisms operate to improve the quality of care provided for people admitted to hospital with dementia and their close others, and their effect on the outcomes of EoLC in hospitals. The only theme that emerged is communication between the hospital and the community health services.

Theme seven: Communication with the Community Health Services

Communication between hospitals and community health services is a pivotal external contextual mechanism that significantly shapes the quality and continuity of EoLC for people with dementia and their families. This theme explores how systems, processes, and gaps in this interface can either enable or undermine key intervention mechanisms previously identified, such as ACP, smooth care transitions, and holistic family support.

A recurring issue in both staff and family accounts was the fragmentation of information systems across health settings. Staff highlighted that the lack of integrated databases across counties and organisations made it difficult to maintain consistent care, especially during patient transitions.

> *"The community records are all on different database. More certain each county has different databases. So, all the communication is not quite linked up to the hospital... I think for it to work, we really need one system that everyone can tap into, and everyone can add to."* (S13, Staff)

This fragmentation acts as a barrier to continuity of care (intervention mechanism from Theme 4) and makes collaborative ACP difficult (relating to Theme 2). The absence of shared systems also means that important information about patients' needs, preferences, or prior care is sometimes lost or inaccessible when transitioning between care settings.

Staff described how challenges in communication with community partners, such as GPs, district nurses, and social services, can cause delays in discharge planning and continuity of care.

> *“Communication becomes challenging when patients transition between community and hospital settings because there's no clear system in place. If teams use different IT services, information exchange becomes even more difficult. This lack of coordination affects patient care both ways.” (S1, Staff)*

> *“With the hospital pathway... patients go out to a community hospital bed to be assessed for nursing home. He actually died here waiting. That could be a real frustration for us... getting a direct discharge from hospital to a nursing home... wasn't possible... it is about the resources of the hospital between the hospital and that community resources and trying to get his family's voice heard was actually difficult.”* (S13, Staff)

These barriers not only slow down discharge but may result in patients dying in hospital while waiting for the next step, underlining the real impact of systemic issues on patient and family experience.

Families also commented on communication gaps, not just at discharge but after the patient’s death. Family 1 described how, after their wife’s death, there was no proactive offer of information or signposting to bereavement charities or support services:

> *"I wasn’t given any information on what to do next, or who to speak to about support after she passed. I thought someone would mention charities or give advice, but nothing was said.”* (F1, Family)

This highlights a missed intervention mechanism, support for bereaved families, which is crucial for holistic, family-centred care (Theme 4) and for ensuring that EoLC extends beyond the patient’s life.

The effectiveness of EoLC interventions in hospital depends not only on what is done within the ward but also on how information, planning, and support are coordinated with community services. System fragmentation, poor communication at transitions, and a lack of after-death family support all undermine the continuity, personalisation, and holistic nature of EoLC. Addressing these external contextual mechanisms, by improving integrated IT systems, collaborative discharge planning, and proactive bereavement support, would strengthen key intervention mechanisms and improve outcomes for people with dementia and their families.

Theme eight: Medical Ideology to save lives

The prevailing medical ideology in acute hospital care prioritises life-preserving interventions, which can shape and sometimes hinder the implementation of high-quality EoLC for people with dementia. This theme explores how these ingrained attitudes influence clinical practice, particularly decisions around withdrawing or withholding aggressive treatments, and the role of staff advocacy in reorienting care towards comfort and dignity.

Staff described how deeply embedded values around saving lives influenced treatment decisions, sometimes leading to the continuation of interventions even when not in the patient’s best interests.

> *"And it's with the hospital, obviously doctors and nurses, they're going to treat the physical aspect of the human. They want the body essentially to stay alive."* (S10, Staff)

> *"I think doctors just want to save lives. They are taught that they are*

This ideology can delay or complicate the shift to palliative, comfort-focused care (intervention mechanisms from Theme 2 and 4), especially for patients with advanced dementia who would benefit from a focus on quality of life rather than prolonged medical intervention.

In the face of this medical ideology, staff advocacy is an important intervention mechanism. Both doctors and nurses described acting as advocates for patients, trying to shift the conversation towards comfort care and aligning practice with the needs and wishes of patients and families.

> *"I try and advocate for the patient. So try and give a bit of a summary. I escalate to my managers all the time."* (S2, Staff)

> *"We try to explain to the team that sometimes it's about comfort, not cure, especially when it's clear that further treatment won't help."* (S11, Staff)

Such advocacy helps ensure that intervention mechanisms such as ACP and person-centred care are actually implemented, despite cultural and professional pressures to continue life-extending interventions.

Medical ideology to save lives remains a powerful external contextual mechanism shaping EoLC for people with dementia. While this can delay the adoption of palliative approaches, staff advocacy, by both doctors and nurses, acts as a counterbalance, helping to reorient care towards comfort and dignity. Addressing these cultural and professional beliefs through education, reflective practice, and leadership is essential for embedding EoLC principles and enabling staff to implement best practices.

5.6. Agency

This section presents the role of the stakeholders in the provision of EoLC for people with dementia and their close others in hospital. It also presents how these stakeholders respond to the intervention mechanisms identified and the factors that inhibited or promoted the provision of care. The themes emerged are culture, staff perceptions about EoLC, and family perceptions about EoLC.

Theme nine: Culture

Culture powerfully shapes the delivery and experience of EoLC for people with dementia in hospital, operating as both an enabler and constraint on key intervention mechanisms. The increasing diversity of the hospital workforce, particularly the influx of overseas-trained staff, brought a spectrum of cultural values, beliefs, and behaviours that influence perceptions of death, dying, and appropriate care. These cultural dynamics, combined with the cultural backgrounds of patients and families themselves, fundamentally shape staff agency and the implementation of person- and family-centred interventions.

Staff described how overseas nurses often arrived with limited experience of dementia or palliative care, and very different attitudes to EoL conversations compared to UK-trained colleagues. As one staff member reflected,

> *"Overseas nurses often aren't confident, particularly about talking to families about dying, as their home countries manage death very differently… you can see how difficult it is for them at first."* (S11, Staff)

Despite initial challenges, agency was often enabled over time through supportive training, mentorship, and learning from more experienced colleagues and specialist teams:

> *"We get training here… Most of us haven't seen a lot of dementia patients until working in the UK. So the first training helps a lot, and then we learn from the senior staff, they guide us on what to do."* (S7, Staff)

Staff also highlighted how learning across cultures could strengthen EoLC practices, with overseas nurses discovering their own capacity to advocate for patients, and British staff recognising new ways of involving families. As one nurse described,

> *"Here, we have our own voice. It's not always the doctor making the decisions, we can speak up if something isn't logical."* (S7, Staff)
>
> A British staff member noted,
> *"Sometimes our understanding of each other's cultures is the barrier… But when I talk with overseas nurses, I realise how families are so integrated in care elsewhere. We don't have that as much in our culture, but maybe we should learn from that."* (S8. Staff)

Culture was also seen as shaping expectations of family involvement and spiritual needs at the end of life. Some staff identified that, in their home countries, families are more present and involved in day-to-day care, contrasting with the UK model where this role often falls to hospital staff. Others noted the challenge of understanding unfamiliar religious or cultural practices, especially in a less diverse small-town setting:

> *"It would be good to learn about different religions, different ways people have lived. We live in a small town; some people have never left it. We need to be aware of that when we have patients passing away."* (FG1P4, Staff)

These cultural mechanisms interact directly with intervention mechanisms such as staff education (Theme 1), MDT collaboration (Theme 3), and person- and family-centred care (Theme 4). For example, overseas nurses' initial lack of confidence may constrain their participation in sensitive conversations or advocacy, but over time, mutual learning enhances the team's capacity for person-centred and culturally sensitive care. Recognising the strengths in each culture, such as strong family involvement or open advocacy, can help build a more inclusive model of EoLC that values difference and leverages cultural diversity for better care outcomes.

Culture, as experienced by both staff and families, acts as both a constraint and a resource for EoLC in hospital. While cultural differences can initially create barriers, especially for overseas staff, they also offer opportunities for mutual learning, innovation, and improved care. Addressing these differences through structured education, mentorship, and ongoing dialogue can strengthen the capacity of staff to deliver person- and family-centred care, advocate for patients, and respect the diverse needs of those at the end of life. A critical realist approach highlights that agency is shaped not just by individual beliefs but by broader organisational and cultural structures, making it essential to recognise and work with cultural diversity as an integral part of effective EoLC interventions.

Theme ten: Staff Perceptions about EoLC

Staff perceptions play a pivotal role in shaping the implementation and outcomes of EoLC interventions for people with dementia in hospital. The way hospital staff conceptualise EoLC, including its definition, scope, and distinction from palliative care, directly influences their recognition of dying, approaches to family communication, and prioritisation of interventions such as ACP and symptom management. These perceptions act as crucial agency mechanisms, enabling or constraining the delivery of compassionate, timely, and person-centred care.

Staff definitions of EoLC for people with dementia were heterogeneous and often reflected underlying uncertainties about when a patient is truly at the end of life. Many associated EoL with the cessation of curative treatments and a transition towards comfort-focused care:

> *"It would be a case of if that person is no longer responding to treatment... any ongoing attempts may cause more harm than benefit. That's when someone might be approaching end-of-life."* (S1, Staff)

Others described EoL in terms of observable physical and behavioural changes, such as reduced mobility, loss of appetite, or increased dependency:

> *"They just don't want to eat and drink... You can see them almost fading away in front of you really."* (S12, Staff)

Notably, some staff struggled to articulate a timeframe for EoL, emphasising the unpredictability of dementia compared to other conditions:

> *"There's never a timeframe you can put on it... For dementia, it's difficult to measure, unlike cancer where the end is a bit more obvious."* (S4, Staff)

The distinction between EoLC and palliative care was also ambiguous for many participants. While some saw them as essentially synonymous, others described palliative care as a broader, symptom-focused approach that leads up to the final phase, whereas EoLC was perceived as care delivered in the last days or hours of life:

> *"I think palliative care is symptom management, long-term, but end-of-life is right at the end... includes more family liaison, involvement of chaplaincy, preparing for death."* (S5, Staff)
> *"They're very similar, but end-of-life is the last days or hours, just right at the end."* (S6, Staff)

This uncertainty sometimes resulted in inconsistent care planning, especially regarding when to transition from active treatment to comfort-focused interventions, and when to initiate sensitive conversations with families.

When asked about specific tasks, staff described EoLC as encompassing symptom management, emotional support, communication with families, and coordination of care with the MDT. Some highlighted the importance of facilitating a peaceful death by controlling distressing symptoms and supporting families throughout the process:

> *"Managing symptoms, distress... giving people the best possible experience at the end of their life."* (S8, Staff)
> *"At end-of-life, you treat pain, secretions, nausea, vomiting... to help patients have a peaceful death."* (S4, Staff)

These perceptions directly interact with key intervention mechanisms. For example, ambiguous definitions of EoLC may delay or complicate timely ACP (Theme 2) and hinder the MDT's ability to coordinate person-centred care (Theme 3 and 4). Conversely, when staff share a clear and nuanced understanding of EoLC and palliative care, they are better positioned to communicate effectively with families, manage expectations, and ensure comfort-oriented care.

Moreover, staff perceptions reflect broader contextual and organisational factors, such as the adequacy of training (Theme 1) and support for reflective practice. Where staff feel equipped and supported to recognise and discuss dying, they are more likely to

Staff perceptions of EoLC for people with dementia in hospital are varied and complex, shaped by both individual experience and systemic factors. This variability influences the recognition of dying, the timing and quality of family communication, and the effectiveness of critical interventions such as ACP, symptom management, and family support. Addressing these ambiguities through targeted education, reflective practice, and organisational support is essential for ensuring that EoLC is delivered in a timely, compassionate, and person-centred manner. Ultimately, strengthening staff agency and shared understanding enhances the overall quality and consistency of EoLC for people with dementia in hospitals.

Theme Eleven: Bereaved Relatives' Perceptions about EoLC

Bereaved relatives' perceptions offer invaluable insights into the quality and effectiveness of hospital-based EoLC for people with dementia. Family perspectives provide a unique lens on the impact of intervention mechanisms such as communication, symptom management, environment, staff compassion, and practical support, both during the dying process and after the patient’s death. These perceptions highlight areas of good practice as well as persistent barriers and unmet needs, underscoring the importance of involving families as partners in care.

Many families described a limited understanding of EoLC and palliative care prior to their loved one’s final hospital admission. This lack of knowledge often contributed to anxiety and uncertainty during the critical end-of-life phase:

> *“End of life, palliative care. So, only, you know, the last week of his life. That was the only experience I've ever had of it.”* (F4, Family*)*
> “End of life when somebody's dying... hospitals do what they can for them... making sure that they're comfortable and everything's right.” (F2, Family)

Relatives consistently highlighted the importance of compassionate care from staff and regular, clear communication as central mechanisms for positive EoLC experiences. When these were present, families felt supported and reassured:

> *“We couldn’t fault any of their care at all.”* (F4, Family*)*
> *“I was getting daily phone calls... explaining how he was that particular day and how he’d been that night up until the Saturday when he passed.”* (F4, Family*)*

However, inconsistencies or breakdowns in communication often created distress:

> *“We didn't seem to be able to get any information about her situation for a long, long time.”* (F3, Family*)*

Family involvement was seen as both valued and necessary, but not always fully realised. The COVID-19 pandemic, in particular, restricted families’ ability to be physically present or participate in care, adding to their emotional burden:

> *“We were actually very involved in her end-of-life care... when it’s not Covid time, you would be spending much more time there.”* (F3, Family*)*

A supportive environment private rooms, quiet spaces, opportunities for family visits was considered essential for a peaceful end-of-life experience. Families emphasised the benefit of having their own room or a quiet space, but also reported that a busy or noisy ward could undermine comfort:

> *"He had his own room... So it was something that helped."* (F4, Family)
>
> *"It was just more peaceful for her because she was in a ward with... some of them were very, very noisy."* (F3, Family)

Practical and emotional support from the hospital bereavement team was highlighted as crucial, especially in the days following death:

> *"The bereavement team were really, really nice and they phoned... they arranged appointments with the registrar... they were very kind."* (F3, Family)
>
> *"I had a phone number to ring on the Monday... it was the bereavement team... and they were excellent."* (F4, Family)

Some families, however, identified gaps in post-bereavement support and advice, noting that further signposting to charities or external services would have been appreciated:

> *"Nobody advised me to contact anyone... it would have helped to* know about *other services out there."* (F1, Family)

Key barriers included inconsistent communication, staff shortages, and limited access to private or quiet spaces—mechanisms previously linked to organisational constraints (Theme 6). The pandemic further exacerbated these issues, with visiting restrictions and protective measures affecting both the quality of care and the grieving process:

> *"It's just that with more staff and better communication... it would have been even better."* (F5, Family)
>
> *"The only thing we had to do was wear a mask... That was the only restriction at the time of the visit."* (F4, Family)
>
> *"You look back and think... there were a lot of things that would've been a lot better in normal situations."* (F3, Family)

Family narratives reinforce the importance of intervention mechanisms identified in earlier themes: clear and timely communication (Theme 2), supportive and person-centred environments (Theme 4), and compassionate staff engagement throughout the care process. These mechanisms operate not only to support patients, but also to ease the emotional burden on relatives and improve the overall experience of EoLC.

Additionally, families' experiences reveal the critical importance of after-death support and follow-up—highlighting the need for improved signposting, bereavement support, and access to external resources as part of holistic, family-centred EoLC.

Bereaved relatives' perceptions of hospital-based EoLC for people with dementia underscore the central role of staff compassion, clear communication, supportive environments, and effective bereavement services. While many families valued the dedication and kindness of healthcare professionals, inconsistencies in communication, staffing challenges, and environmental barriers persisted. The pandemic highlighted both the adaptability and the vulnerabilities of the system. Ongoing efforts to address these challenges—through enhanced training, structured communication protocols, better physical environments, and robust bereavement support—are essential to improving EoLC experiences for both patients and their families.

5.7. Outcomes

The outcomes section provides a comprehensive exploration of the changes observed through the application of a CRE of interventions. By adopting this approach, the focus is on understanding how interventions brought about change, providing valuable insights for hospital staff, bereaved relatives, and practitioners in the field of evaluation and interventions.

Outcomes of Training and Education

This section explores the outcomes of education and training initiatives aimed at improving end-of-life (EoL) care for people with dementia in acute hospital settings. As part of the critical realist evaluation, training was conceptualised as a mechanism intended to enhance staff knowledge, empathy, communication, and care coordination. The interventions examined included video-based learning, simulation exercises, nurse champion programmes, and cultural competence sessions. These activities were designed to address identified gaps in practice and to promote person-centred, consistent, and culturally sensitive care. The following outcomes reflect staff perceptions, behavioural shifts, and barriers identified during data collection.

The evaluation of training and education interventions for hospital staff caring for people with dementia at the end of life revealed several important outcomes. A particularly notable outcome was the development of enhanced empathy and a deeper understanding of the patient experience. This shift was especially attributed to the video intervention, which depicted the lived realities and emotional worlds of people with dementia.

> *"The video really opened my eyes to what they go through. It made me think more about how I can make their experience better"* (S7, Staff).

This was echoed in the focus groups, where a healthcare professionals shared:

> *"When we watched the simulation and discussed it afterwards, I could see how much it changed people's attitudes. You start thinking less clinically and more emotionally"* (FG2P3, Staff).

> *"I had colleagues say it made them stop and think they looked at dementia not as confusion, but as fear and frustration"* (FG1P1, Staff).

These reflections suggest that well-designed training does more than transfer knowledge; it facilitates a cognitive and emotional shift that strengthens staff capacity for compassionate, person-centred care.

Another important outcome was the improvement in communication skills, particularly in addressing sensitive topics with families. Simulation-based training, where staff practised interactions with actors portraying relatives, significantly enhanced their ability to communicate with empathy and confidence. One participant described the experience as transformative:

> *"Practising with actors helped me handle real-life conversations better. I feel more confident now when talking to families about difficult topics"* (S5, Staff).

This sentiment was echoed in focus group discussions, where a participant noted,

> *"When we had those role-plays, it wasn't just about what to say, it was how to say it with compassion"* (FG2P4, Staff).
>
> Another added, *"It made me realise how often we default to medical jargon. The simulation helped me slow down and listen"* (FG1P2, Staff).

These outcomes highlight the value of experiential learning in equipping staff with practical tools to support families during emotionally charged end-of-life moments.

The training and education of nurse champions frontline role models equipped with specialist EoL knowledge also yielded significant outcomes. These champions not only gained advanced skills but also felt empowered to lead and mentor their teams.

> *"Being a nurse champion has given me the tools to help my team improve our care standards. It's been very empowering"* (S8, Staff).
>
> *"It's not just about having the knowledge, it's about guiding others, answering questions, and being the go-to person when things get tough"* (FG1P4, Staff).

This mechanism cultivated a culture of leadership, accountability, and peer-to-peer learning across wards, reinforcing a shared commitment to improving care quality for people with dementia at the end of life.

The dissemination of information about policies and practices through emails, written guidelines, and visual booklets was reported as a key enabler in improving consistency across end-of-life care. These resources ensured staff were better informed, contributing to a more standardised and cohesive approach to dementia care.

> *"The booklets and emails keep us updated on best practices, which is crucial for providing consistent care"* (S6, Staff).
>
> *"We often refer back to those pocket guides especially in crisis moments when you need quick clarity"* (FG1P3, Staff).

> *"Having clear written protocols made me feel safer. I knew I wasn't missing something important"* (FG2P2, Staff).

These accessible resources helped operationalise policy into bedside practice, promoting reliable implementation of EoL strategies across multidisciplinary teams.

Educational sessions tailored for overseas staff significantly enhanced their understanding of the cultural expectations surrounding death and dying in the UK, improving cultural sensitivity and communication. These sessions enabled staff to foster stronger relationships with patients and their families by acknowledging cultural needs.

> *"Learning about the cultural aspects of EoL care in the UK helped me connect better with patients and their families"* (S10, Staff).

> *"Sometimes we've become aware of a patient from a different culture… and everyone was scrambling around in the last [moments]"* (FG1P1, Staff)

This underscores how training helped prevent reactive rather than proactive care.

However, several challenges impeded the full implementation and impact of the education and training programme. These included limited resources, ad hoc scheduling, and a high turnover of staff. One participant noted,

> *"I didn't really have much training apart from the week I started. That was it"* (FG2P4, Staff),

> *"Training's been stopped because of COVID… you had to volunteer to get a study day"* (FG2P3, Staff).

Such inconsistencies meant that not all staff could benefit equally. Additionally, the competence and preparedness of trainers played a vital role in how effective the sessions were perceived.

"If we had a half-day training… it would be more relevant and creative in how it's delivered" (FG1P5, Staff).

These reflections highlight that educational impact was not only content-dependent, but also shaped by structural, logistical, and pedagogical factors.

In summary, education and training mechanisms produced a range of positive outcomes, including improved empathy, communication skills, leadership among nurse champions, and greater cultural competence, especially among overseas staff. The provision of structured resources and guidelines further supported consistent care practices. However, the success of these mechanisms was moderated by structural limitations such as time constraints, staff turnover, and variable trainer quality. These findings suggest that while training can be transformative, its effectiveness is contingent on ongoing organisational support, regular delivery, and the quality of facilitation.

Outcomes of Advance Care Planning (ACP)

This section evaluates the outcomes of implementing Advance Care Planning (ACP) for people with dementia at the end of life in hospital settings. ACP is designed to ensure that patients' wishes and preferences are known, documented, and respected during their final stages of care. In this critical realist evaluation, ACP was conceptualised as both a process and a communication tool, intended to guide clinical decisions and reduce uncertainty for staff and families. The following outcomes explore both the enabling effects and persistent barriers to ACP implementation in acute hospital contexts.

The evaluation of ACP for people with dementia at the end of life in hospital settings highlighted several important outcomes. A primary outcome was increased awareness and improved implementation of ACP, which enabled staff to better identify and honour patient preferences.

> *"Having a clear ACP helps us respect the patient's wishes, making their final days more comfortable"* (S3, Staff).

In the focus groups, staff reinforced this value:

> *"We support and advise… and also speak to families, look at patient's wishes"* (FG2P1, Staff)

> *“You are managing the next phase of someone’s life… supporting their wishes and trying to make them as comfortable and settled as possible”* (FG1P5, Staff).

However, implementation faced multiple challenges. Staff often struggled to find time for ACP conversations due to demanding workloads.

> *“We’re so busy with day-to-day tasks that finding time for detailed ACP discussions is tough”* (S9, Staff).

Platform fragmentation further impeded care:

> *“Sometimes we can't find the ACP documents quickly, which complicates providing the right care”* (S12, Staff).

Others noted disparities in document availability:

> *“Patients from care homes usually have ACPs, but those from home often don’t, which impacts our care planning”* (S11, Staff).

These patterns were echoed in focus groups, where one participant commented,

> *“I've seen those documents… if they're from residential homes”* (FG1P2, Staff).

Effective ACP was also linked to communication competence. As one staff member noted, *“Better training in handling these conversations is needed to make ACPs more effective”* (S2, Staff).

Focus group members also acknowledged this connection, with one referencing the value of documents like “*Heading Ahead*” as tools that guide staff when structured ACP conversations occur (FG1P5, Staff).

Notably, no explicit references to ACP or documented preferences were found in interviews with bereaved relatives. This absence is significant: it may reflect a lack of involvement in planning discussions, insufficient explanation from staff, or poor communication about documented care plans. The silence suggests that, while ACP may be embedded in professional practice, its visibility and relevance to families remain limited, highlighting a gap between documentation and family inclusion.

In summary, ACP showed potential for guiding care aligned with patients' values, reducing uncertainty for staff, and promoting trust with families when implemented effectively. However, significant challenges remain. These include time constraints, fragmented information systems, and variable availability of ACPs based on admission source. Staff recognised the value of training in navigating difficult conversations, but practical limitations often hindered comprehensive planning. Crucially, the absence of ACP discussion among bereaved relatives points to a need for better communication and involvement strategies. This finding suggests that for ACP to be truly effective, it must not only exist in documentation but be known, shared, and understood by all parties involved.

Outcomes of Multidisciplinary Care Approach (MDT)

Multidisciplinary Team (MDT) collaboration is a cornerstone of effective end-of-life (EoL) care for people with dementia in hospital settings. This theory explored how mechanisms such as holistic assessment, team-based decision-making, and care coordination translate into outcomes for patients and families. The following analysis outlines the strengths and limitations observed in practice, based on feedback from staff and bereaved relatives.

The evaluation of MDT collaboration highlighted several key outcomes. One prominent outcome was the development of comprehensive and holistic care plans, enabled by collaborative assessment of the patient's clinical, emotional, and social needs. As one staff member noted, *"The MDT approach ensures we consider all aspects of a patient's well-being"* (S5, Staff). This sentiment was echoed in the focus groups: *"That's what anybody working with patients with dementia has to do... to acknowledge all of those needs"* (FG1P5, Staff).

Decision-making within the MDT was also enhanced by interdisciplinary perspectives. Staff reported that the inclusion of professionals from varied backgrounds led to more balanced and informed decisions.

> *"Having input from different professionals helps us make better care decisions"* (S7, Staff).

Similarly, focus group participants valued structured team input:

> *"We have everything under one building... we all get together to make it right for the patient"* (FG2P1, Staff).

Another outcome was improved continuity and coordination of care. Tracking patient status across disciplines ensured consistency, minimised care fragmentation, and improved transitions.

> *"Tracking and coordinating care across the MDT prevents gaps and ensures smooth transitions"* (S8, Staff). A doctor added, *"The communication between nurses and doctors has got so much better... it works really well"* (FG2P1, Staff).

Despite these strengths, several challenges emerged. The prevailing curative medical model sometimes conflicted with palliative values.

> *"There's still a strong focus on curing, which sometimes makes it hard to adopt a purely palliative approach"* (S1, Staff)

> *"Hospitals are still cure-driven... that's why you've got hospices, which are a different environment altogether"* (FG1P5, Staff).

Inconsistent collaboration across disciplines was also a concern.

> *"Not all team members are always on the same page, which can be frustrating"* (S4, Staff).

Communication breakdowns across teams and unclear roles were common barriers.

> *"I think it comes back to communication... there are so many teams, and you don't know who does what"* (FG1P3, Staff).

From the perspective of bereaved relatives, MDT processes were largely invisible or only partially perceived. One relative recalled:

> *"I never found anyone ever talking to my wife when I went to visit... the nurses didn't seem to sit and engage with her"* (F1, Family)

This suggests missed opportunities for consistent and person-centred team involvement. Another noted:

> *"The bereavement team were really, really nice and arranged everything... but no one spoke to us before she passed"* (F3, Family)

This highlights a gap between MDT coordination and direct family inclusion.

MDT collaboration contributed to better care planning, communication, and patient monitoring, with interdisciplinary input leading to more responsive and person-centred decisions. However, barriers such as medical hierarchies, inconsistent team engagement, and lack of communication with families limited the full realisation of this model. The absence of visible MDT interaction reported by bereaved relatives underscores the need for greater transparency and family-facing coordination in the delivery of EoL care.

Outcomes of Person and Family-Centred Approach

This section explores the outcomes of employing a person and family-centred approach in end-of-life care (EoLC) for patients with dementia in acute hospital settings. Data from both healthcare professionals and bereaved relatives highlight key mechanisms such as shared decision-making, holistic support, environmental considerations, and cultural sensitivity. Together, these elements shaped the overall experience of EoLC and offered insights into what practices enhanced or hindered care quality.
Providing holistic support to both patients and their families promoted emotional well-being and reduced caregiver burden. Staff reflected on the importance of seeing the person behind the patient:

> *"Supporting both the patient and family holistically makes a big difference in their overall experience." (S10,* Staff*)*

> *“I think end-of-life care is about something a bit more holistic ... about who somebody is as a person, maybe things that have brought somebody meaning.”* (FG1P1, Staff)

> *“My mum was lucky that we were going in and we'd go in with the grandchildren... so she had us around her.”* (F2, Family)

Collaborative care planning that included family input empowered families and reinforced person-centred values:

> “Including families in decisions makes them feel more involved and respected.” (S9, Staff)

> “The dementia team will come in, look through the notes, and speak to families... also they support the nurses on the ward.” (FG2P1, Staff)

> “*They did ask if we would want someone with him and we said yes... That was quite comforting to know that he wasn't just in a room on his own.”* (F4, Family)

Improving the physical hospital environment was seen as beneficial to both patient comfort and emotional experience:

> “*Simple changes like having a window view or private space make a big difference in comfort.”* (S14, Staff)

> “*Hospitals are not homey... to be far more empowered as to how they control that environment is important.”* (FG1P1, Staff)

> “*He was warm, comfortable, and pain-free, relatively... so I did feel grateful for that*.” (F5, Family)

Issues like the inaccessibility of dementia gardens and frequent ward transfers disrupted continuity of care:

> “*The dementia garden is often not accessible, and moving between wards disrupts continuity of care.”* (S6, Staff)

> "*If we're going to move patients, we should do it sooner rather than later… into an environment where they can stay."* (FG2P3, Staff)

Language, cultural, and faith-based differences posed barriers in communication and family engagement:

> "*Language and cultural barriers complicate communication, and resource limits affect discharge planning.*" (S13, Staff)

> "*We've become aware of a patient from a different culture… everyone was scrambling around at the last minute."* (FG1P1, Staff)

> "*A good example we had was a dementia patient whose first language was French… small things like that matter.*" (FG1P1, Staff)

The person and family-centred care approach in dementia EoLC produced meaningful outcomes such as better emotional support, shared decision-making, and improved patient comfort. However, systemic and environmental barriers, including cultural misalignment, inaccessible amenities, and communication hurdles, limited its full realisation. Interestingly, bereaved relatives largely validated these outcomes through positive accounts, yet their input also surfaced gaps, particularly in emotional support for carers and systemic coordination. Addressing these challenges through better communication training, culturally sensitive practices, and a more enabling care environment remains essential for delivering compassionate, equitable, and person-centred care.

5.8. Initial Theories

This section presents four programme theories that emerged as a result of rigorous analysis and thematic exploration of the collected data. These theories provide valuable insights into the functioning and intended operation of EoLC for individuals with dementia in hospital settings. By examining the data within the framework of the study's objectives, these theories offer a deeper understanding of how the care programme is currently working, its intended goals, and potential effectiveness. The identification of these theories represents a significant step towards unravelling the complexities and dynamics of the EoLC for people with dementia in hospital. The programme theories informed questions aim to gather insights from both hospital staff and bereaved relatives to refine the understanding of the mechanisms and further develop the programme theories related to EoLC for people with dementia in hospitals.

Training and education theory

The programme theory proposes that education and training for hospital staff providing care for people with dementia at the EoL is influenced by factors such as limited resources, irregular training, and staff turnover. Some benefits education and training offered were related to understanding the perceptions and feelings of people with dementia through video-based education, developing communication skills with families through simulated scenarios, training and educating frontline role model staff, informing staff about policies and practices through communication channels, and providing educational sessions for overseas staff to break the cultural barrier. The trainers' skills and competences are important in delivering effective education. The expected outcomes include enhanced understanding and empathy, improved communication skills, motivated and supported teams, increased awareness of policies and practices, and culturally sensitive care.

Questions I asked for Hospital Staff for the next Phase data collection:

The following questions aim to gather insights from hospital staff regarding their agreement with the initial theory, potential changes, or modifications to enhance the theory, and clarification on specific mechanisms and contextual factors. By exploring their perspectives and experiences, a refined theory can be developed to better capture the dynamics of education and training for hospital staff providing EoLC to people with dementia.

1. To what extent do you agree with the theory in terms of the change the education and training program can provide in hospital staff behaviours and practices while providing care for people with dementia at their end-of-life? Are there any aspects of the theory that resonate with your experiences and observations, or do you have differing perspectives?

2. Based on your experience, what changes would you suggest improving the theory? Are there any additional factors that should be considered?

3. Regarding understanding perceptions and feelings of people with dementia and developing communication skills with families, do you believe these have the potential *to positively impact the care provided? Are there any limitations or challenges you foresee in implementing these mechanisms?*

4. Can you provide examples of specific policies or practices that were effectively communicated to you through emails and information booklets? How did these resources contribute to your understanding and adherence to the standards of EoLC for people with dementia?

5. In your opinion, how can the education and training address the specific needs and cultural differences related to death and dying among overseas staff members? Are there any cultural sensitivities or challenges that should be considered when delivering educational sessions to this group?

6. In your opinion, how can people put the things they learnt during the education into practice?

Advance Care Planning Theory

The initial programme theory proposes that the effectiveness of ACP for people with dementia at the EoL in hospitals can be enhanced by addressing the identified mechanisms. By identifying the required and preferred wishes of care for individuals with dementia and involving them in decision-making, a more personalised and patient-centred care plan can be developed. Despite time constraints and competing priorities, efforts can be made to prioritise ACP discussions by allocating sufficient time and resources. In addition, involving MDT and alleviating the workload of GPs can support the integration of ACP into the care pathway. Implementing a uniformed platform to identify ACP documents prior to admission and raising community awareness about the importance of early ACP can further enhance the effectiveness of ACP. Strengthening healthcare professionals' documentation and communication skills, providing education and training on initiating sensitive conversations, and fostering family collaboration are crucial human agency mechanisms. Additionally, creating a short document as an alternative to the full ACP document and offering education and resources for healthcare professionals can mitigate the barriers and improve the effectiveness of ACP for people with dementia at the EoL in hospital settings.

Questions to be asked for the hospital staff

The following questions aim to gather insights from hospital staff regarding their agreement with the initial theory, potential changes, or modifications to enhance the theory, and clarification on specific mechanisms and contextual factors. By exploring their perspectives and experiences, a refined theory can be developed to better capture the dynamics of education and training for hospital staff providing EoLC to people with dementia.

1. To what degree do you agree with the initial programme theory regarding the effectiveness of ACP for people with dementia at the EoL in hospitals? Are there any aspects of the theory that you strongly agree or disagree with? Please provide specific examples or explanations to support your response.

2. Based on your experience and observations, what changes or modifications would you suggest improving the initial programme theory? Are there any additional mechanisms or factors that you believe should be considered in the theory? How do these changes align with your understanding of ACP for people with dementia in hospital settings?

3. In the initial programme theory, several mechanisms were identified. Are there any mechanisms that are unclear or require further clarification? Please specify which mechanisms you would like more information about and explain why they are not clear to you.

4. From your perspective, what are the key challenges or barriers that hinder the effective implementation of ACP for people with dementia at the EoL in hospital settings? Are there any additional mechanisms or contextual factors that you believe influence the success of ACP, but were not included in the initial theory? Please elaborate on these factors and their potential impact.

5. In terms of the human agency mechanisms mentioned in the initial theory (e.g., documentation and communication skills, staff confidence, family collaboration), how do you perceive their role in facilitating or hindering the implementation of ACP for people with dementia? Are there specific strategies or interventions that you believe could enhance these human agency mechanisms and improve the overall effectiveness of ACP?

Questions to be asked for the bereaved relatives

The following questions aim to gather insights from bereaved relatives regarding their agreement with the initial theory, potential changes, or modifications to enhance the theory, and clarification on specific mechanisms and contextual factors. By exploring their perspectives and experiences, a refined theory can be developed to better capture the dynamics of education and training for hospital staff providing EoLC to people with dementia.

1. To what extent do you agree with the initial programme theory regarding the effectiveness of ACP for your loved one with dementia at the EoL in the hospital? Are there any aspects of the theory that resonate with your experience, or are there elements that you feel do not accurately capture your experience? Please share specific examples or instances to support your perspective.
2. In your opinion, what changes or adjustments would you suggest enhancing the initial programme theory regarding ACP for people with dementia at the EoL in hospitals? Are there any mechanisms or factors that you believe should be considered or given more weight in the theory? How do these proposed changes align with your own experiences and observations during your loved one's EoL journey?
3. As a bereaved relative, were there any specific challenges or barriers that you encountered regarding the implementation of ACP for your loved one with dementia? Do these challenges align with the mechanisms identified in the initial theory, or were there other factors at play? Please provide details about any additional mechanisms or contextual factors that you believe influenced the effectiveness of ACP for your loved one's care.
4. In the initial programme theory, certain human agency mechanisms were highlighted, such as documentation and communication skills, staff confidence, and family collaboration. From your perspective, how significant were these mechanisms in the ACP process for your loved one? Were there any specific instances where these mechanisms positively or negatively impacted the care provided? Additionally, are there any specific interventions or approaches that you believe could have improved the involvement of these mechanisms during your loved one's EoLC?
5. Within the initial programme theory, are there any aspects or mechanisms that are unclear or need further explanation from your point of view? Is there anything that you would like to have a better understanding of regarding ACP for people with dementia at the EoL in hospitals? Please feel free to share any specific areas that you find unclear or would like to delve deeper into for a more comprehensive understanding.

Questions to be asked for the hospital staff

The following questions aim to gather insights from hospital staff regarding their agreement with the initial theory, potential changes, or modifications to enhance the theory, and clarification on specific mechanisms and contextual factors. By exploring their perspectives and experiences, a refined theory can be developed to better capture the dynamics of education and training for hospital staff providing EoLC to people with dementia.

1. To what extent do you agree with the initial programme theory regarding the effectiveness of ACP for your loved one with dementia at the EoL in the hospital? Are there any aspects of the theory that resonate with your experience, or are there elements that you feel do not accurately capture your experience? Please share specific examples or instances to support your perspective.

2. In your opinion, what changes or adjustments would you suggest enhancing the initial programme theory regarding ACP for people with dementia at the EoL in hospitals? Are there any mechanisms or factors that you believe should be considered or given more weight in the theory? How do these proposed changes align with your own experiences and observations during your loved one's EoL journey?

3. As a staff, were there any specific challenges or barriers that you encountered regarding the implementation of ACP for your loved one with dementia? Do these challenges align with the mechanisms identified in the initial theory, or were there other factors at play? Please provide details about any additional mechanisms or contextual factors that you believe influenced the effectiveness of ACP for your loved one's care.

4. In the initial programme theory, certain human agency mechanisms were highlighted, such as documentation and communication skills, staff confidence, and family collaboration. From your perspective, how significant were these mechanisms in the ACP process for your loved one? Were there any specific instances where these mechanisms positively or negatively impacted the care provided? Additionally, are there any specific interventions or approaches that you believe could have improved the involvement of these mechanisms during your loved one's EoLC?

5. Within the initial programme theory, are there any aspects or mechanisms that are unclear or need further explanation from your point of view? Is there anything that you would like to have a better understanding of regarding ACP for people with dementia at *the EoL in hospitals? Please feel free to share any specific areas that you find unclear or would like to delve deeper into for a more comprehensive understanding.*

Multidisciplinary Care Approach Theory

The initial programme theory proposes that by implementing MDT collaboration for people with dementia at the EoL in a hospital setting, several intervention mechanisms can improve the quality of care. These mechanisms include identifying holistic assessments of patients' needs, sharing decision-making among the team, and tracking patients' care. However, there are internal conceptual mechanisms to address, such as the medical ideology of curing and saving lives, reduced frequency and depth of meetings, and the clarity of health documents. External conceptual mechanisms involve fostering a supportive environment, encouraging education and training, ensuring an appropriate physical environment for communication, and challenging the prevailing medical ideology. The agency lies with senior doctors' perceptions and the engagement of nurses and allied healthcare professionals. By addressing these mechanisms, the programme aims to enhance collaboration, decision-making, and care for individuals with dementia at the EoL in a hospital setting.

Questions to be asked for the hospital staff

The following questions aim to gather insights from hospital staff regarding their agreement with the initial theory, potential changes, or modifications to enhance the theory, and clarification on specific mechanisms and contextual factors. By exploring their perspectives and experiences, a refined theory can be developed to better capture the dynamics of education and training for hospital staff providing EoLC to people with dementia.

1. To what degree do you agree with the initial programme theory regarding MDT collaboration for people with dementia at the EoL in the hospital? Please provide your perspective on the identified intervention mechanisms and their effectiveness in improving the quality of care.

2. Based on your experience and observations, what changes or modifications would you suggest refining the initial programme theory? Are there any additional intervention mechanisms that you believe should be included or any existing mechanisms that should be modified or removed?

3. Regarding the internal conceptual mechanisms identified, such as the medical ideology of curing and saving lives, reduced frequency and depth of meetings, and the clarity of health documents, to what extent do you perceive these as significant barriers or challenges in implementing MDT collaboration for EoLC? What strategies or solutions do you propose to address these challenges?

4. Are there any aspects of the initial programme theory that are not clear or need further clarification? Please highlight any areas where you require additional information or where the theory may need to be more explicit in its assumptions or mechanisms.

5. From your perspective, what are the key contextual factors within our hospital setting that could influence the effectiveness of MDT collaboration for people with dementia at the EoL? How do these factors interact with the proposed intervention mechanisms, and what adjustments might be necessary to accommodate the unique context of our hospital?

Person and Family-Centred Approach Theory

The theory proposes that implementing a family and person-centred approach of care for people with dementia at the EoL in a hospital setting can lead to several expected outcomes. By identifying holistic support for both the individual with dementia and their close others, sharing decision-making, connecting families with supportive resources, and acknowledging patient preferences, positive impacts can be achieved. This approach aims to improve emotional well-being, reduce caregiver burden, enhance person-centred care planning, empower patients and families, increase access to community services, respect patient autonomy, and improve overall satisfaction with care. However, challenges such as an inaccessible dementia garden, staff turnover, cultural and communication barriers, and limited resources may hinder the realisation of these outcomes. Addressing these factors and utilising the identified factors can contribute to the successful implementation of a family and person-centred approach to care for people with dementia at the EoL in a hospital setting.

Questions to be asked for the hospital staff

The following questions aim to gather insights from hospital staff regarding their agreement with the initial theory, potential changes, or modifications to enhance the theory, and clarification on specific mechanisms and contextual factors. By exploring their perspectives and experiences, a refined theory can be developed to better capture the dynamics of education and training for hospital staff providing EoLC to people with dementia.

1. To what degree do you agree with the initial programme theory regarding the implementation of a family and person-centred approach to care for people with dementia at the EoL in our hospital? Are there any aspects that you strongly agree or disagree with?
2. Based on your experience and observations, what changes or modifications would you suggest refining the initial theory and improve its applicability in our hospital setting? Are there any additional mechanisms or contextual factors that you believe should be included?
3. In reviewing the initial theory, are there any aspects that are not clear enough or require further clarification? Are there any assumptions or connections that you find confusing or would like more information about?
4. How do you perceive the potential impact of the identified mechanisms in the initial theory on the overall care and outcomes for individuals with dementia at the EoL? Are there any mechanisms that you believe may have a greater or lesser influence than initially proposed?
5. From your perspective, are there any contextual factors or challenges not addressed in the initial theory that significantly impact the implementation of a family and person-centred approach for individuals with dementia at the EoL in our hospital? How do you think these factors should be considered in refining the theory?

Questions to be asked for the bereaved relatives

The following questions aim to gather insights from the bereaved relatives regarding their agreement with the initial theory, potential changes, or modifications to enhance the theory, and clarification on specific mechanisms and contextual factors. By exploring their perspectives and experiences, a refined theory can be developed to better capture the dynamics of education and training for hospital staff providing EoLC to people with dementia.

1. To what extent do you agree with the initial programme theory regarding the implementation of a family and person-centred approach to care for individuals with

dementia at the EoL in our hospital, based on your experience with your loved one? Are there any aspects that you strongly agree or disagree with?
2. In your opinion, what changes or modifications would you suggest refining the initial theory and improve its applicability in our hospital setting, considering your experience as a bereaved relative? Are there any additional mechanisms or contextual factors that you believe should be included?
3. How clear and understandable was the initial theory presented to you as a bereaved relative? Were there any aspects that were unclear or could benefit from further explanation or clarification?
4. From your perspective, how do you believe the identified mechanisms in the initial theory influenced the care and outcomes for your loved one with dementia at the EoL? Were there any mechanisms that you think had a greater or lesser impact than initially proposed?
5. Were there any contextual factors or challenges that you observed during your loved one's EoLC in the hospital that were not adequately addressed in the initial theory? How do you think these factors should be considered in refining the theory?

5.9. Chapter Summary

This chapter introduces the initial programme theories (phase one) that aimed to examine and comprehend the functioning and intended operation of EoLC for individuals with dementia in hospital settings. I explored the effectiveness of this care approach, as well as the influence of intervention mechanisms, agency, and contextual factors on outcomes, drawing upon the Intervention Mechanisms + Internal Contextual Mechanisms + External Contextual + Mechanism + Agency= Outcomes configuration framework. The data collected from semi-structured interviews and focus groups with hospital staff and bereaved relatives were subjected to thematic analysis and organised into five major categories, as per Sam Porter's CRE approach (Porter 2015).

To ensure the accuracy of initial assumptions, capture contextual nuances, identify unintended outcomes and mechanisms, and foster iterative learning and adaptation in programme evaluation, a second round of data collection and analysis was conducted to refine the programme theories. By incorporating new insights and data, I aimed to validate or revise the initial programme theory, leading to a more precise and evidence-based understanding of the program's operations and underlying mechanisms within specific contexts. This iterative approach facilitates continuous improvement of the programme theory, empowering informed decision-making and programme enhancement.

Consequently, the subsequent chapter presents the refined programme theories by sharing the initial theories with the interviewees to solicit their feedback and responses. This collaborative process further contributes to enhancing the accuracy and validity of the theories.

Chapter 6 Stage Two: Refining Programme Theories

6.1. Introduction

This chapter presents the second stage of the research process: the refinement of the initial programme theories developed in Phase One. The overarching aim of this stage was to test, develop, and improve these initial theories by drawing on new empirical data gathered through semi-structured interviews and focus group discussions with hospital staff and bereaved relatives. This refinement was essential to ensure that the theories not only reflected lived realities but also supported the development of practical, context-sensitive strategies for improving EoLC for people with dementia in hospital settings.

To achieve this objective, I conducted a second round of data collection involving interviews and focus groups with a purposively selected sample. The data were then analysed through the lens of critical realist evaluation (CRE), focusing on the generative mechanisms that underpin change. In particular, I used the heuristic model of 'intervention mechanisms + internal contextual mechanisms + external contextual mechanisms + agency = outcomes' to interrogate and refine each initial theory.

The chapter is structured around four refined programme theories, each addressing a key area identified in earlier stages of the research: (1) education and training for hospital staff, (2) advance care planning (ACP), (3) multidisciplinary team collaboration, and (4) person- and family-centred care. For each theory, I first present the initial theoretical proposition, followed by a detailed account of how it was refined in light of new data. The chapter concludes with a revised programme theory that incorporates participant insights and captures the complex interplay of mechanisms, context, and agency.

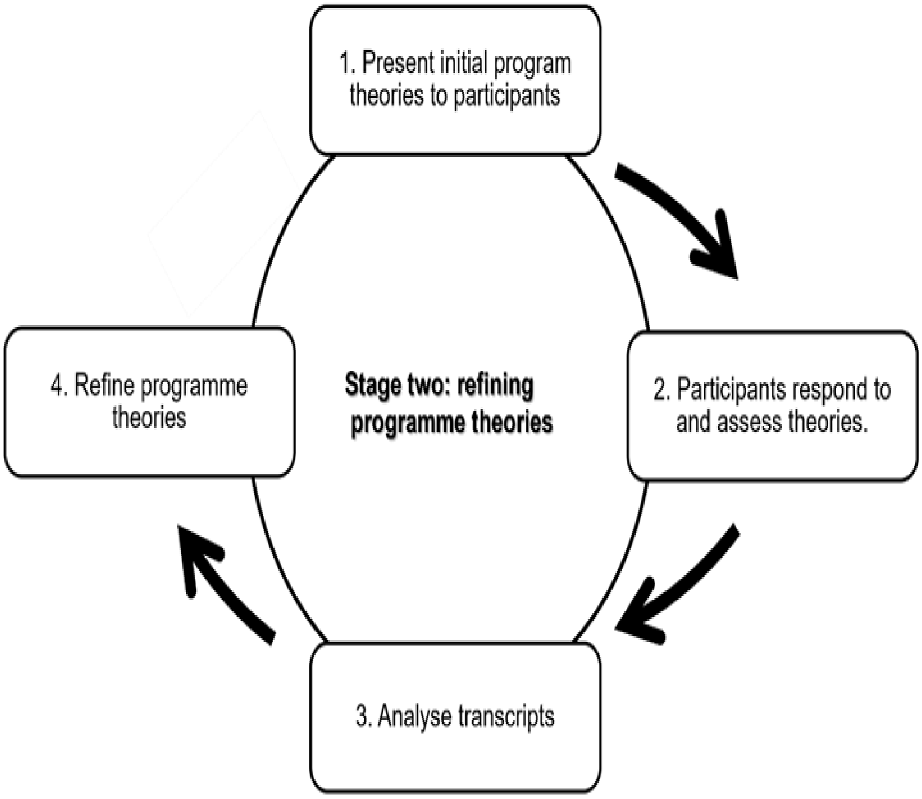


Figure 6-1 CRE Flowchart: Phase two.

6.2. Participants

At this stage of the study, seven staff participated in individual semi-structured interviews, five staff were involved in a focus groups interviews, and three bereaved relatives of people who died with dementia in one district hospital for semi-structured interviews, this was reflected on the imbalanced evidence in the quotes between staff and families. For the staff, all the interviews and the focus groups were conducted face-to-face in the hospital. The bereaved relatives were interviewed over the telephone. The demographics of the participants are presented in Table 6-1. for the staff, and Table 6-2 for the bereaved relatives. The participants were recruited from a district hospital in the UK. For more information about the recruitment process (see Chapter 4). Participants were a mix of the previous participants as well as new ones. Finally, I anonymised the participants as presented in Table 6-3.

Table 6-1 Hospital Staff Demographics.

Gender	
Male	4
Female	8
Age Range	
20-29	3
30-39	2
40-49	6
50+	1
Years of experience	
Less than 1	1
1-10	4
11-20	6
+20	1
Post	
Consultant Nurse	3
Registered Nurse	2
GP Trainee	1
Student Nurse	1
Dietitian	1
Consultant Physiotherapist	1
Art Design Coordinator	1
Patient Experience Assistant-Bereavement Office	1

Country of origin United Kingdom Oversees	0 10 2

Table 6-2 Bereaved Relatives Demographics.	
Total interviewed	5
Gender	
Male	1
Female	2
Age range	
40-59	1
60-79	2
Next of Ken	
Spouse	0
Adult child	2
Family Friend	1

Table 6-3 Participants anonymisation process.	
Participants	Anonymisation
Hospital staff from one-to-one interviews	P1 – P7
Staff focus group interviews	PG1 - PG5
Bereaved Families	PF1 – PF3

6.3. Refined Theory One: Enhancing End-of-Life Care for People with Dementia through Comprehensive Education and Training

6.3.1. Initial Theory

Education and training theory

The programme theory proposes that education and training for hospital staff providing care for people with dementia at the EoL is influenced by contextual mechanisms such as limited resources, irregular training, and staff turnover. The intervention mechanisms include understanding the perceptions and feelings of people with dementia through video-based education, developing communication skills with families through simulated scenarios, training and educating frontline role model staff, informing staff about policies and practices through communication channels, and providing educational sessions for overseas staff. The trainers' skills and competencies are crucial in delivering effective education. The expected outcomes include enhanced understanding and empathy, improved communication skills, motivated and supported teams, increased awareness of policies and practices, and culturally sensitive care.

6.3.2. Findings

The refined programme theory explores the intricate interplay of intervention mechanisms, contextual mechanisms, agency, and outcomes in the context of education and training for hospital staff providing care for individuals with dementia at the EoL. The initial programme theory established a foundation, emphasising the influence of contextual mechanisms like limited resources, irregular training, and staff turnover. Intervention mechanisms were identified, including the importance of understanding dementia from patients' perspectives, dedicated dementia education teams, cultural sensitivity, and tailored training for different staff groups. Now, through the CRE framework, this PhD study delve deeper into this theory by incorporating insights from participants and gaining a nuanced understanding of how these elements work together to yield specific outcomes.

Table 6-4 Refined theory one themes.

Category	Subthemes
Intervention Mechanisms	- Incorporating Cultural Sensitivity. - Dedicated Dementia Education Team - Broadening education to all staff (Two-Tier Training System) - Online training
Internal Contextual Mechanisms	- Mandating Training and Encourage Involvement. - Online training facilities within the hospital. - Staff shortage.
External Contextual Mechanisms	- Challenges of Online Training. - Collaborative Learning with Hospice Professional
Agency Responses	- Collaboration Between Dementia and EoLC Teams. - Passionate and Experienced Facilitators. - Staff interest and availability. - Importance of Ward Leaders' Engagement.
Outcomes	- Improved Understanding and Empathy. - Person-Centred and Comprehensive Care. - Increased effectiveness of education due to having Passionate and Experienced Facilitators. - Collaboration between the dementia and the palliative team increased the quality of the education provided. - less effective online training compared as face-to-face. - Increased the effectiveness of education engagement due to fostering EoL and dementia education and training through dementia champions. - The inability to mandate training and education led to low engagement.

6.3.3. Intervention Mechanisms

The understanding of dementia from patients' perspectives stands as a fundamental intervention mechanism in enhancing *EoLC* for individuals with dementia. This mechanism, as highlighted by participants, forms the cornerstone of empathy, essential for delivering compassionate care. Education plays a pivotal role in developing a deeper understanding of dementia and its complexities, with many participants advocating hands-on, immersive training as the most effective method. Additionally, incorporating cultural sensitivity into education and training is crucial, considering the varying views on dying influenced by cultural and religious backgrounds. The recent establishment of a dedicated dementia education team in the hospital underscores the importance of having a team focused solely on education, research, and content development. Furthermore, a two-tier training system tailored to different job roles ensures that all staff members, regardless of their position, have a basic understanding of dementia care. Effective collaboration between dementia care teams and EoLC teams, alongside the adoption of online training during the COVID-19 pandemic, highlights the multifaceted approach needed to improve education and training in this field.

The understanding of dementia from patients' perspectives stands as a fundamental intervention mechanism.

> *PG4: "So, it's trying to think from the perspective of a patient...what is it about that person, why are they behaving like that?"*

This mechanism forms the cornerstone of empathy, essential for delivering compassionate care. Participants unanimously agreed on the pivotal role of education in developing a deeper understanding of dementia and its complexities. *P7* emphasised, *"The more we know, the better it is for the care."*

Many participants advocated hands-on, immersive training as an effective training method to put learning into practice. *PG3: "The more immersive and experiential that you can do it...the better because we all learn differently."* However, to practice safely, it was suggested to undergo supervised practice before being allowed to work independently. Supervision ensures that staff members apply what they have learned effectively and confidently.

> *P1: "we will start with one supervision first, this is to see that we are doing everything properly, then if we are doing properly, we can start independent."*

The participants highlighted the importance of incorporating cultural sensitivity into education and training.

> *P2: "I think people from different cultures and backgrounds have varying views on dying, whether that has a religious connotation or not."*

Addressing cultural differences in perceptions of death and dying was a recurring theme among participants. This underscores the significance of cultural competence and sensitivity, not just in clinical care but also in education.

Furthermore, participants highlighted the need to overcome communication barriers, particularly concerning overseas staff. Tailoring training and education to address language and cultural differences emerged as a solution that could improve understanding and communication.

> *P3"I think it's quite difficult, especially with overseas, I think the communication's difficult anyway."*

Nonetheless, it is recognised that a cultural education deficiency is present in the identified hospital.

> **P3:** *"There isn't any training about the cultural side, not that I've seen. There's some online stuff, but that's about it."*

A recent intervention introduced to the hospital where the study was conducted was establishing a dedicated dementia education team. The participants saw that as an essential intervention. The intervention mechanism influences the quality and availability of education and training. Participants highlighted the importance of having a team that is solely focused on education, research, and content development, which allowed for the creation of comprehensive training sessions and continuous improvement of educational materials.

> *PG3: "We also obviously didn't have the time to be able to put so much into, you know, putting the packages of education together... whereas the new team, their role is focusing on education 24/7."*

The introduction of a two-tier training system, differentiating training levels based on job roles, offers a tailored approach. *P7*stressed the importance of basic understanding for all staff members, stating, *"Not only just the medical staff, doctors, porters. Everyone needs to have some basic understanding... staff should have some basics."* This system recognises the varied needs of different staff roles, thus enhancing the relevance and effectiveness of educational programs. However, this system seems to apply solely to autism training, emphasising the need for a similar stratification approach in the context of EoL dementia care. *P3: "So, with the two tiers, so say there's training that's just gone out and it's regarding autism only."*

Effective collaboration between dementia care teams and EoLC teams emerged as a significant intervention influencing education and training outcomes. A participant from the dementia care team stressed the interconnectedness of these teams and the need for joint efforts. This underscores the importance of a multidisciplinary approach where both teams work together to provide education and training for staff regarding dementia at the EoL. However, a vital point was also raised, questioning whether this collaboration should solely rest on the shoulders of the dementia care team or involve joint efforts with the palliative care team.

> *P4: "it kind of goes hand in hand with the palliative care team as well. But that would be, I don't know necessarily if that would just fall on our shoulders. That would need to be joint with the palliative team, really."*

In the context of the COVID-19 pandemic, the interviewees acknowledged the significance of online training when face-to-face options were limited. *P1* pointed out the availability of online training classes through the hospital education platform, showcasing the role of technology-mediated learning in improving staff knowledge and skills *P1 "We do have training classes online, so if anybody just applies on the online academy, they can get training."* It was also acknowledged that although online training doesn't come without limitations but it's better than having no training options at all.

> *PG3: "We literally had nothing in COVID, did we? Not really…, it's not ideal (online training), but it's better than nothing if you have nothing else."*

In conclusion, the intervention mechanisms identified in the study underscore the importance of a comprehensive and multifaceted approach to dementia care education and training. Understanding dementia from patients' perspectives is essential for fostering empathy and delivering compassionate care. The implementation of hands-on, immersive training methods ensures that staff can effectively put their learning into practice, with supervised practice enhancing confidence and competence. Incorporating cultural sensitivity into training addresses the diverse views on death and dying, promoting cultural competence in care. The establishment of a dedicated dementia education team has significantly improved the quality and availability of training, while the two-tier training system ensures that all staff members have a basic understanding of dementia care. Effective collaboration between dementia and EoLC teams further enhances training outcomes, and the adoption of online training during the COVID-19 pandemic has provided an alternative means of continuing education despite its limitations. Overall, these intervention mechanisms collectively contribute to improved understanding, empathy, and person-centred care for individuals with dementia at the EoL.

6.3.4. Internal Contextual Mechanisms

The internal contextual mechanisms play a pivotal role in shaping the effectiveness of education and training programs for EoLC in people with dementia. Mandating training and encouraging active involvement by hospital staff emerged as a critical mechanism. Participants underscored the necessity of mandatory training within each ward to ensure comprehensive staff participation. Additionally, the practical challenges posed by online training facilities and staff shortages are significant factors that impact the success of these programs. While online training offers convenience and accessibility, the lack of dedicated spaces for staff to attend these sessions within the hospital limits its effectiveness. Moreover, the ongoing issue of staff shortages exacerbates the situation by increasing workloads and reducing the time available for training. Addressing these internal contextual mechanisms is essential to refining the education and training theory, ensuring that these programs can be implemented effectively and have a substantial impact on the quality of care provided to individuals with dementia.
One mechanism is mandating training and encouraging involvement by the hospital. Active participation and mandatory training within each ward were highlighted by several participants as important contextual mechanisms that needs to be considered. *PG3* suggested, *"I would like to see each ward mandate that training for their staff."*

PG3 (elsewhere): "People will always say they're too busy unless it's something they have to do."

The challenges posed by online training facilities and staff shortages are critical aspects of the refined theory, impacting the effectiveness of education and training programs. Participants noted that online training, despite its convenience and accessibility, faces limitations due to the lack of dedicated spaces within the hospital for staff to attend online sessions. Participants pointed out that finding quiet, conducive spaces for online training sessions was a significant challenge. This issue highlights the practical difficulties faced in implementing online training and suggests that merely having the training available online doesn't guarantee its effectiveness.

> *PG1: "I think virtual learning for us, a barrier is actually people having somewhere to go to attend. I think it's seen as it's easy because it's out there and anyone can access it. But actually here, we have a huge problem with finding quiet spaces to attend, and it's sometimes not actually easier than face to face because face to face generally has a venue. It's really hard."*

Furthermore, the issue of staff shortages emerged as an internal contextual mechanism that can hinder the successful execution of education and training programs. The shortage of healthcare staff, as highlighted by participants, can lead to increased workloads and reduced availability for training, potentially impacting the overall quality of care. Even when training is available, limited time and resources due to staff shortages may limit its effective delivery. These factors underscore the importance of addressing staffing issues as a crucial part of refining the programme theory to ensure that education and training efforts can be successfully implemented and have a meaningful impact on EoLC for individuals with dementia.

> *P1: "At the moment, the only challenge is that we have too many patients entering, and then we are definitely going to have a staff shortage. There is a staff shortage, so we can’t leave the wards to attend training."*
>
> *P3: “I just don't know how much training they're given. The only thing that I know from the office that I work in is that the palliative care team sometimes sort of say there's just never enough time in the day to give everybody the training that they need.”*

In summary, the internal contextual mechanisms identified highlight the importance of mandatory training and active involvement by hospital staff, addressing practical challenges related to online training facilities, and mitigating the impact of staff shortages. Mandating training within each ward ensures comprehensive staff participation, fostering a consistent level of knowledge and skill across the board. However, the practical difficulties of finding quiet, conducive spaces for online training within the hospital underline the need for dedicated facilities to enhance the effectiveness of virtual learning. Staff shortages further complicate the successful execution of education and training programs by increasing workloads and limiting the time available for training, ultimately affecting the overall quality of care. Addressing these issues is crucial for refining the programme theory, ensuring that education and training efforts can be successfully implemented and have a meaningful impact on EoLC for individuals with dementia.

6.3.5. External contextual mechanisms

External contextual mechanisms significantly influence the effectiveness of education and training programs for EoLC in people with dementia. Two critical external factors that emerged from interviews and focus groups are the challenges associated with online training, particularly highlighted during the COVID-19 pandemic, and the potential benefits of collaborative learning with hospice professionals. These mechanisms provide essential insights into how external conditions can shape and sometimes hinder the implementation and success of training initiatives. Understanding these factors is crucial for refining educational strategies to ensure they are resilient and adaptable to varying external circumstances.

The challenges associated with online training, particularly in the context of the COVID-19 pandemic, are essential to acknowledge. Virtual training became a necessity during the pandemic, but it posed several challenges. Participants articulated their concerns about the limitations of online training. They highlighted a significant issue - the perceived lack of dynamic interaction and engagement in comparison to face-to-face sessions. Participants described the absence of a true connection, emphasising that the online format doesn't replicate the richness of in-person training where non-verbal cues, facial expressions, and real-time interactions play vital roles in effective learning. Even one participant who provided online training, echoed this sentiment, noting that online training often leads to participants turning off their cameras, which further diminishes the sense of connection and engagement. This commentary underscores the significance of human interaction and the potential drawbacks of relying solely on online training. One example to highlight these challenges is the following conversation between participants in the focus group:

> *PG1:" The dynamic's just not the same, even with the chat. PG3: And then people turn their cameras off, you don't know if they're still there." PG1: "It's awful, you just feel like you're talking to nothing. You can't see people's faces, it's really - So even the trainer doesn't feel that" - PG3: "And I just think the impact of virtual training is not the same as face to face. It's not. You need that interaction."*

On the other hand, collaborative learning with hospice professionals emerges as a potentially valuable agency within the programme theory. P5's perspective introduces an intriguing concept of hands-on mentoring and guidance by experienced practitioners. Collaborative learning with hospice professionals could offer practical insights and strategies that might not be attainable through traditional training methods alone. P5's mention of a mentor-like approach to training highlights the potential benefits of pairing experienced professionals with staff who may be struggling with specific aspects of EoLC. This approach has the potential to enhance staff knowledge and confidence, ultimately leading to improved care for individuals with dementia at the EoL.

> *P5: "So if that's something we could look at doing, so it's not – again, that's someone so removed in that specialist role that's not hands-on but actually someone who can give them little, 'Right, okay if you're really struggling to work out if your patient's in pain, this is what you could do'. That almost, mentor kind of way in training would be really useful."*

In summary, external contextual mechanisms such as the challenges of online training and the benefits of collaborative learning with hospice professionals are pivotal in shaping the theory of education and training for EoLC in dementia. The limitations of online training, especially during the COVID-19 pandemic, underscore the importance of dynamic, face-to-face interactions that foster engagement and effective learning. The absence of non-verbal cues and real-time interactions in virtual training environments diminishes the richness of the learning experience, as highlighted by participants. Conversely, the integration of collaborative learning with hospice professionals presents a valuable opportunity for practical, hands-on mentoring. This approach can significantly enhance staff knowledge and confidence, leading to improved care for individuals with dementia at the end of life. By addressing these external contextual mechanisms, educational programs can be better tailored to meet the needs of healthcare professionals, ensuring a more effective and empathetic approach to dementia care.

6.3.6. Agency

The agency of staff plays a pivotal role in determining the effectiveness and success of education and training programs designed for those caring for people with dementia at the EoL. The responses and attitudes of staff towards these interventions can significantly shape the outcomes of such educational efforts. Key elements of agency that emerged from the study include the presence of passionate and experienced facilitators, the interest and availability of staff, and the critical engagement of ward leaders. These factors collectively influence the participation rates, the quality of the training experience, and the practical application of the skills learned.

One agency response that emerged was the presence of passionate and experienced facilitators in the education process. Participants emphasised the value of facilitators who had first-hand experience in dementia care and could share their lived experiences. Some participants eloquently described how passionate and knowledgeable facilitators positively impact training.

> *PG2: "Some of the best trainings I've had is from people that are like really passionate and involved in their aspect."*

Staff interest and availability were identified as crucial factors influencing attendance at training sessions. Participants noted that while training sessions related to dementia and EoLC are available, attendance often depends on individual interest and availability. This highlights the voluntary nature of these sessions and the need to align training programs with staff interests to maximise participation.

> *P1: "That depending on who's available, so we have the academy team, and they have some classes related to dementia. If you're interested in dementia, you can attend the dementia introductory and you can go and ask them…End-of-life training is the same. Palliative team have training courses available but depending on the interests of the staff."*

Lastly, the importance of ward leaders' engagement in education and training initiatives was underscored. Participants emphasised that staff engagement, rather than the availability of training, can be a barrier. Ward leaders play a pivotal role in encouraging and motivating their teams to participate in training sessions. This aspect points to the potential for making training sessions mandatory or implementing strategies to gain active support from ward leaders.

> *P4: "I think the problem is staff engagement, not necessarily that the training is not there, it's that the staff won't engage with it…But we have to get engagement from the ward leaders because if we haven't got that then we're stuck."*

In conclusion, the agency of staff is a critical determinant in the success of education and training programs for dementia care at the EoL. Passionate and experienced facilitators enhance the quality and impact of training through their first-hand knowledge and enthusiasm. Staff interest and availability are essential for ensuring high participation rates, highlighting the need for training programs that resonate with the personal and professional interests of the healthcare workers. Moreover, the engagement of ward leaders is vital in motivating and mandating staff participation in training sessions. Without active support and encouragement from ward leaders, even the most well-designed training programs may fail to achieve their intended outcomes. Therefore, fostering a supportive and engaging environment is crucial for the effective implementation of education and training initiatives in dementia care.

6.3.7. Outcomes

The data from Phase Two of the study highlighted multiple positive outcomes stemming from dementia-specific education and training for hospital staff involved in EoLC. A primary outcome was the enhanced understanding and empathy among staff. Participants noted that training helped them better interpret and respond to behaviours typically associated with advanced dementia, especially agitation or withdrawal. This understanding was vital for delivering more compassionate care.

> P4: *"It's not necessarily about putting anything into practice, it's about understanding why somebody behaves the way they do… If you have somebody who doesn't really understand that someone with dementia is lashing out because they're scared or in pain… So it's about making staff understand that."*

This reinforced the mechanism by which education fosters relational and emotional competence, enabling staff to respond with sensitivity rather than misinterpret behaviours as resistance or non-compliance.

Another outcome was the promotion of person-centred care. Education was reported to help staff develop individualised care strategies based on an understanding of the person behind the diagnosis — their history, preferences, and what mattered most at EoL.

> P7: *"What is end of life care in dementia? So what is best for them? How can you do proper person-centred care? How can you value that person?"*

This understanding was often complemented by the staff's collaboration with family members, further aligning care with the person's values. Where such collaboration occurred, it led to the co-creation of holistic care plans that balanced clinical and emotional priorities.

Multidisciplinary collaboration was also identified as a key enabler. Working jointly with specialist teams, especially dementia care practitioners and palliative care clinicians, allowed learning to take place in real-time and created a shared responsibility for care outcomes.

> PG1: *“So if we're managing a case and we involve somebody from [the] dementia team, it’s then about managing that case together. And I think that's how my staff learn... it's there in front of you.”*

Another positive outcome related to the influence of facilitator quality. While not deeply explored by all participants, there was a general consensus that passionate, skilled trainers were more likely to inspire staff and create impactful learning experiences.

Alongside facilitator quality, participants repeatedly emphasised that the format of training delivery mattered significantly. In particular, staff expressed concerns about the limited effectiveness of online modules and mandatory e-learning platforms, which were often seen as too passive and lacking in contextual depth.

> P7: *“Even though they get their mandatory training, that is not sufficient… something like a snap box, some additional training for end of life care… makes a difference.”*

In contrast, face-to-face training, simulation, and real-patient case reflection were described as more engaging and transformative, especially when they involved scenario-based learning.

> PG3: *“Simulation and interactive learning really helps – putting yourself in the place of the patient.”*

This preference aligns with evidence on adult learning theories, which support experiential methods for building practical empathy and reflexivity in care contexts.

The dementia champion model was identified as another important strategy for reinforcing knowledge and embedding a culture of care. Trained frontline staff were viewed as role models who could support colleagues and help sustain practice change.

However, challenges were noted with the consistency of this approach, particularly in teams with high staff turnover or rotational staff.

> PG1: *"The champion model doesn't always work in teams that have a lot of throughput… people get very involved and very interested and then you lose them."*

Additionally, the voluntary nature of many training programmes emerged as a limiting factor. Several participants believed that making training optional reduced overall engagement and left gaps in staff capability across hospital wards.

> PG3: *"Now we've got the education in place, what we need is the attendance… each ward [should] mandate that training for their staff."*

This suggests that more localised accountability, such as ward-level training mandates, may be more feasible and effective than Trust-wide enforcement.

Dementia-specific education and training significantly improved hospital staff's empathy, understanding, and communication in EoLC, enabling more compassionate and person-centred approaches. Staff valued experiential formats like face-to-face and simulation-based learning over online modules, which were seen as less effective. Interdisciplinary collaboration, especially between dementia and palliative care teams, further enhanced care quality and staff learning. Passionate facilitators and dementia champions supported knowledge retention, though challenges such as staff turnover and the voluntary nature of training limited consistency. Overall, outcomes suggest that well-delivered, mandatory, and context-sensitive training is key to improving EoLC for people with dementia.

6.3.8. Theory Refining

The refined programme theory integrates elements from the initial theory and Phase Two analysis to illuminate the intricate dynamics that enhance EoLC for people with dementia through comprehensive education and training. At its core are the intervention mechanisms, including understanding dementia from patients' perspectives, incorporating cultural sensitivity, establishing a dedicated dementia education team, implementing a two-tier training system, utilising online training, and tailoring training for specific staff groups. These mechanisms are propelled by internal contextual mechanisms like mandating training and encouraging involvement, grappling with online training facilities' challenges, and coping with staff shortages. External contextual mechanisms encompass the challenges posed by online training and the potential benefits of collaborative learning with hospice professionals.

Agency emerges as a critical driving force, with passionate and experienced facilitators, staff interest and availability, and the importance of ward leaders' engagement playing pivotal roles. Together, these components synergise to yield multiple outcomes, including improved understanding and empathy among staff, person-centred and comprehensive care for patients, increased effectiveness of education through passionate facilitators, and enhanced collaboration between dementia and palliative care teams. However, online training challenges, marked by reduced engagement and interaction, underscore the need for further refinement. Furthermore, the involvement of dementia champions in education fosters engagement, while the absence of mandated training leads to variable levels of staff participation. This refined theory illuminates the complex interplay between intervention mechanisms, contextual factors, agency, and outcomes, underscoring the significance of tailored education, cultural sensitivity, and dedicated teams in advancing dementia care.

6.3.9. Refined Theory One

The refined education and training theory

The refined programme theory centres on education and training as essential mechanisms for enhancing EoLC for individuals with dementia. Key intervention mechanisms include understanding dementia from the patient's perspective, incorporating cultural sensitivity, establishing a dedicated dementia education team, implementing a two-tier training system, utilising online training, and tailoring training for specific staff groups. These mechanisms, driven by passionate facilitators, staff engagement, and ward leaders' support, converge to produce significant outcomes. These outcomes encompass improved staff understanding and empathy, resulting in more person-centred and comprehensive patient care, along with increased collaboration between dementia and palliative care teams.

6.4. Theme two: Enhancing Advance Care Planning and its Implementation Theory

6.4.1. Initial Theory

Advance Care Planning theory

The initial programme theory proposes that the effectiveness of ACP for people with dementia at the EoL in hospitals can be enhanced by addressing the identified mechanisms. By identifying the required and preferred wishes of care for individuals with dementia and involving them in decision-making, a more personalised and patient-centred care plan can be developed. Despite time constraints and competing priorities, efforts can be made to prioritise ACP discussions by allocating sufficient time and resources. In addition, involving MDT and alleviating the workload of GPs can support the integration of ACP into the care pathway. Implementing a uniformed platform to identify ACP documents prior to admission and raising community awareness about the importance of early ACP can further enhance the effectiveness of ACP. Strengthening healthcare professionals' documentation and communication skills, providing education and training on initiating sensitive conversations, and fostering family collaboration are crucial human agency mechanisms. Additionally, creating a short document as an alternative to the full ACP document and offering education and resources for healthcare professionals can mitigate the barriers and improve the effectiveness of ACP for people with dementia at the EoL in hospital settings.

6.4.2. Findings

Table 6-5 Refined theory two themes (ACP).

Category	Subthemes
Intervention Mechanisms	- Creation of Comprehensive Advanced Care Plans. - Integration of Advanced Care Planning Early in Patient's Journey. - Role of ACP Documents.

	- Mitigating Unnecessary Trauma. - Effective Communication Skills. - Family Guidance and Support. - Proactive Patients and Families.
Internal Contextual Mechanisms	- Education about Communication. - Internal Protocols and Guidelines.
External Contextual Mechanisms	- Medical Ideologies and Priorities. - Lack of Unified Platforms. - General Practice Workload. - Lack of Awareness. - Cultural Barriers. - Topic sensitivity.
Agency Responses	- Communication Skills and Empathy. - Family Dynamics and Relationships.
Outcomes	-Improved Patient-Centred Care. -Avoidance of Unwanted Interventions. -Improved Communication and Patient Care. -Cultural Competence .

6.4.3. Intervention Mechanisms

ACP represents a critical intervention mechanism within healthcare, aimed at understanding patients' lives comprehensively, encompassing personal preferences and lifestyle choices beyond mere medical decisions. The creation of comprehensive ACPs underscores the importance of holistic and patient-centred care. Early integration of ACP discussions ensures that patients have sufficient time to contemplate their preferences while they still possess the capacity to provide informed consent. ACP is a dynamic and ongoing process, necessitating continuous review and monitoring to maintain its effectiveness. Moreover, ACP enhances patient care by empowering healthcare providers to make informed, patient-aligned decisions. ACP documents serve as vital tools for guiding medical decisions, particularly in critical situations such as resuscitation and ITU referrals. Additionally, ACP mitigates unnecessary trauma for patients by ensuring that care aligns with their preferences, thus contributing to a more compassionate EoLC.

The participants in the interviews stressed the significance of creating comprehensive ACPs. ACPs were perceived to serve as essential tools for gaining insights into patients' lives, extending beyond medical decisions to encompass personal preferences and lifestyle choices. This underscores the importance of including a wide range of information in ACP documents to ensure holistic and patient-centred care.

> *PG2: "I think to the best of our ability at times... the advanced care plans are very, very important. I think they're very good to be brought in," emphasises the pivotal role of comprehensive ACPs in understanding and addressing patients' unique needs and wishes.*

Moreover, the interviews highlighted the necessity of integrating ACP discussions early in a patient's healthcare journey as early integration of ACP plays a crucial intervention mechanism in ensuring that the patient is given time to think about his/her preferences and choices, and that the patient is still have the capacity to give consent.

> *P6: "You have a plan now: if this disease progresses, then I want you to do this. And that is what is important: your wants. Because it's all you. You're the one who's got the disease, not them."*

Early initiation of ACP at the time of diagnosis and being continuously reviewed and monitored, underscores that ACP is a dynamic and ongoing process. This intervention mechanism suggests that healthcare professionals should integrate ACP discussions into the patient's healthcare journey from the outset to ensure its effectiveness.

> *PG3's: "I feel that needs to be a document that's created quite early on in the patient's journey... and constantly reviewed and monitored... patient always knows where it is," emphasises the importance of ACP as an evolving and patient-centred document.*

The interviews also underscored the importance of ACP in enhancing patient care. ACP ensures proper care and decision-making during critical moments, making it a valuable tool for empowering healthcare providers to provide patient-centred care. This intervention mechanism implies that ACP not only involves documentation but also enables healthcare professionals to align treatment with patient preferences, ultimately enhancing the quality and appropriateness of care.

> *P1: "Definitely, with the advanced care plan we don't have to worry about anything... anything happens, we make sure our patients have a TEP form when admitting,"*

This highlights how ACP contributes to ensuring that patients receive appropriate care, aligning with the importance of ACP in improving patient care.

The ACP documents emerged as crucial in guiding medical decisions. the interviewees emphasised that ACP documents, especially those outlining aspects like resuscitation and intensive care unit (ITU) referrals, play a pivotal role in guiding medical decisions. This suggests that ACP documents serve as tangible and essential components of the ACP process, ensuring that healthcare professionals have clear guidance for treatment decisions.

> *P2: "So me personally probably, that's where I can have experiences with advanced care planning about resuscitation, referral to ITU and that kind of thing," emphasises the practical utility of ACP documents in guiding critical medical decisions."*

Furthermore, ACP was noted to mitigate unnecessary trauma for patients. P2 eloquently explained how ACP can prevent unnecessary suffering by ensuring that care aligns with patients' preferences. This intervention mechanism highlights ACP's potential to contribute to a kinder and more compassionate EoLC, reducing emotional and physical trauma for patients and their families.

> *P2: "So in that respect, it can prevent unnecessary trauma for patients who, for example, shouldn't be resuscitated... it's one of the kindest things you can do,"*

This highlights the role of ACP in promoting compassionate care.

The multifaceted role of ACP as a crucial intervention mechanism in healthcare is evident. Comprehensive ACPs provide a thorough understanding of patients' preferences, fostering holistic and patient-centred care. Early integration of ACP discussions ensures patients can thoughtfully consider their choices while retaining the capacity to make informed decisions. The dynamic nature of ACP, with its need for continuous review, highlights its evolving relevance throughout a patient's healthcare journey. The enhancement of patient care through ACP enables healthcare providers to deliver treatments that align closely with patients' wishes, thus improving the quality and appropriateness of care. The practical utility of ACP documents in guiding critical medical decisions further solidifies their importance within the ACP process. By preventing unnecessary trauma and promoting compassionate care, ACP plays a vital role in enhancing the overall patient experience, particularly at the end of life. These findings underscore the essential nature of ACP in ensuring that healthcare remains responsive, compassionate, and aligned with the values and preferences of patients.

6.4.4. Internal Contextual Mechanisms

In terms of internal contextual mechanisms regarding ACP, none of the participants disagreed with or expanded on the mechanisms presented to them. All showed agreement.

6.4.5. External Contextual Mechanisms

External contextual mechanisms play a crucial role in shaping the implementation and success of Advanced Care Planning (ACP). Public awareness and education about ACP are pivotal, as the lack of knowledge among the public emphasises the need for effective educational campaigns to demystify ACP and highlight its importance. Cultural sensitivity and diversity also significantly impact ACP, requiring healthcare providers to adapt their communication styles to respect and accommodate various cultural perspectives on aging, death, and dying. Language barriers and translation challenges further complicate ACP discussions, necessitating the provision of effective translation services to ensure clear communication. Additionally, societal norms and cultural factors influence the perception and practice of ACP within different communities, highlighting the need for culturally aware approaches. The tension between life-preserving medical ideologies and the necessity of holistic, patient-centred care points to the influence of healthcare policies and practices on ACP. Community engagement and the availability of unified platforms for accessing ACP documents also emerged as essential factors, underscoring the importance of external initiatives and infrastructure in facilitating ACP engagement and implementation.

Public Awareness and Education about the importance of initiating ACPs emerged as a pressing external contextual challenge, exemplified by the observation that there is a notable lack of public awareness regarding ACP. This knowledge gap emphasises the necessity for public education to demystify ACP's intricacies and underscore its significance. A well-executed public awareness campaign has the potential to bridge this gap and encourage individuals to initiate ACP discussions with healthcare providers.

> *PG3: "I think, yeah, you're right that the awareness of being able to do that isn't widespread at all... We need a campaign, don't we?"*

Cultural Sensitivity and Diversity play a crucial role, as illustrated through discussions highlighting the complexities stemming from varying cultural perspectives on aging, death, and dying. This external contextual factor underscores the importance of cultural competence when engaging in sensitive ACP conversations. Healthcare providers must adapt their communication styles to accommodate diverse cultural backgrounds, recognising that these backgrounds significantly shape how individuals’ approach and perceive ACP discussions.

> *P1:"Because we are coming from different countries, and they have different ways of talking about things... we have to tell them... it could happen."*

Language Barriers and Translation challenges were raised as significant external contextual issues, emphasising the complexities surrounding language barriers and the utilisation of family members as translators. This can potentially lead to legal and communication challenges, highlighting the importance of healthcare systems addressing language barriers and providing effective translation services to facilitate clear and productive ACP discussions.

> *P2: “Language barriers is another one, it makes it difficult obviously, needing a translator, having to use a phone to translate, also, having a family member translating for you and, I suppose, in that context, that can be difficult, potentially difficult legally, because I’m not sure, in terms of the legalities of having a family member translate for you, I would’ve thought that that is not valid because they can obviously change things.”*

The tension between medical ideologies centred on preserving life and the imperative of holistic, patient-centred care illustrates external contextual mechanisms. It suggests that external factors, such as healthcare policies and practices, wield significant influence over the approach to ACP discussions. This underscores the importance of aligning these external factors with the goal of patient-centred care.

> *P4: “we have 98-year-old ladies who are coming to the end of their life that they’re taking bloods and trying to but NG tubes in and it’s – what are we doing? It’s easy for me, I can kind of look – I think, I’m probably gonna go off on a real tangent here, but I think for some medics, their train of thought is very, very different in that they are taught to preserve life at all costs and not*

> *think about necessarily the quality of that life. Ethical – I get that, but actually, you're actually causing that patient more harm and more distress by doing that than you are by not doing anything."*

The absence of a unified platform for accessing ACP documents, as discussed, reflects external contextual mechanisms related to the external infrastructure and technology environment. It implies that the availability of external tools and systems significantly affects ACP implementation, emphasising the importance of seamless access to ACP-related documents.

> *PG1 statement "think that's a really valid point about the platforms, because quite often when someone comes in, we sort of feel like we're detectives. You have to look in so many different places to gather all the little bits of information, all the different community services. So I can see that if, yeah if we were using the same systems, it would be dramatically better."*

Emphasis on comprehensive education and heightened community awareness underscores the external contextual mechanism of external education and awareness campaigns. These campaigns can facilitate ACP engagement by enhancing public understanding and promoting its significance. This illustrates the role of external factors in shaping ACP practices.

> *P4: "So, you think that education can – and what about the awareness of the community in general about advanced care planning, do we have that awareness?"*

The interviews revealed several internal contextual mechanisms that play a critical role in the success and implementation of Advanced Care Planning (ACP). One prominent mechanism is the Collaborative Approach between Healthcare Professionals, as highlighted by PG1 and PG3.

> *PG1: "I think that's a really valid point about the platforms because quite often when someone comes in, we sort of feel like we're detectives. You have to look in so many different places to gather all the little bits of information, all the different community services."*

PG3 also noted improvements in information exchange facilitated by the RIO database, saying, *"I think things are slightly better in that we do have access to RIO."*

The exploration of external contextual mechanisms reveals their profound impact on the efficacy of ACP. Public education campaigns are crucial in raising awareness and encouraging individuals to engage in ACP discussions, bridging the knowledge gap that currently exists. Cultural competence is essential for healthcare providers to effectively navigate diverse perspectives on aging, death, and dying, ensuring that ACP discussions are respectful and meaningful. Addressing language barriers through effective translation services is vital for clear communication and legal clarity in ACP. The influence of societal norms and healthcare policies underscores the need for a patient-centred approach that prioritises quality of life over merely preserving life. Community engagement initiatives play a significant role in shaping public understanding and participation in ACP, while the integration of unified platforms for ACP documents enhances the accessibility and coordination of care. Collectively, these external contextual mechanisms highlight the multifaceted challenges and opportunities in implementing ACP, emphasising the need for a comprehensive and culturally sensitive approach to ensure its success.

6.4.6. Agency

The findings shed light on several crucial mechanisms related to stakeholders' responses that significantly influence the implementation of ACP. These mechanisms centre on the role of healthcare professionals and the importance of effective communication in ACP discussions. PG3's emphasis on the necessity of education and training for healthcare staff illuminates the pivotal role of healthcare professionals in ACP implementation. PG3's viewpoint underscores that healthcare providers must be equipped with the skills and knowledge to engage in discussions that prioritise a patient's quality of life over mere preservation of life, emphasising the need for a patient-centred approach.

Effective communication skills emerged as a critical facilitating ACP discussion. P6 emphasised the significance of these skills in conducting ACP conversations, underscoring the need for healthcare professionals to possess the necessary communication skills. This highlights the importance of clear, empathetic, and sensitive communication in ensuring that patients' preferences are accurately captured and respected. P6's statement as how they might communicate with the patient and the family, *"You have a plan now [ACP]: if this disease progresses, then I want you to do this. And that is what is important: your wants. Because it's all you. You're the one who's got the disease, not us,"* emphasises the role of effective communication in facilitating ACP discussions and respecting patients' preferences.

> *P2: "Communication skills are crucial in those scenarios... discuss."*
> *P6: "…staff documentation and communication skills are essential, their confidence and creating sensitive conversations with the patient or the families is also essential…"*

Moreover, the interviews revealed the complexities that families face in making decisions related to ACP. P7's discussion highlighted these challenges, emphasising the role of healthcare professionals in community and in the hospital in providing guidance and support as well as the families significant role in navigating the complexities of ACP, especially when legal arrangements like power of attorney are not in place or when patients' cognitive abilities impede their active participation.

> *P7: "I think, as you clearly said, that should be realised between community services and the hospitals. Especially ones that are diagnosed with dementia, usually they do recommend, I think, those services to have those discussions, but apparently it is up to the families,"*

This was in the context of the significance of family guidance and support in the ACP process.

Developing competencies over time, as candidly reflected upon by P2, reveal that healthcare providers experience challenges such as fatigue and time pressures in conducting ACP discussions. P2's statement, *"After six months… you're used to that. So, it's time that hel"s,*" underscores the dynamic nature of ACP discussions and how healthcare providers' internal growth and adaptation can impact these discussions.

The findings underscore the critical role of healthcare professionals and effective communication in the implementation of ACP. The necessity for education and training equips healthcare providers with the skills to prioritise a patient's quality of life, facilitating patient-centred care. Effective communication skills are essential in capturing and respecting patients' preferences, as highlighted by the importance of clear, empathetic, and sensitive interactions. The complexities families face in ACP decisions, especially without legal arrangements like power of attorney, further emphasise the need for professional guidance and support. The dynamic nature of ACP discussions, influenced by healthcare providers' internal growth and adaptation, illustrates the ongoing challenges and learning curve in effectively conducting ACP. These mechanisms highlight the significance of stakeholder responses in fostering a compassionate and patient-centred approach to ACP.

6.4.7. Outcomes

The refined theory stemming from the interviews underscores the transformative impact of ACP on patient-centred care. ACP acts as a foundational mechanism by aligning care with patients' individual preferences and values, thereby supporting autonomy and dignity in end-of-life (EoL) care.

> P3 :*"I think if a person has already written their ACP... it just makes it easier for the team to know what they want, and we can follow that."*

This highlights how documented patient wishes guide the clinical team and ensure care delivery is congruent with what the patient values most.

In addition to promoting autonomy, participants noted that ACP contributes to more efficient resource allocation and avoidance of unwanted interventions. PG1 reflected on the challenges that arise when ACP is not operationalised:

> *PG1:"There's always this issue that someone's ACP says 'don't resuscitate' or 'don't escalate' but then there are no resources, or no time to check it, and things get done anyway."*

This statement illustrates the tension between recorded patient wishes and real-time decision-making within constrained systems, reinforcing the need for timely access and institutional commitment to honour ACP documents.

Cultural competence emerged as a crucial dimension in ACP effectiveness. Participants noted that cultural beliefs influence how patients and families engage in end-of-life planning.

> P2 remarked, *"I think some families don't understand what ACP is about because in their culture they don't talk about death openly… So, it's hard to explain why we're asking."*

This underscores the importance of culturally sensitive approaches that respect different perspectives on death and dying and tailor ACP discussions accordingly.

The legal and ethical complexity of ACP discussions was also highlighted. Concerns around translation and communication were voiced, especially when informal interpreters are used.

> P2 : *"Sometimes we use family to translate but it's risky. What if they don't say exactly what we mean? That could be a legal problem."*

This reflects the need for professional communication support and structured approaches that ensure legally sound and ethically responsible ACP conversations.

Beyond clinical and legal aspects, ACP also influences family dynamics and bereavement outcomes.

> P3 shared, *"It definitely helps when the family knows what the patient wanted. There's less arguing. It's more peaceful after."*

This exemplifies how ACP can foster emotional relief, prevent familial conflict, and provide comfort during the bereavement process by affirming that care aligned with the patient's wishes.

The integration of tools like the 'This Is Me' document was also seen as a valuable extension of ACP.

> P4:*"If we had that ['This Is Me'] in the care plan, we'd know what's important to them ... not just medical stuff, but what matters to them as a person."*

This demonstrates that ACP can transcend clinical decisions by acknowledging identity, preferences, and personhood in a holistic care model.

Initiating ACP early was repeatedly emphasised, especially for people with dementia. P5 noted, *"If you wait too long, they might not be able to say what they want. Better to do it early, especially with dementia."* Similarly, P6 affirmed, *"ACP gives them a voice ... before they lose capacity. That's the point, isn't it?"* These reflections reinforce the importance of early ACP initiation as a means of safeguarding agency before cognitive decline progresses.

The consequences of missing ACP planning were also brought to light.

> P7: *"We had a patient who didn't have an ACP and no power of attorney — the family didn't know what to do. He stayed in hospital for weeks."* Similarly, PF2 shared, *"My dad never had an ACP. We couldn't talk to him because of his hearing and dementia, and now we're just guessing."*

These accounts highlight the emotional strain and system-level inefficiencies that can arise when ACP is absent or delayed.

> Finally, PF1 reflected on a proactive and positive example: *"My mother-in-law completed her ACP before her diagnosis. It gave her control over her care and gave us peace of mind."*

This statement captures the holistic value of ACP—not only as a clinical tool but as a mechanism for empowerment, clarity, and relational reassurance for families during difficult transitions.

In conclusion, the interviews reveal that ACP plays a multidimensional role in enhancing person-centred care, fostering cultural and legal sensitivity, empowering patients, and promoting family cohesion. At the same time, the absence of ACP can create systemic, emotional, and ethical burdens. These insights reinforce the refined theory that ACP is not merely a planning instrument but a vital mechanism for achieving dignified, compassionate, and responsive EoL care.

6.4.8. Refining the Theory

The refinement of the initial theory of ACP integrated insights from participant interviews, highlighting crucial mechanisms and interactions not fully captured in the original theory. This process illuminated the interplay between intervention mechanisms, external contextual mechanisms, agency responses, and outcomes, resulting in a more comprehensive and nuanced understanding of ACP implementation. The initial theory primarily focused on the fundamental components of ACP, such as creating ACP documents, the role of healthcare professionals, and the importance of patient-centred care. However, the final theory incorporates additional layers of complexity and specific mechanisms that emerged from the participant interviews, leading to a richer and more detailed framework.

The final theory includes several new mechanisms. Public awareness and education emerged as a significant factor influencing ACP engagement, highlighting the need for public campaigns to demystify ACP and encourage early discussions. Cultural sensitivity and diversity became crucial, stressing the need for culturally sensitive communication to address the impact of diverse cultural perspectives on ACP practices. Language barriers and translation challenges were also introduced, addressing the complications that arise from language barriers and the use of family members as translators. Additionally, community engagement and external infrastructure were emphasised, encompassing the need for unified platforms for accessing ACP documents and the role of external tools in supporting ACP practices.

Disagreements and refinements between the initial and final theories were also identified. The final theory refined the understanding of the tension between medical ideologies focused on life preservation and the principles of patient-centred care. This tension highlighted the need to align healthcare practices with holistic, patient-centred approaches. The role of healthcare professionals and effective communication was further emphasised, stressing the necessity for continuous education and training to equip them with the skills required for effective ACP discussions. Moreover, the final theory expanded on the complexities faced by families in the ACP process, detailing the significant role of healthcare professionals in providing comprehensive support and guidance.

The interaction of these mechanisms in the final theory produces a more integrated and holistic approach to ACP. Public awareness campaigns (external contextual mechanism) can enhance the readiness of individuals and families to engage in ACP discussions, supporting healthcare professionals (agency response) in facilitating these conversations. Effective communication skills (intervention mechanism) are crucial in ensuring that patients' preferences are accurately captured and respected, leading to improved patient-centred care (outcome).

Additionally, the inclusion of cultural sensitivity and addressing language barriers ensures that ACP discussions are accessible and respectful of diverse populations, further enhancing the overall effectiveness and equity of ACP implementation. The interplay between these mechanisms creates a robust framework that addresses the multifaceted challenges of ACP, ultimately leading to more informed, compassionate, and patient-centred care.

In conclusion, the refined theory of ACP, shaped by the dynamic and interconnected mechanisms identified through participant insights, provides a comprehensive and nuanced understanding of the factors influencing ACP implementation. This refined theory better captures the complexities of real-world ACP practices and offers actionable insights for improving the quality and effectiveness of ACP.

6.4.9. Refined Theory

The effectiveness of ACP for people with dementia at the end of life in hospitals can be enhanced by addressing identified mechanisms. A person-centred approach, comprehensive ACP documents, early integration of ACP, and multidisciplinary team involvement enable the development of personalised and holistic care plans. Efficient resource allocation and avoidance of unwanted interventions result from clear guidance provided by ACP documents. Cultural competence, communication skills, and family support facilitate ACP discussions. Public awareness and education campaigns, along with unified platforms for ACP documents, promote proactive ACP initiation. Ultimately, ACP empowers patients, aligns care with preferences, and enhances patient-centred care, reducing trauma for patients and families.

6.5. Theme Three: Multidisciplinary Team Collaboration Theory

6.5.1. Initial Theory

Multidisciplinary team collaboration

The initial programme theory proposes that by implementing MDT collaboration for people with dementia at the EoL in a hospital setting, several intervention mechanisms can improve the quality of care. These mechanisms include identifying holistic assessments of patients' needs, sharing decision-making among the team, and tracking patients' care. However, there are internal conceptual mechanisms to address, such as the medical ideology of curing and saving lives, reduced frequency and depth of meetings, and the clarity of health documents. External conceptual mechanisms involve fostering a supportive environment, encouraging education and training, ensuring an appropriate physical environment for communication, and challenging the prevailing medical ideology. The agency lies with senior doctors' perceptions and the engagement of nurses and allied healthcare professionals. By addressing these mechanisms, the programme aims to enhance collaboration, decision-making, and care for individuals with dementia at the EoL in a hospital setting.

6.5.2. Findings

Table 6-6 Refined theory Three themes (MDT collaboration).

Category	Subthemes
Intervention Mechanisms	- Collaborative Decision-Making. - Effective Communication. - Holistic Assessment.
Internal Contextual Mechanisms	- Hierarchical Structure. - Organisational Culture. -Staffing Constraints.
External Contextual Mechanisms	- Impact of COVID-19. - Resource Constrain. - External Support Services.
Agency Responses	- Empowerment of Healthcare Professionals. - Patient Advocacy. -Family involvement.
Outcomes	- Informed, Patient-Centred Care. - Enhanced Post-Bereavement Support. - Improved Communication and Collaboration. - Comprehensive Patient Car.

6.5.3. Intervention Mechanisms

Intervention mechanisms such as collaborative decision-making, effective communication among healthcare professionals, and holistic assessments are essential for providing high-quality, person-centred care. These mechanisms ensure that patient care is well-coordinated, comprehensive, and tailored to individual needs, ultimately enhancing the overall healthcare experience.

Collaborative decision-making stands as a cornerstone of effective multidisciplinary healthcare. P1 expresses its significance by stating, *"The team is very good. They will* *discuss everything with the patient and the family."* This quote underscores the vital role of including patients and their families in discussions related to their care. Collaborative decision-making ensures that diverse perspectives are considered, leading to well-informed choices that align with the patient's preferences and values. It exemplifies the essence of person-centred care, where patients actively participate in shaping their healthcare journey through shared decision-making.

Effective communication among healthcare professionals is an indispensable element in achieving seamless care coordination.

> *P5*: "*MDT involvement does improve things because we're not just one specialty or whatever looking after a patient."*

This emphasises the transformative power of multidisciplinary team (MDT) engagement in enhancing patient care. It signifies that when different specialties engage in open and effective communication, it prevents the fragmentation of care that often arises when healthcare professionals work in isolation within their specialties. Effective communication fosters a holistic approach to healthcare, where information flows seamlessly among team members, ultimately benefiting the patient by ensuring comprehensive and well-coordinated care.

Holistic assessment, a fundamental aspect of patient care, involves considering all facets of a patient's health and well-being.

> *PF3: "In an ideal world where everything has enough staff... yeah, and this will never be achieved."*

This highlights the goal of comprehensive patient assessment but also acknowledges the practical challenges posed by resource constraints, particularly staffing shortages. Holistic assessment strives to address physical, psychological, and social dimensions of care, but the realisation of this ideal can be hampered by real-world limitations. It also underscores the pressing need for resource optimisation within healthcare systems to ensure that patients receive the well-rounded care they deserve. Achieving holistic assessment remains a worthy aspiration, even in the face of resource challenges, as it embodies the essence of patient-centred care.

Collaborative decision-making, effective communication, and holistic assessments are fundamental intervention mechanisms that drive person-centred care. These strategies collectively enhance patient outcomes by ensuring that care is coordinated, informed by diverse perspectives, and addresses all aspects of a patient's well-being. Despite challenges such as resource constraints, striving to enhance these mechanisms remains crucial for delivering empathetic and effective healthcare.

6.5.4. Internal Contextual Mechanisms

Internal contextual mechanisms, such as hierarchical structures, hospital culture, and staffing constraints, significantly influence the effectiveness of multidisciplinary healthcare teams. These mechanisms shape how healthcare professionals communicate, collaborate, and deliver patient care. Addressing these internal factors is crucial for fostering an environment that supports open hierarchical structures within hospitals can pose significant challenges to open communication and collaboration among multidisciplinary teams. P5 highlights *"I agree with that a lot, actually... because of that hierarchical approach..."* This agreement underscores the pressing need to address hierarchical barriers that may exist within healthcare institutions. Hierarchical structures often create power differentials that can discourage junior healthcare professionals from speaking up, contributing to a culture of silence and potential missed opportunities for collaborative decision-making. Recognising and challenging hierarchical norms is essential to fostering an environment where healthcare professionals from various specialties can work together effectively and engage in open dialogue.

Hospital culture plays a pivotal role in shaping the dynamics of multidisciplinary teams. P6 emphasises *"What you’re trying to say is communication with all the health team members is important."* This highlights the critical role that culture plays in promoting collaboration and effective communication. A culture that values and encourages communication with all team members, irrespective of their specialties, creates an environment where healthcare professionals feel empowered to share their insights and engage in meaningful dialogue.

Staffing constraints are a persistent challenge within healthcare organisations, and external factors such as the COVID-19 pandemic can exacerbate these constraints. PF2 points out *"The trouble was at Yeovil, they had COVID ongoing...they didn’t have enough staff."* This underscores the impact of external contextual factors on internal mechanisms. Staffing shortages can compromise the ability to provide effective care, and when coupled with external crises like a pandemic, the strain on healthcare systems becomes even more pronounced. Addressing staffing constraints from an internal perspective, such as through workforce planning and resource allocation, becomes paramount in maintaining the quality of care and supporting multidisciplinary teams in their efforts to provide comprehensive and patient-centred care.

Internal contextual mechanisms play a pivotal role in shaping the dynamics of multidisciplinary teams in healthcare settings. Hierarchical structures, hospital culture, and staffing constraints each present unique challenges that can impact communication, collaboration, and the delivery of patient-centred care. By recognising and addressing these internal factors, healthcare institutions can create a more supportive and effective environment for both healthcare professionals and patients.

6.5.5. External Contextual Mechanisms

External contextual mechanisms, such as the COVID-19 pandemic, resource constraints, and support services from charitable organisations, significantly impact the functioning of multidisciplinary healthcare teams. These external factors shape the environment in which healthcare is delivered, influencing staffing, resource availability, and the support provided to patients and families.

The external contextual factor of the COVID-19 pandemic has had a profound impact on healthcare systems globally, and this impact extends to the context of multidisciplinary care. PF2 states *"The trouble was at Yeovil, they had COVID ongoing... they didn’t have enough staff."* This highlights the challenges healthcare institutions faces during pandemics, including the strain on staffing and resources. It underscores the external pressures that can affect the ability to maintain effective multidisciplinary care. Responding to such external contextual factors involves strategic planning, resource allocation, and crisis management to ensure that comprehensive care remains a priority even in the face of significant challenges.

Resource constraints, particularly staffing shortages, represent an ongoing challenge within healthcare systems.

> *P1: "In an ideal world where everything has enough staff... yeah, and this will never be achieved."*

P1's quote succinctly captures the ideal scenario of having sufficient staff for effective teamwork. Resource constraints can hinder the delivery of comprehensive care and collaboration among multidisciplinary teams. As such, healthcare institutions must explore strategies for resource enhancing, workforce planning, and skill utilisation to ensure that the available resources are used to their fullest potential, supporting effective multidisciplinary care.

External support services provided by charitable organisations and specialised agencies play a vital role in enhancing the overall care experience, particularly in the context of post-bereavement support for families.

> *P3: "So, you've got like Good Trust, Good Grief, Marie Curie, Mind, but they're not... they haven't got the ongoing help."*

This highlights the presence of external support services and emphasises the need for continuous and ongoing assistance beyond hospital care. Collaborating with external services that offer post-bereavement support can fill critical gaps in the care continuum, ensuring that families receive the necessary emotional and psychological support during a challenging period. This collaboration contributes to a more holistic approach to care that extends beyond the healthcare institution's walls.

External contextual mechanisms play a crucial role in shaping the delivery of multidisciplinary care. The COVID-19 pandemic, ongoing resource constraints, and the involvement of external support services highlight the need for strategic planning and collaboration beyond the hospital setting. By addressing these external factors, healthcare systems can enhance their resilience and capacity to provide comprehensive and patient-centred care.

6.5.6. Agency

Empowering healthcare professionals to voice concerns and actively participate in patient care is crucial for fostering a culture of openness and continuous improvement within multidisciplinary teams. This empowerment enhances patient safety and ensures a patient-centred approach to healthcare. Additionally, patient advocacy and family-centred care are fundamental in aligning healthcare decisions with patients' needs and preferences, promoting transparency, trust, and active participation in the care process.

Empowering healthcare professionals to voice concerns and actively participate in patient care is integral to fostering a culture of openness and continuous improvement within multidisciplinary teams.

> *P5: "FT1s, FT2s [junior general practitioners], and registrars should be marked on their ability to say, 'I don't think you're doing this right,' and stand up and speak out."*

P5's quote underscores the significance of junior doctors feeling encouraged to challenge decisions and express their opinions when they believe it is in the best interest of the patient. This empowerment not only contributes to a culture of patient safety but also ensures a patient-centred approach where healthcare decisions are made with the utmost care and scrutiny.

Patient advocacy is a fundamental aspect of ensuring that healthcare decisions align with the patients' needs and preferences.

> *PF2: "I did feel that they were on the ball in letting me know what was happening."*

PF2's quote highlights the crucial role of healthcare professionals in advocating for patients’ family by staff keeping them informed about their care. Effective patient advocacy promotes transparency, fosters trust, and empowers patients to actively participate in their care decisions. It exemplifies a commitment to patient-centred care where patients are not passive recipients but active partners in their healthcare journey.

Family-centred care recognises the importance of involving families in healthcare decisions, acknowledging that the family's perspective is a valuable component of patient care. P1 affirms the practice of family-centred care, stating, *"The team is very good. They will discuss everything with the patient and the family."* P1's quote underscores the significance of open and inclusive communication with both the patient and their family members. By engaging the family in care discussions, healthcare teams ensure that decisions are not made in isolation but are informed by an understanding of the patient's context and preferences. This approach reinforces the importance of considering the family as an essential part of the care team, promoting a more holistic and patient-centric model of care.

The agency theme highlights the importance of empowering healthcare professionals, advocating for patients, and involving families in healthcare decisions. By encouraging junior doctors to speak up, keeping patients informed, and engaging families in care discussions, healthcare teams can ensure that decisions are made with thorough consideration and respect for patients' contexts and preferences. This approach fosters a more holistic, patient-centred model of care that prioritises safety, transparency, and collaboration.

6.5.7. Outcomes

Collaborative decision-making and effective communication within a multidisciplinary team lead to the delivery of informed, patient-centred care. Participant 1 (P1) lauds the team, stating, *"The team is very good. They will discuss everything with the patient and the family."* P1's quote underscores the value of involving both the patient and their family in care discussions. This inclusive approach ensures that healthcare choices are aligned with the patient's preferences, fostering a sense of empowerment and trust in the care provided.

Effective post-bereavement support services are pivotal for families coping with the loss of a loved one. Participant 3 (P3) raises a pertinent concern, asking, *"I don't then know are they going to be okay in three months time?"* P3's quote highlights the lingering uncertainty that families may experience after a bereavement. Strengthening post-bereavement support services is imperative to offer ongoing assistance and guidance, addressing the emotional and practical needs of grieving families. Such support not only aids in coping but also contributes to improved overall outcomes.

Empowering healthcare professionals to communicate openly and collaborate effectively results in enhanced communication and collaboration within multidisciplinary teams. Participant 5 (P5) advocates for this empowerment, asserting, *"F1s, F2s, Regs (registrars) should be marked on their ability to say, 'I don't think you're doing this right', and stand up and speak out."* P5's quote underscores the importance of fostering a culture where healthcare professionals are encouraged to express concerns and actively participate in improving patient care. This culture of openness and accountability enhances communication and collaboration, ultimately benefiting patient outcomes.

Achieving comprehensive patient care hinges on holistic assessment and collaboration among healthcare professionals. Participant 4 (P4) highlights this, stating, *"With the right people at the right time, it's a very positive thing. And it can steer the outcome for that patient in a more positive direction..."* P4's quote emphasises the significance of assembling the appropriate team members to address a patient's specific needs. This multidisciplinary approach ensures that all aspects of a patient's well-being are considered, leading to improved patient outcomes. It exemplifies the value of a holistic and patient-centred model of care.

In conclusion, the detailed analysis of each mechanism within its respective category provides a comprehensive understanding of the intricate dynamics involved in EoLC for individuals with dementia. The integration of direct quotes from the interviews adds authenticity and real-world perspective to the analysis, reinforcing the importance of these mechanisms in achieving positive outcomes for both patients and their families.

6.5.8. Refining the Theory

Comparing the refined theory with the initial theory reveals areas of agreement, disagreement, and new elements introduced in the final analysis. Both the initial and refined theories agree on the importance of a multidisciplinary approach to enhance the quality of care for individuals with dementia at the end of life in a hospital setting. They highlight the significance of collaborative decision-making, effective communication, and holistic assessment as key intervention mechanisms. Additionally, both theories acknowledge the impact of internal contextual mechanisms, such as hierarchical structures, organisational culture, and staffing constraints, on multidisciplinary collaboration. They agree that addressing these internal factors is crucial to enhancing care. Furthermore, both theories recognise the role of external contextual mechanisms, including the impact of COVID-19, resource constraints, and external support services, and agree that these external factors can significantly influence the ability to provide comprehensive care. Finally, both theories emphasise the importance of empowering healthcare professionals, patient advocacy, and family-centred care as agency-related factors that can improve care quality.

However, there are areas of disagreement. The initial theory mentions tracking patients' care as an intervention mechanism, while the refined theory does not explicitly address this mechanism. The refined theory focuses more on communication, collaboration, and holistic assessment. Additionally, the initial theory identifies the clarity of health documents as an internal contextual mechanism, but the refined theory does not explicitly mention it. Instead, the refined theory emphasises hierarchical structures, organisational culture, and staffing constraints.

The refined theory also introduces new elements related to outcomes. It highlights the importance of enhanced post-bereavement support, addressing the uncertainty and emotional needs of families after a loved one's passing. The refined theory places a strong emphasis on the role of improved communication and collaboration as outcomes of the multidisciplinary approach and agency-related factors. Moreover, the concept of comprehensive patient care, achieved through holistic assessment and collaboration, is introduced in the refined theory as an outcome. It underscores the value of assembling the right team members to address a patient's specific needs.

In summary, while the refined theory maintains many elements of agreement with the initial theory, it introduces new elements related to outcomes, such as enhanced post-bereavement support, improved communication and collaboration, and comprehensive patient care. Additionally, it provides a more detailed and nuanced analysis of intervention mechanisms, internal contextual mechanisms, external contextual mechanisms, agency-related factors, and their interplay in the context of EoLC for individuals with dementia in a hospital setting.

6.5.9. Refined Theory

Implementing a Multidisciplinary Team (MDT) collaboration approach for individuals with dementia at the end of life in a hospital setting can significantly enhance the quality of care. This improvement is achieved through various intervention mechanisms, including collaborative decision-making, effective communication, and holistic assessment. However, addressing internal contextual mechanisms such as hierarchical structures, hospital culture, and staffing constraints is crucial. External contextual mechanisms, including the impact of external factors like the COVID-19 pandemic, resource constraints, and the role of external support services, also play a pivotal role. Agency-related factors, such as empowering healthcare professionals, patient advocacy, and family-centred care, further contribute to the enhancement of care quality. The ultimate outcomes of this approach encompass informed, patient-centred care, enhanced post-bereavement support, improved communication and collaboration, and comprehensive patient care.

6.6. Theme Four: Patient and family-centred End-of-Life Care

6.6.1. Initial Theory

The effectiveness of ACP for people with dementia at the end of life in hospitals can be enhanced by addressing identified mechanisms. A person-centred approach, comprehensive ACP documents, early integration of ACP, and multidisciplinary team involvement enable the development of personalised and holistic care plans. Efficient resource allocation and avoidance of unwanted interventions result from clear guidance provided by ACP documents. Cultural competence, communication skills, and family support facilitate ACP discussions. Public awareness and education campaigns, along with unified platforms for ACP documents, promote proactive ACP initiation. Ultimately, ACP empowers patients, aligns care with preferences, and enhances patient-centred care, reducing trauma for patients and families.

Person and Family-Centred Approach Theory

The theory proposes that implementing a family and person-centred approach of care for people with dementia at the EoL in a hospital setting can lead to several expected outcomes. By identifying holistic support for both the individual with dementia and their close others, sharing decision-making, connecting families with supportive resources, and acknowledging patient preferences, positive impacts can be achieved. This approach aims to improve emotional well-being, reduce caregiver burden, enhance person-centred care planning, empower patients and families, increase access to community services, respect patient autonomy, and improve overall satisfaction with care. However, challenges such as an inaccessible dementia garden, staff turnover, cultural and communication barriers, and limited resources may hinder the realisation of these outcomes. Addressing these factors and utilising the identified factors can contribute to the successful implementation of a family and person-centred approach to care for people with dementia at the EoL in a hospital setting.

6.6.2. Findings

Table 6-7 Person and Family-Centred Approach Theory

Category	Subthemes
Intervention Mechanisms	- Effective Communication. - Family Involvement and Empowerment.
Internal Contextual Mechanisms	- Resource Allocation. - Staff Education and Training. - Hospital culture.
External Contextual Mechanisms	- Resource Availability. - Regulatory Frameworks. - Broader Societal Attitudes.
Agency Responses	- healthcare providers role. - Patient and family. - Organisational leadership.
Outcomes	-Patient well-being (enhanced or decreased). -Staff satisfaction and retention.

	-More effective use of resources. - Reduction in patient anxiety and behavioural issues.

6.6.3. Intervention Mechanisms

Intervention mechanisms employed to implement a person- and family-centred approach in dementia care. These mechanisms aim to create meaningful connections, provide personalised care, and enhance the overall well-being of patients and their families. These mechanisms include Effective communication and family involvement an empowerment.

Effective communication is vital in implementing person- and family-centred care. It involves clear and meaningful exchanges between healthcare professionals, patients, and families, ensuring everyone is informed about the patient's condition, treatment options, and care plans.

> *P7:"I think, yeah, to give you an example: the family involvement... makes a big difference for the patients."*
>
> *PF1: "It was just, 'Oh this is what's going to happen,' rather than, you know. I had to sort of move on to the care home people to say, 'Can you intervene in any way?'"*

Involving families in care decisions and ensuring their preferences are considered can significantly impact the quality of care. This approach aligns with the theory's emphasis on person- and family-centred care, where patients and their families actively participate in shaping care plans and treatment approaches.

> *PF3: "Yeah, it made us feel like, included in what was basically his treatment towards the end. We were definitely told about stuff."*

Intervention mechanisms such as effective communication and family involvement are essential for implementing a person- and family-centred approach to dementia care. These strategies help in creating a supportive environment for patients and their families, ensuring that care is tailored to their unique needs and preferences.

6.6.4. Internal Contextual Mechanisms

Internal contextual mechanisms refer to the intrinsic factors within the healthcare setting that influence the implementation of person- and family-centred care. These include staff education and training, internal communication practices, and organisational culture.

Adequate resources and funding are crucial for the successful implementation of person- and family-centred care. This includes sufficient staffing levels and access to specialised care for people with dementia.

> *P1: "That depends on the outcomes coming from the after you present. If you get them more funding and everything for dementia, that would be great... Resources and funding, yes. With our staff, we can't do everything."*

Education and training for healthcare professionals are crucial for effectively implementing person- and family-centred care. This includes training in communication skills, dealing with difficult scenarios, and understanding non-verbal communication.

> *P2: "Staff education... communication, training and communication, difficult communication would I think be a good thing to cover. Non-verbal communication..."*

A supportive organisational culture that values and promotes person- and family-centred care can significantly impact its implementation. This involves fostering an environment where staff feel empowered and supported in their roles.

> *P4: "Lack of staff, lack of understanding, lack of education... we're not even getting the fundamentals of care right for patients who don't have dementia... I don't have time, I'm too busy..."*

Internal contextual mechanisms such as resources adequate allocation, staff education and training, and a supportive organisational culture, are vital for the successful implementation of person- and family-centred care. These factors help create an environment that supports personalised and compassionate care for people with dementia and their families.

6.6.5. External Contextual Mechanisms

External contextual mechanisms involve external factors that influence the implementation of person- and family-centred care. These include resource availability, regulatory frameworks, and broader societal attitudes towards dementia care.

The availability of resources, including funding and staffing, is a critical external factor that impacts the implementation of person- and family-centred care. Adequate resources ensure that healthcare providers can deliver high-quality, personalised care.

> *PF1: "So you think it's not about they don't offer food, but they don't offer food the way he can eat it... not having enough staff... just a lot of it was down to COVID."*

External contextual mechanisms such as resource availability. Addressing these factors is crucial for creating an environment that supports high-quality care for people with dementia and their families.

6.6.6. Agency

Agency refers to the capacity of individuals and organisations to act independently and make choices in implementing person- and family-centred care. It encompasses the actions of healthcare providers, patients, and families in advocating for and delivering personalised care.

Healthcare providers play a critical role in advocating for and implementing person- and family-centred care. Their commitment to this approach can drive its adoption and success.

> *P4:"Lack of staff, lack of understanding, lack of education... we're not even getting the fundamentals of care right for patients who don't have dementia... I don't have time, I'm too busy..."*

Patients and families also have a significant role in advocating for their preferences and needs. Their involvement and empowerment are crucial for ensuring that care is tailored to their unique circumstances.

> *P7:"So, like, if you're going to get coffee, you might cause confusion... these things at home... family-oriented not only care about end of life but general care also."*

Leadership within healthcare organisations is essential for promoting and supporting the implementation of person- and family-centred care. Leaders are positioned to advocate for necessary resources, model expectations, and drive cultural and policy change. As P4 emphasised, *"We have to get engagement from the ward leaders because if we haven't got that then we're stuck."* This underscores the reality that even when training opportunities exist, leadership involvement is often the key variable in whether staff engage meaningfully.

Agency, encompassing the actions of healthcare providers, patients, families, and organisational leaders, is vital for implementing person- and family-centred care. Empowering these stakeholders and supporting their efforts can significantly enhance the quality of care provided to people with dementia and their families.

6.6.7. Outcomes

The outcomes of implementing person- and family-centred care in dementia settings can be profound and multifaceted. This approach not only benefits patients and their families but also enhances the overall quality of care provided by healthcare professionals. This section will discuss the primary outcomes associated with this care model, drawing on quotes from the interviews to illustrate key points.

One of the most significant outcomes of person- and family-centred care is the improvement in patient well-being. By focusing on the individual needs and preferences of people with dementia, healthcare providers can create a more comforting and supportive environment.

> *P6: "If the dementia patient is really anxious... trying to make it as homey as possible... helps them feel more secure."*

Family members play a crucial role in the care of people with dementia. When they are involved in care decisions and supported by healthcare providers, their satisfaction with the care process increases significantly.

> *P7: "Family-oriented care not only helps with end-of-life issues but with general care as well. It's essential for families to feel involved and heard."*

Effective communication between healthcare providers, patients, and their families is a cornerstone of person- and family-centred care. Improved communication leads to stronger relationships and better care outcomes.

> *P2: "Staff education... especially on communication, training and communication, difficult communication would I think be a good thing to cover. Non-verbal communication..."*

Healthcare staff who are well-trained and supported in providing person-centred care often experience greater job satisfaction. This can lead to increased staff retention and a more positive working environment.

> *P5: "I agree, especially with the families getting involved... can always be helpful for the care and for us to understand the patients better."*

By tailoring care to the specific needs of people with dementia and their families, healthcare organisations can make more effective use of their resources. This includes better allocation of staffing and funding, leading to more efficient care delivery.

> *P1: "That depends on the outcomes coming from the after you present. If you get them more funding and everything for dementia, that would be great... Resources and funding, yes. With our staff, we can't do everything."*

A person-centred approach can help reduce anxiety and behavioural issues in people with dementia by creating a more familiar and reassuring environment.

> *P6: "If the dementia patient is really anxious... trying to make it as homey as possible... helps them feel more secure."*

The outcomes of implementing person- and family-centred care in dementia settings are overwhelmingly positive. Improved patient well-being, enhanced family satisfaction, better communication, increased staff satisfaction, more effective resource use, and a reduction in patient anxiety and behavioural issues are all significant benefits of this approach. By prioritising the individual needs and preferences of patients and their families, healthcare providers can deliver higher quality care and achieve better overall outcomes in dementia care.

6.6.8. Refining the Theory

The refinement of the initial theory on implementing a person- and family-centred approach to EoLC for people with dementia in hospital settings integrates the new insights gained from the second phase of data collection. This revised theory builds on the foundational principles of holistic support, shared decision-making, and the acknowledgement of patient preferences while addressing the newly identified mechanisms and outcomes that emerged from the feedback of participants.

The initial theory emphasised holistic support, shared decision-making, and connection with supportive resources as key elements of a person- and family-centred approach. These elements remain central but are now expanded upon with additional mechanisms such as effective communication, family involvement, and staff empowerment. These mechanisms are crucial in creating meaningful connections and providing personalised care, which in turn enhance the well-being of patients and their families.

Effective communication has been underscored as vital in ensuring that healthcare professionals, patients, and their families are all informed and engaged in the care process. This ensures clarity in understanding the patient's condition and the available treatment options. Family involvement in care decisions not only respects the preferences of patients but also ensures that care plans are more attuned to the needs and desires of the patient and their families, thus improving overall care satisfaction.

The internal contextual mechanisms identified include staff education, internal communication practices, and organisational culture. These are crucial for the successful implementation of person- and family-centred care. Adequate resources, such as staffing and funding, remain fundamental, as they ensure that healthcare providers can deliver high-quality, personalised care. The importance of staff education and training in communication skills and non-verbal communication has been highlighted as essential for effectively managing dementia care scenarios. Furthermore, a supportive organisational culture that promotes and values person- and family-centred care can significantly impact its successful implementation.

External contextual mechanisms, such as resource availability and regulatory frameworks, also play a crucial role. Addressing these factors is critical for creating an environment that supports high-quality care for people with dementia and their families. Ensuring sufficient funding and staffing levels, as well as adapting to broader societal attitudes towards dementia care, are necessary steps for fostering a supportive care environment.

The refined theory also incorporates the newly identified outcomes of implementing a person- and family-centred approach. These include improved patient well-being, enhanced family satisfaction, better communication, increased staff satisfaction, more effective resource use, and a reduction in patient anxiety and behavioural issues. These outcomes align with the initial theory but are now supported by specific examples from the data, illustrating how these benefits manifest in practice.

Improved patient well-being is achieved by focusing on individual needs and creating a comforting environment, which can reduce anxiety and behavioural issues. Enhanced family satisfaction results from involving families in care decisions, ensuring they feel heard and supported. Better communication fosters stronger relationships between healthcare providers, patients, and families, leading to more effective care outcomes. Increased staff satisfaction and retention are achieved through adequate training and support, creating a positive working environment. More effective resource use is facilitated by tailoring care to the specific needs of patients and their families, ensuring efficient allocation of staffing and funding.

The refined theory of person- and family-centred care for people with dementia at the EoL in hospital settings provides a comprehensive framework for achieving improved care outcomes. By integrating new insights on effective communication, family involvement, and contextual mechanisms, the revised theory offers a robust approach to delivering personalised and compassionate care. This approach not only enhances the well-being of patients and their families but also supports healthcare professionals in providing high-quality care, ultimately leading to better overall satisfaction and outcomes in dementia care.

6.6.9. Refined Theory

Patient and family-centred EoLC

The refined programme theory proposes that implementing a person- and family-centred approach to care for people with dementia at the EoL in a hospital setting can lead to significant positive outcomes. This approach focuses on holistic support for both the individual with dementia and their close others, sharing decision-making, and connecting families with supportive resources. Effective communication and family involvement are central to this theory, ensuring that everyone is informed about the patient's condition and care plans, and that family preferences are respected. Internally, adequate resources, staff education, and a supportive organisational culture are crucial for successful implementation. Externally, sufficient funding, regulatory support, and societal attitudes towards dementia care play a vital role. This approach aims to improve emotional well-being, reduce caregiver burden, enhance person-centred care planning, empower patients and families, increase access to community services, respect patient autonomy, and improve overall satisfaction with care. Addressing challenges such as staff turnover, cultural barriers, and resource limitations is essential for realising these outcomes. By prioritising individual needs and fostering a collaborative care environment, the refined theory seeks to deliver high-quality, compassionate care for people with dementia at the EoL.

6.7 Chapter Summary

This chapter presented phase two of data collection, which used semi-structured interviews and focus groups to gather participants’ feedback on the initial programme theories developed from phase one. The participants' responses to the initial programme theories were used to refine these theories. Additionally, the refinement process highlighted the benefits of combining the programme theories to form an 'overall' programme theory. The following discussion and conclusion chapter discusses the findings of this present study in relation to relevant literature. Additionally, I discuss the implications of these findings on the stakeholders, their contributions to the field, and potential avenues for future research.

Chapter 7 General Discussion and Conclusions

7.1. Introduction

This chapter brings together the key findings of the study to provide a critical analysis of how EoLC for people with dementia in acute hospitals is experienced, understood, and shaped by contextual and structural factors. Framed by a critical realist approach, the discussion draws on the refined programme theories developed in Chapter 6 to explore how mechanisms are activated or constrained in particular settings, and how these mechanisms interact with agency and structure to produce specific outcomes.

The aim of this chapter is threefold. First, it revisits and interprets the findings through the lens of critical realism, focusing on the generative mechanisms underpinning observed phenomena. Second, it examines how these findings relate to existing literature on dementia care, EoLC, and healthcare delivery in hospital contexts. Third, it articulates the study's contribution to theory and practice, particularly the development of a context-sensitive, critical realist-informed model of EoLC for people with dementia in hospital settings.

The chapter begins by re-engaging with the four refined programme theories and exploring the implications of each. These programme theories are treated as theoretical tools generated through retroduction to explain how and why certain outcomes emerge under particular contextual conditions. In line with critical realism's stratified ontology, the discussion distinguishes between empirical patterns, actual practices, and the underlying real mechanisms that structure care experiences. By identifying enabling and constraining conditions, this discussion offers insights into how hospitals might transform care environments to better support people with dementia approaching the end of life.

7.2. Discussion of the Findings in Relation to the Literature

This section explores how the findings of this PhD study contribute to, confirm, or challenge existing knowledge within the field EoLC for people with dementia in hospital settings. Drawing on both the systematic review and the critical realist review conducted in earlier chapters, I focus on two core domains where persistent challenges and explanatory depth emerged: (1) how death and dying are approached, and (2) the persistence of life-sustaining interventions. These areas were selected for closer analysis because they encompass powerful generative mechanisms, such as medical ideology, cultural norms, ethical discomfort, and emotional reasoning, which were identified across all datasets and are central to understanding variation in EoLC delivery.

In selecting these domains, I aim not to describe individual practices, but to theorise how broader structures and meanings shape front-line decision-making and behaviour. These issues surfaced strongly in both reviews. The systematic review identified inconsistent practices and ethical uncertainty around EoL transitions in dementia, while the CRR mapped a constellation of mechanisms, including institutional logic, cultural framing, and professional identity, that help explain why good practice is difficult to sustain. My empirical study builds on this by showing how these mechanisms manifest and interact in acute hospital contexts, offering explanatory rather than merely descriptive insights.

7.2.1 Approaching Death and Dying

This section explores how the findings of this PhD study contribute to, confirm, or challenge existing knowledge within the field of EoLC for people with dementia in hospital settings. Drawing on both the systematic review and the critical realist review conducted in earlier chapters, I focus on two core domains where persistent challenges and explanatory depth emerged: (1) how death and dying are approached, and (2) the persistence of life-sustaining interventions. These areas were discussed because they encompass mechanisms, such as medical ideology, cultural norms, ethical discomfort, and emotional reasoning, which were identified across all datasets and are central to understanding variation in EoLC delivery.

In selecting these domains, I aim not to describe individual practices, but to theorise how broader structures and meanings shape front-line decision-making and behaviour. These issues surfaced strongly in both reviews. The systematic review identified inconsistent practices and ethical uncertainty around end-of-life transitions in dementia, while the critical realist review mapped a constellation of mechanisms, including institutional logic, cultural framing, and professional identity, that help explain why good practice is difficult to sustain. My empirical study builds on this by showing how these mechanisms manifest and interact in acute hospital contexts, offering explanatory rather than merely descriptive insights.

7.2.2. Life-Sustaining Interventions

This study reveals significant insights into the prevalence and persistence of life-sustaining interventions in the care of individuals with dementia at the EoL in hospital settings. The findings highlight that senior medical professional, particularly consultants with surgical backgrounds, and overseas healthcare staff are the primary practitioners of these interventions. This trend is linked to a prevailing medical ideology focused on preserving life, which appears to extend beyond the hospital environment and is influenced by broader cultural beliefs.

The study identifies a counterforce to this trend among younger nurses and foundation year doctors, who, armed with education in EoL care and a culture of autonomy, are beginning to challenge established practices. Although the decision-making hierarchy still favours consultants, the potential for long-term behavioural shifts is evident as this younger generation rises to decision-making roles. This aligns with existing literature that emphasises the positive impact of education and advocacy in EoL nursing (Thacker, 2008).

One notable finding of this study is the shift away from parental feeding practices in EoL care for individuals with dementia, a practice that was highlighted as persistent in a 2021 critical review. Participants in this study indicated a move towards focusing on oral hygiene, marking a significant departure from previous practices. Several factors contribute to this shift, including hospital-specific changes that may not be universally applicable across the UK. Additionally, larger hospitals, with their more extensive staff, might facilitate such changes more effectively (Kupersmith, 2005).

The COVID-19 pandemic emerges as a significant factor influencing this change. Participants noted that parental feeding was already on the decline before the pandemic, but the crisis accelerated this trend. Limited family accessibility during the pandemic likely reduced family involvement in care decisions, leaving clinical staff to make more independent decisions regarding EoL care (Stilos & Moore, 2020). This context appears to have facilitated a shift away from unnecessary parental feeding practices.

In summary, this study adds new knowledge by identifying key factors influencing the persistence of life-sustaining interventions and highlighting a gradual shift in practices among younger healthcare professionals. It underscores the importance of cultural competency and the impact of education in shaping EoL care practices. Furthermore, it identifies the significant role of the COVID-19 pandemic in accelerating changes in EoL care, particularly regarding parental feeding practices. These findings reinforce and, in some cases, challenge existing literature, providing a nuanced understanding of EoL care dynamics in hospital settings.

7.3. A Multicomponent End-of-Life Care for People with Dementia

This PhD study makes the case for a contextually grounded, multicomponent intervention tailored to support the delivery of quality EoLC for people with dementia in UK hospitals. A CRE framework enabled the identification and refinement of several programme theories that together constitute the components of this intervention. These include: (1) education and training, (2) ACP, (3) MDT collaboration, and (4) person and family-centred care. The findings suggest that it is not any single intervention but rather the interplay between generative mechanisms, agency, and specific contextual configurations that enables meaningful change in EoLC practice.

As demonstrated in the systematic review (Chapter 2), multicomponent interventions offer the strongest evidence base for improving EoLC, particularly in complex and variable contexts such as dementia care. The CRR (Chapter 3) further highlighted how the success of such interventions depends not on components alone but on their capacity to activate mechanisms such as moral agency, professional reflection, relational care, and interprofessional coordination within supportive contexts. These insights were borne out in this study’s empirical phase, where each refined theory was shown to both contribute independently and interact with the others to enhance or limit outcomes.

One of the study’s key explanatory contributions is that education emerges not only as a component but also as a generative mechanism that conditions the effectiveness of the others. For instance, staff training influences not just knowledge, but also communication confidence, ethical positioning, and willingness to participate in shared decision-making, each of which impacts ACP uptake, MDT coherence, and the authenticity of person-centred care. Education thereby acts as a cross-cutting mechanism, capable of strengthening or weakening the entire intervention depending on contextual conditions such as leadership, time resources, and team culture.

This multicomponent model diverges from reductionist approaches that isolate technical elements of care (e.g. documentation, symptom management) from relational and contextual dynamics. In contrast, this study conceptualises EoLC improvement as a morphogenetic process: changes in care practices result from interactions between individual agency (e.g. moral courage, reflective capacity), social structures (e.g. medical hierarchies, team norms), and cultural logics (e.g. beliefs about death and personhood). Therefore, intervention design must acknowledge and engage with these deeper strata of reality, not just empirical processes observable at the point of care.

Moreover, this study highlights how context can both constrain and enable these mechanisms. For example, where hospitals lacked culturally sensitive infrastructure, or when staff had minimal exposure to palliative care models, mechanisms such as empathy or advance planning failed to be triggered. Conversely, in teams where reflective learning was encouraged, space was made for complexity, and personhood was prioritised over prognosis, mechanisms supporting better EoLC became visible and actionable. In CRE terms, this points to the importance of aligning intervention resources with context-specific enabling conditions.

In conclusion, this study advances a theoretically grounded and empirically supported case for a multicomponent EoLC intervention for people with dementia. Rather than proposing a one-size-fits-all toolkit, the findings support a relational and adaptive model one that integrates education, planning, collaboration, and personhood into a coherent system of care. Grounded in the critical realist commitment to explanatory depth, this intervention aims not only to improve care processes but to transform the conditions under which compassionate, culturally competent, and person-centred EoLC becomes the norm rather than the exception in hospital settings.

7.3.1. Discussion of the Refined Education and Training Theory

This study positions education and training not merely as a technical input but as a pivotal generative mechanism through which broader improvements in EoLC for people with dementia are realised. Drawing from the critical realist perspective, education in this context functions as a causal power that enables agency, alters perceptions of dying, challenges dominant ideologies, and mediates the relationship between professional knowledge and compassionate care. The refined programme theory developed in this study demonstrates that education plays a cross-cutting role, shaping the effectiveness of other mechanisms such as ACP implementation, MDT collaboration, and the enactment of person-centred values.

The earlier systematic review (Chapter 2) found that education was a recurrent feature in successful interventions aimed at improving EoLC, but often insufficiently theorised. Meanwhile, the CRR (Chapter 3) illuminated that while knowledge acquisition is necessary, transformative change only occurs when education supports reflection, emotional engagement, and shifts in normative assumptions, particularly around what it means to die well with dementia. This study's findings substantiate and extend this view by identifying how education supports moral agency, enhances interdisciplinary communication, and fosters attunement to the relational and existential aspects of care.

Importantly, the study found that education had differential impacts depending on how it was delivered, who accessed it, and whether contextual enablers were in place. For example, online training, although scalable, was frequently undermined by practical constraints, such as the absence of private and quiet spaces, and low engagement (e.g. camera use), echoing findings by Blackman et al. (2019). These contextual constraints muted the activation of the mechanism (reflective learning), and in some cases created empirical outcomes (attendance) without real change in understanding or practice.

This study also reveals a mechanism rarely explored in existing literature: the absence of training for non-clinical and auxiliary staff such as porters, domestic workers, and bereavement teams. These individuals often interact with patients and families in emotionally charged contexts yet lack the tools to provide reassurance or even understand EoLC goals. Their exclusion represents a missed opportunity for holistic person-centred care and points to the stratified nature of knowledge access within hospital hierarchies. These findings challenge assumptions embedded in prior work, such as Surr et al. (2017), focusing primarily on nurses and medical staff.

Further, the study identifies the importance of tailored education models, such as two-tier training pathways, to accommodate healthcare professionals' varied responsibilities and prior experiences. This aligns with Moyle et al. (2018), who argue for the importance of role-specific education. Ensuring that the training mechanisms (e.g.

empathy building, understanding the dying process) are activated in contexts where they are most likely to produce sustained behavioural change.

The findings also highlight the role of leadership and facilitation in determining whether education becomes embedded into everyday practice. Teams with engaged leaders and passionate facilitators were more likely to report attitudinal change, increased confidence in EoLC communication, and interprofessional respect. These observations resonate with Hossain et al. (2017), who stressed the role of supportive leadership in creating learning environments conducive to person-centred care.

From a CRE perspective, the transformative outcomes associated with education depend not simply on content delivery, but on whether mechanisms such as moral reflexivity, empathic engagement, and contextual attunement are activated. In this study, these mechanisms were often latent unless supported by safe spaces for reflection, interprofessional dialogue, and positive reinforcement from peers and leaders.

In conclusion, this PhD study positions education and training as a mechanism that influences EoLC quality across multiple levels. By conceptualising education as more than knowledge transmission, instead, as a relational, situated, and morally engaged process, the study advances a more robust understanding of how to operationalise multicomponent dementia care in hospitals. The refined theory underscores the importance of role-sensitive training, whole-team inclusion, engaged facilitation, and supportive contexts. These findings lay the foundation for a strategic, holistic training model embedded within the broader multicomponent EoLC intervention proposed by this research.

7.3.2. Discussion of the Advance Care Planning Theory

ACP emerged in this study as a central component of the multicomponent intervention, one shaped by intersecting mechanisms of ethical agency, communication clarity, and cultural understanding, and deeply conditioned by contextual factors such as time, staffing, and record systems. From a critical realist evaluation perspective, ACP does not function as a static tool or form; it is a process embedded within social relations, shaped by values, institutional norms, and the ontological uncertainty of dementia trajectories.

The systematic review (Chapter 2) supported the idea that ACP can improve care outcomes and reduce family distress when implemented early and appropriately. However, the critical realist review (Chapter 3) illuminated how ACP's success depends less on the existence of documentation and more on how key mechanisms, such as respect for autonomy and interprofessional coordination, are activated within contextually enabling conditions.

This study builds on those insights by identifying a critical misunderstanding among staff regarding the nature and purpose of ACP. Many participants believed that ACP documents could be completed solely with families, bypassing the person with dementia even when they still had capacity. This reflects a collapse of the mechanism of autonomy due to epistemic gaps and role uncertainty. As highlighted in NHS (2022) guidance and Hayhoe & Howe (2011), ACP is ethically and legally intended to prioritise the patient's voice. The distortion observed in this study risks reinforcing paternalistic or family-centred decision-making models, especially in acute hospital environments.

Moreover, staff frequently conflated ACP with treatment escalation plans and documents like This Is Me, signalling a conceptual blurring between proactive, person-led planning and reactive, clinical risk management. This confusion undermines ACP's original intent and weakens its implementation, particularly when documentation becomes a bureaucratic substitute for dialogue. The failure to activate key mechanisms of personhood and anticipatory care in these instances demonstrates how poor conceptual clarity can block the generative potential of otherwise sound interventions.

Culturally, the study found that discussions around death and future care were often avoided or delayed, particularly by overseas staff who, as shown in earlier sections (see 7.2.1), may come from care systems where such conversations are taboo or family-led. This reflects a cultural mechanism of discomfort, silence, or reverence toward elders, which, when combined with systemic barriers, contributes to ACP avoidance. While the literature (Middleton-Green et al., 2017) has acknowledged the sensitivity of ACP, this study adds depth by showing how cultural backgrounds and healthcare migration experiences shape the conditions under which ACP is either engaged or avoided.

The findings also point to contextual inhibitors of ACP, including short hospital stays, limited community-hospital communication, and incompatible electronic health record (EHR) systems, issues corroborated by Singer et al. (2015). These conditions frustrate continuity, leading to fragmented planning that fails to follow patients across care transitions. One example was a frail patient admitted with pneumonia whose ACP had been recorded in the community but was not visible to the hospital team due to incompatible systems. This undermined care continuity and added avoidable distress for the family.

Another key observation is that ACP discussions were rarely integrated into regular MDT meetings, despite widespread acknowledgement that they should be. This points to a failure in interprofessional responsibility sharing and further reflects how institutional culture prioritises immediate clinical decisions over anticipatory care planning.

Nevertheless, some promising mechanisms were identified. For example, in wards where palliative care teams were embedded and supported by education initiatives, staff reported greater confidence in initiating ACP earlier, more nuanced communication with families, and clearer documentation. These settings demonstrated CRE formula (intervention mechanisms + contextual mechanisms + agency = outcomes) alignment, where cultural acceptance of ACP, visible leadership support, and embedded training enabled proactive engagement.

The study also introduced innovative suggestions not well covered in existing literature, such as:

- Involving non-clinical staff (e.g. administrative, porters, bereavement teams) in basic ACP awareness training to ensure consistent messaging,
- Digitally enhanced ACP tools to support asynchronous conversations and preserve documentation across settings,
- Creating dementia-friendly hospital environments with quiet spaces conducive to reflective discussions, enhancing the potential for activating empathic and ethical mechanisms.

In conclusion, this PhD study advances the understanding of ACP in dementia care by showing that its effectiveness is dependent not only on policy or protocol but on how deep mechanisms of respect, communication, and identity are activated or suppressed in specific contexts. Through a CRE lens, ACP is revealed to be a relational, ethical process whose outcomes hinge on trust, clarity, and context. The study underscores the need for early, interdisciplinary, and culturally competent engagement with ACP, backed by comprehensive education and supported by coherent information systems. By embedding these principles into the multicomponent EoLC model, the study contributes a critical, explanatory layer to how ACP can better serve people with dementia in hospital settings.

7.3.3. Discussion of the Multidisciplinary Team Cooperation

This PhD study's findings underscore the pivotal role that effective MDT collaboration plays in providing person-centred, high-quality EoLC for people with dementia in hospital settings. The refined programme theory developed through this study situates MDT collaboration as a central mechanism that is shaped by and acts upon wider contextual features such as institutional culture, time constraints, resource allocation, and clinical hierarchies. This theory reflects not only what teams do but how interprofessional relationships and values mediate shared decision-making, holistic assessment, and the coordination of care.

The CRR conducted earlier in this thesis highlighted MDT collaboration as a potential mechanism for improving EoLC, particularly when supported by positive contextual features such as team trust, leadership engagement, and a shared care philosophy. My study extends this understanding by identifying both enabling and constraining generative mechanisms that influence MDT function in real hospital settings. These include entrenched medical ideologies that prioritise curative over palliative aims, disparities in team composition and leadership across wards, and varying attitudes toward collaborative working. These findings align with Aldridge et al. (2017) and Van der Steen et al. (2014), who argue that medicalised norms can obstruct palliative goals, particularly in acute care environments.

This study adds to this literature by demonstrating how these medical ideologies are not abstract cultural forces but operate as real, stratified mechanisms. For example, senior doctors’ perceptions of their professional remit significantly influenced whether EoLC was framed as legitimate clinical work or seen as a deviation from curative goals. In some settings, this framing limited the involvement of allied health professionals and nurses in decision-making, particularly within surgical teams. These findings reflect what the critical realist review identified as the “ideological inertia” of biomedicine, a real mechanism that sustains power imbalances and narrows the scope of collaborative care.

In contrast, frailty teams were more likely to operationalise MDT collaboration through inclusive case discussions involving physiotherapists, speech and language therapists, dietitians, and dementia specialists. These practices created micro-contexts in which mechanisms of trust, mutual respect, and shared understanding could be activated. This supports Wilhelmsson et al. (2012), who emphasised the value of consistent, well-facilitated MDT meetings for comprehensive care planning. My findings suggest that such positive collaboration is not solely a function of team composition but is context-dependent, shaped by time availability, leadership priorities, and local work cultures.

This study also uncovered mechanisms related to information sharing and documentation. Fragmented electronic health record systems, with over 21 different platforms used across NHS Trusts (Alford, 2019), created structural barriers to seamless communication. These fractured systems not only delayed information exchange between primary and secondary care but also disrupted continuity of care and undermined the implementation of ACPs. In CRE terms, the absence of a unifying data infrastructure functioned as a contextual constraint, limiting the activation of collaborative mechanisms.

The inconsistent use and quality of clinical documentation, including poorly completed or misunderstood forms like TEPs and “This Is Me” documents, was another significant barrier identified. As Cooper et al. (2009) and Campbell et al. (2018) have shown, these gaps in documentation are not merely clerical issues but affect patient safety and contribute to fragmented care. My findings reveal that these breakdowns are often underpinned by cognitive and emotional mechanisms, such as time pressure, uncertainty, and professional discomfort in navigating death-related conversations.

Without institutional support to address these pressures, such mechanisms are likely to reproduce suboptimal outcomes.

Finally, this study found that MDT collaboration could be enhanced by cultivating relational agency, wherein team members actively negotiate their roles, share decision-making, and develop a collective understanding of patient needs. This was particularly visible in teams where regular debriefs, joint care planning, and mutual appreciation of roles were embedded. However, in settings where collaboration was hierarchical or task-oriented, such relational agency was less visible, and care became more fragmented. This contrast illustrates how MDT collaboration is not a static structure but a dynamic interplay of agency and context**,** in line with the morphogenetic cycle at the heart of critical realist theory.

In summary, this PhD study advances understanding of MDT collaboration by showing how it is both enabled and constrained by structural, cultural, and interpersonal mechanisms. While the literature affirms the value of multidisciplinary care, my findings explain why its implementation remains inconsistent, dependent not only on team composition but on deep contextual layers such as institutional culture, technological infrastructure, and professional ideology. By addressing these underlying mechanisms through leadership engagement, consistent documentation, and cross-disciplinary education, hospitals can foster more effective and person-centred EoLC for people with dementia.

7.3.4. Discussion of the Person and Family-Centred Theory

Person and family-centred care emerged in this PhD study as the core integrative principle that binds the other programme theories together within the multicomponent EoLC intervention. In critical realist terms, it functions not merely as a philosophy but as a mechanism that is either activated or suppressed depending on how contextual factors (staffing, training, environment) and agency (values, emotional labour, professional reflexivity) interact in specific settings.

This study extends the findings of both the systematic review (Chapter 2), which identified person-centred approaches as fundamental but often inconsistently implemented, and the critical realist review (Chapter 3), which highlighted the importance of relational and ethical mechanisms in realising personalised care at the EoL. Importantly, the empirical data presented here demonstrate that the mechanism of personhood recognition is frequently present but not always actualised, particularly in high-pressure or resource-constrained contexts such as acute hospital wards.

A key insight from this study is that person-centred care cannot be isolated from structural and relational dynamics. For example, interventions like Namaste Care, while rooted in sensory connection and presence, depend on enabling contexts such as time, staffing, space, and confidence. Although supported by literature (Simard, 2010; St Johns & Koffman, 2017), participants in this study reported significant barriers to Namaste Care in hospitals, especially during the COVID-19 pandemic, when isolation protocols, restricted family access, and staff redeployment limited continuity and personalisation. This demonstrates how even theoretically sound interventions fail to generate change when key contextual conditions are absent, a central insight in CRE methodology.

Furthermore, this study found that many staff compensated for structural constraints through moral agency, choosing to sit with dying patients during breaks or going beyond their roles to reassure families. These examples highlight a mechanism of emotional investment, which, although informal, plays a critical role in preserving dignity at the EoL. However, such acts are unevenly distributed and unsustainable without systemic support, reinforcing the need to institutionalise these practices through training, leadership support, and culture change.

Family involvement also emerged as a crucial mechanism in facilitating meaningful and compassionate EoLC. This study revealed that families valued proximity, flexible visitation, and clear updates, all of which foster trust and shared decision-making, consistent with findings by Lawrence et al. (2011). However, the degree to which family members were involved often depended on staff confidence, ward policies, and space availability. These conditions either enabled or obstructed the activation of collaborative planning mechanisms, particularly when deterioration occurred rapidly or when language and cultural differences were present.

The study also identified a shift from aggressive, life-sustaining interventions toward symptom-focused, comfort-based care, particularly where families were well-informed and ACPs were in place. This reflects a mechanism where staff and families co-construct an understanding of the dying process, enabling more person-centred decisions. Yet, in the absence of MDT cohesion or accessible documentation, these discussions often remained reactive or inconsistent.

Importantly, the findings highlight gaps in emotional and spiritual support for both people with dementia and their families. Despite NHS commitments to holistic EoLC, participants noted that religious and cultural needs were often unmet, particularly among minority faith groups. Poor community-hospital links, limited knowledge of local spiritual leaders, and a lack of post-bereavement follow-up beyond leaflet distribution exacerbated this. These challenges echo the concerns raised in Giezendanner et al. (2017), underscoring the need to see spiritual care as a core, not peripheral, component of person-centred care.

Additionally, the study revealed that administrative staff, such as the bereavement team, lacked training in culturally sensitive communication and grief support, despite being tasked with contacting families post-death. This lack of preparedness muted the mechanism of relational closure, which is critical for bereaved families' emotional recovery and overall care experience.

From a CRE lens, person-centred care is not simply a value to be adopted but it requires the presence of specific contexts (supportive teams, continuity, flexible policies) and the activation of particular mechanisms (empathy, shared meaning-making). When these align, person and family-centred care is not only possible but transformative. When they do not, care risks becoming procedural, depersonalised, or even traumatic.

7.4 Meeting the Aim and Objectives of the Study

This study aimed to develop programme theories to inform interventions that support hospitals in delivering quality EoLC for people with dementia. The six objectives guided a structured and phased research design. Below, I reflect on how each objective was met through the two stages of data collection and theory development, within a CRE framework.

Objective 1: To identify the needs of this group of patients.

This objective was addressed in both phases of data collection. Interviews and focus groups with healthcare staff and bereaved relatives consistently highlighted the unique needs of people with dementia at the end of life. These included the need for compassionate communication, recognition of pain and distress, continuity of care, and person-centred decision-making. For example, in the refined Education and Training theory, understanding dementia from the patient's perspective was identified as a key mechanism for fostering empathy and improving care practices.

Objective 2: To identify the needs of patients' close others.

The needs of family members and close others were prominently discussed by both staff and bereaved relatives. These included emotional support, involvement in care decisions, timely and clear communication, and post-bereavement follow-up. These needs were especially prominent in the refined Person- and Family-Centred EoLC theory, where communication and inclusion in care planning were shown to influence satisfaction and well-being. Bereaved relatives emphasised how feeling informed and included impacted their experience of their loved one's death and their own coping process.

Objective 3: To identify current clinical practice in response to these needs.

This objective was met through empirical insights in both phases. Current practices included the use of documentation tools (e.g. Treatment Escalation Plans), reliance on individual staff commitment, and efforts by palliative care teams to engage families. However, variation in practice was noted, particularly regarding staff training, advance care planning, and multidisciplinary collaboration. These insights directly informed all four programme theories, which captured both strengths and gaps in current hospital-based EoLC for people with dementia.

Objective 4: To examine the hospital context to identify factors that may support or inhibit good practice.

Both internal and external contextual mechanisms were analysed in depth in Chapters 5 and 6. Factors such as staff shortages, high turnover, lack of dedicated training time, the impact of COVID-19, and organisational hierarchies emerged as inhibitors. Supportive mechanisms included the presence of dementia champions, dedicated education teams, and proactive ward leadership. These were systematically mapped in each theory using the adapted critical realist formula: intervention mechanisms + contextual mechanisms + agency = outcomes.

Objective 5: To identify the mechanisms required to narrow the gap between needs and the provision of care.

Across the refined theories, key mechanisms were identified that directly address the gap between patients' and families' needs and the care provided. Examples include immersive training that builds empathy (Education and Training theory), early initiation and regular review of advance care planning (ACP theory), inclusive decision-making processes (MDT theory), and family empowerment through clear communication (Person- and Family-Centred theory). These mechanisms were revealed through careful thematic coding and validated by stakeholders during Phase Two.

Objective 6: To develop programme theories to support quality EoLC for people with dementia in hospitals incorporating identified mechanisms, taking contextual factors and agency (stakeholders) into account.

This overarching objective was met through the development and refinement of four detailed programme theories. Each theory was constructed using a critical realist framework and reflects the interplay of interventions, contexts, stakeholder agency, and outcomes. These theories were grounded in empirical data and shaped through a two-stage process: initial theory development in Phase One and refinement via stakeholder engagement in Phase Two. The final theories offer a nuanced understanding of what works, for whom, in what contexts, and why, thereby directly informing intervention development.

Through a phased design and the application of CRE, this study successfully met its aim and all six objectives. The resulting programme theories provide a theoretically rich and context-sensitive foundation for designing hospital-based interventions to improve EoLC for people with dementia.

7.5. Implications for Stakeholders

In this section, I explore the implications of my findings for key stakeholders involved in EoLC for individuals with dementia in hospital settings. These include patients and relatives, clinical staff, healthcare managers, healthcare commissioners and funders, and policymakers. By aligning the refined programme theories with practical applications, I aim to demonstrate how each stakeholder group can contribute to the delivery of person-centred, compassionate, and context-sensitive EoLC. This critical realist evaluation recognises that interventions operate differently depending on the interaction between contextual conditions and agency (Pawson and Tilley, 1997), and the following discussion presents how mechanisms can be activated within stakeholder-specific environments.

7.5.1 Patients and Relatives

Informed by a critical realist perspective, I understand that enhancing EoLC for individuals with dementia requires attention not only to the observable outcomes but also to the underlying mechanisms and structures that shape those outcomes. One key domain of impact is the experience of patients and their relatives, who are central to the provision and reception of compassionate, person-centred care.

My findings suggest that patients and their relatives benefit significantly when healthcare professionals are equipped with tailored education and training in dementia-specific EoLC. Participants reported that increased staff understanding of dementia and its trajectory enabled more compassionate communication, reduced confusion about prognosis, and created a greater sense of emotional safety. This reflects the activation of causal mechanisms such as trust-building and validation, which are mediated through the relational agency of informed staff working within supportive organisational contexts.

From a critical realist perspective, the education and training of staff work through generative mechanisms like increased empathy, enhanced communication skills, and moral confidence, all of which are conditioned by both the internal context of the hospital environment and the broader socio-political structures shaping healthcare delivery. These mechanisms lead to outcomes such as improved shared decision-making and reduced distress among relatives, particularly when difficult topics such as prognosis and treatment limitations are addressed with clarity and compassion (O’Brien et al., 2018).

ACP also emerged as a key mechanism through which patient and relative agency is enabled. When implemented early and inclusively, ACP fosters open dialogue about values, goals, and care preferences. The literature shows that this process reduces uncertainty and offers families a sense of control and assurance (NHS, 2022). In critical realist terms, ACP is effective when it is supported by structures such as accessible documentation systems, interprofessional communication, and culturally competent facilitation. However, where these structures are absent or underdeveloped, the mechanisms of autonomy and preparedness may be constrained, reducing the intervention's impact.

MDT collaboration plays a vital role in translating ACP and person-centred care principles into practice. From a critical realist standpoint, MDTs provide the structural conditions for multiple mechanisms, such as professional knowledge integration and collective moral reasoning, to be activated in support of holistic and coherent care. Patients benefit when care is not fragmented, and families gain confidence in the system’s ability to address complex and evolving needs.

Finally, a focus on person and family-centred care shifts the dominant logic from disease management to human experience. This study highlights the importance of preserving dignity, attending to emotional and spiritual needs, and involving families meaningfully. Such outcomes emerge when care systems create the right affordances, such as flexible visiting hours, designated family liaison roles, and culturally sensitive environments, that enable staff and families to collaborate as partners.

In sum, improving EoLC for individuals with dementia and their relatives requires activating multiple mechanisms, empathy, trust, communication, and autonomy, through targeted interventions embedded within appropriate contextual structures. This aligns with the aims of my study to develop critical realist-informed theories that can guide transformative and sustainable improvements in dementia care.

7.5.2. Staff

From a critical realist perspective, I recognise that the transformation of EoLC practices is deeply influenced by the agency of clinical staff operating within specific structural and cultural contexts. This study revealed that when healthcare staff are provided with education and training tailored to dementia care, they not only develop greater competence and confidence but also experience enhanced professional satisfaction. These outcomes are underpinned by mechanisms such as increased self-efficacy, role clarity, and moral validation, all of which are enabled by supportive organisational structures.

Participants in my study described how training on dementia and person-centred care contributed to an improved understanding of patients' needs and facilitated more meaningful interactions. This aligns with findings by Nowaskie et al. (2020), who emphasised the role of tailored training in fostering job satisfaction and empathy among care staff. As a mechanism, education functions by enhancing the interpretive capacities of staff, enabling them to reframe behaviours, anticipate needs, and provide compassionate responses.

Furthermore, ACP initiatives played an important role in strengthening staff-patient relationships and fostering a culture of open dialogue. From a critical realist viewpoint, ACP serves not only as a tool for care planning but also as a mechanism through which relational agency, emotional attunement, and trust are activated. Participants shared that initiating these conversations helped them feel more connected to the individuals they were caring for, reducing emotional distance and burnout.

MDT collaboration was identified as another key contributor to positive staff experiences. Working with professionals from various disciplines allowed staff to rely on one another’s expertise, share decision-making burdens, and feel supported in complex care situations. These collaborative processes align with what Engström et al. (2005) identified as important organisational conditions that improve perceived quality of care and job satisfaction.

The integration of person and family-centred care also contributed to a sense of fulfilment among staff. Being able to provide care that honoured patients' identities and values not only improved patient outcomes but also deepened staff's sense of purpose. This outcome can be explained through the mechanism of moral engagement, the process by which staff derive meaning and validation from providing ethically grounded, compassionate care.

Taken together, these findings suggest that staff are not passive recipients of policy or training but active agents whose actions are shaped by and shape the structures around them. My critical realist evaluation highlights that education, ACP, MDT collaboration, and person-centred values can transform staff experiences by triggering internal mechanisms, such as confidence, empathy, and moral agency, within a context that supports learning and interdisciplinary practice.

7.5.3. Management

From a critical realist standpoint, I recognise that healthcare managers operate within complex organisational structures that shape and are shaped by their actions. In this study, the findings demonstrate that the successful implementation of EoLC improvements for people with dementia depends significantly on how management enables the right contextual conditions to activate key mechanisms such as collaboration, compassion, and role satisfaction among staff.

Management's role in fostering a culture of MDT collaboration emerged as a critical enabler. Participants highlighted that when managers prioritised collaborative working, the resulting team dynamics became more cohesive, efficient, and responsive to the needs of individuals with dementia. From a critical realist lens, this reflects the activation of mechanisms such as trust, psychological safety, and mutual accountability, all of which are contingent upon supportive organisational policies and leadership practices.

Equally important was the promotion of person and family-centred care as a core organisational value. Managers who embedded these principles into service design helped cultivate a more compassionate and empathetic workplace. This finding aligns with research suggesting that the cultivation of compassionate leadership is a key determinant of healthcare quality and staff morale (West et al., 2017). Compassion, when legitimised through managerial support, functions as a mechanism that boosts staff engagement and job satisfaction.

Managers also play a crucial role in improving patient outcomes. When the values of person-centred care are reflected in everyday practices, such as flexible visiting policies, dedicated spaces for private conversations, or investment in dementia-friendly design, patients and their families experience a greater sense of dignity and respect. These contextual enhancements support mechanisms like emotional security, relational continuity, and therapeutic presence, which are vital to quality EoLC.

In addition, the presence of strong leadership and well-articulated program theories, including those on education, ACP, and MDT collaboration, contributes to a more supportive and sustainable work environment. Managers who understand and implement these components contribute to staff retention by addressing mechanisms such as burnout reduction, recognition, and professional fulfilment (Anandavica et al., 2018).

By interpreting these findings through a critical realist lens, I highlight how the success of dementia EoLC interventions is not merely a result of individual competence or compassion but of systemic structures that either enable or constrain human agency. Managers hold a key position in aligning organisational resources, policies, and values with the needs of both patients and staff, creating the conditions for quality care to flourish.

7.5.4. Organisational Effectiveness

From a critical realist perspective, I understand that organisational effectiveness in the context of EoLC for people with dementia emerges through the interaction of structural enablers, staff agency, and specific contextual conditions. My findings suggest that implementing the refined programme theories, including those focused on multidisciplinary collaboration, education and training, ACP, and person and family-centred care, can significantly improve how healthcare organisations operate.

A key mechanism underpinning this improvement is more efficient resource utilisation. When managers align resources with clearly articulated programme theories, staff are better supported in their roles, which improves workflow and reduces duplication. For example, investment in team-based training fosters shared understanding across roles, thereby reducing miscommunication and improving the continuity of care. These organisational changes create conditions that allow mechanisms such as confidence, teamwork, and consistency to be activated across the system (Pawson and Tilley, 1997).

The refined programme theories also suggest that organisational culture shifts are crucial. By embedding person and family-centred care into organisational policies and procedures, management can foster an environment where emotional support, dignity, and individualised care are prioritised. These structural supports enable mechanisms such as empathy and relational care to emerge in everyday practice (Manley et al., 2011).

Another outcome of implementing these theories is an enhanced organisational reputation. Participants in this study observed that when their workplace promoted high-quality dementia care, it not only improved patient experiences but also contributed to staff retention and job satisfaction. In turn, this reinforced the organisation's capacity to maintain consistent, high-quality services, a cyclical relationship between effective structures and positive outcomes.

From a critical realist standpoint, I interpret organisational effectiveness not as a static endpoint but as an emergent property arising from the interplay of policies, staff action, and external pressures. Therefore, the successful operationalisation of these programme theories depends on recognising and responding to the complexity of hospital environments, particularly those delivering care to vulnerable populations like people with dementia at the EoL.

7.5.5. Healthcare Commissioners and Funders

From a critical realist perspective, I understand healthcare commissioners and funders as key structural agents whose decisions can enable or constrain the implementation of high-quality EoLC for people with dementia. My findings suggest that when commissioners support initiatives aligned with the refined programme theories, education and training, ACP, MDT collaboration, and person and family-centred care, they create the conditions for essential mechanisms to be activated across health systems.

Commissioners play a pivotal role in resourcing joint training and interdisciplinary learning opportunities. My findings demonstrate that joint training can improve professional understanding across disciplines, contributing to better communication and integrated care delivery. Commissioners' decisions to invest in such training enable the mechanism of shared knowledge and collaborative agency, which in turn improves care outcomes (Health Education England, 2018).

Additionally, by funding ongoing professional development and offering incentives for dementia and EoLC training, commissioners can support staff to stay current with best practices. This mechanism, professional motivation through recognition and reward, is contingent on structural support and fosters a culture of continuous improvement (NICE, 2018).

The refined programme theories also suggest the need for strategic commissioning of ACP. My findings highlight how embedding ACP into routine clinical pathways can reduce crisis-driven decisions and ensure care aligns with patients' values. Commissioners can facilitate this by supporting the development of digital tools for ACP documentation and encouraging their integration across care settings. These structures support the mechanisms of preparedness, autonomy, and reduced emotional burden for families (Dixon et al., 2019).

Another important area involves public awareness. Commissioners are well-placed to fund campaigns that normalise ACP discussions, especially among communities unfamiliar with such practices. My data indicate that many patients and families encounter ACP for the first time during hospital admissions, often too late for meaningful involvement. By supporting proactive engagement, commissioners can address a critical contextual gap and enhance the capacity for informed decision-making.

In summary, I see commissioners and funders not only as enablers of structural change but also as actors who can catalyse cultural and behavioural shifts. Their strategic choices shape the healthcare environment and create the potential for programme theories to be activated and sustained in practice.

7.5.6. Policy Makers

Although I did not directly engage policymakers during this research, I recognise their vital role in shaping the structural conditions under which EoLC for people with dementia is delivered. From a critical realist perspective, policymakers operate as higher-level agents who influence the broader structural and cultural context within which frontline care is enacted. My findings suggest several ways in which they can support the activation of mechanisms identified in the refined programme theories.

First, policymakers can support structural change by embedding education and training for dementia and EoLC into national professional standards. This would reinforce a culture of learning and person-centred care, ensuring that mechanisms such as improved communication, empathy, and confidence are more consistently triggered across health and care services (Department of Health and Social Care, 2023). My findings show that many staff feel underprepared to deliver EoLC for people with dementia. Mandating dementia-specific education as a core requirement for continuing professional development would be a powerful enabler.

Second, my data emphasise the importance of ACP, which remains inconsistently implemented across settings. Policymakers can contribute to a more systematic approach by ensuring ACP is included in routine care pathways and by mandating interoperability across digital record systems. Such policies would strengthen mechanisms like shared decision-making, reduced hospital admissions, and greater alignment with patients’ wishes, all of which depend on structural support and cross-organisational communication (Rietjens et al., 2017).

Policymakers can also play a central role in legitimising and resourcing MDT working. By requiring MDT structures to be part of service standards and by funding protected time for collaborative care planning, policies can create the conditions for mutual respect, information sharing, and holistic assessment, mechanisms identified in my study as key to high-quality dementia care.

Furthermore, national policy can enshrine person and family-centred care as a standard, moving beyond rhetoric to operational requirements. This might include outcome measures that assess patient experience, family involvement, and cultural competence. My findings indicate that spiritual and emotional needs are often unmet due to limited hospital resources and weak links with community or faith organisations. Policies that encourage partnerships between hospitals and community leaders could help address these gaps.

In summary, I see policymakers as critical in shaping the healthcare landscape by defining the expectations, incentives, and resources that underpin practice. By aligning policies with the mechanisms and contextual enablers identified in this study, they can foster a system that supports compassionate, person-centred EoLC for people with dementia.

7.6. Contribution to the Field

This research makes a substantial contribution to both academic and societal understanding of EoLC for individuals with dementia, tackling critical challenges associated with this life-limiting illness.

7.6.1. Academic Contribution

A notable academic contribution of this study lies in advocating for a methodological shift towards CRE within programme evaluation methodologies. CRE is particularly valuable for policymakers because it addresses the complexities of real-world healthcare delivery. This approach acknowledges the nuanced challenges of healthcare practice, providing evidence that is both theoretically sound and practically meaningful. By integrating CRE into research and evaluation practices, policymakers can ensure that interventions are rigorously assessed in real-world contexts, ultimately enhancing the effectiveness of EoLC for individuals with dementia.

The study introduces refined programme theories, specifically focusing on education and training, ACP, and MDT collaboration. This theoretical advancement enriches the existing knowledge base in palliative care and dementia studies, offering a nuanced understanding of the mechanisms and contextual factors influencing EoLC for people with dementia. The application of CRE as a methodological framework enhances the rigour of the study, providing a robust analytical foundation for future studies in the field of EoLC and CRE. The multifaceted approach to data collection, including systematic literature reviews, interviews, and focus groups with bereaved relatives, healthcare professionals, and managers, contributes to a rich and diverse dataset. This comprehensive data collection approach allows for a holistic exploration of the complexities surrounding EoLC for individuals with dementia. The development and refinement of programme theories, such as education and training, ACP, and MDT collaboration, offer practical insights into potential interventions and mechanisms for improving EoLC, shaping academic research and clinical practice trajectory.

7.6.2. Societal Contribution

With the increasing prevalence of dementia and its profound impact on individuals and their families, the study directly addresses an urgent societal need for improved EoLC. By identifying specific areas for intervention, the research lays the groundwork for enhancing the quality of life for those affected by dementia during their final stages. The study's findings, particularly the refined programme theories, hold the potential for informing healthcare policies related to EoLC for people with dementia. The practical implications of the research can guide policymakers in developing targeted strategies to address the unique challenges associated with providing compassionate and effective care in the face of this complex illness. Including perspectives from bereaved relatives, healthcare professionals, and managers empowers key stakeholders in the healthcare system. The study fosters a more inclusive and patient-centred approach by amplifying the voices of those directly involved in EoLC, aligning with the broader societal movement toward person-centred care.

In conclusion, this research significantly advances the academic understanding of EoLC for individuals with dementia while addressing pressing societal needs. By providing nuanced insights and practical recommendations, the study serves as a valuable resource for shaping future research agendas, informing healthcare policies, and ultimately improving the lived experiences of individuals with dementia and their families during this critical stage of care.

7.7. Strengths and Limitations

While this study has made significant contributions to the understanding of EoLC for people with dementia in hospital settings, it is important to acknowledge both its strengths and limitations.

7.7.1. Strengths

One of the key strengths of my study lies in its multi-method design, which combined a systematic literature review, a critical realist review, and qualitative data collection through interviews and focus groups. This diverse methodological approach allowed me to develop a rich, contextually grounded understanding of EoLC for people with dementia in hospital settings. By integrating different types of evidence, I was able to triangulate findings and enhance the robustness of the programme theories I developed (Pawson, 2013).

Applying CRE was a particular strength, as it enabled me to explore the causal mechanisms underlying complex care practices and how these mechanisms interacted with contextual conditions to produce specific outcomes. CRE allowed me to examine how structural and cultural constraints, staff agency, and institutional norms influenced EoLC interventions (Westhorp, 2014). Through this lens, I could move beyond surface-level observations and identify deeper generative mechanisms and tendencies that shape practice. This approach offered not only explanatory power but also practical insights into how care might be improved.

Another strength was my commitment to theory refinement through iterative engagement with participants. I used a participatory approach to refine programme theories based on feedback from healthcare professionals and bereaved relatives during the second phase of data collection. This process enhanced the trustworthiness and practical relevance of my findings while aligning with critical realism's emphasis on collaborative theory-building (Fletcher, 2017).

The inclusion of multiple stakeholder perspectives—including bereaved relatives, frontline clinical staff, and hospital managers—further strengthened the study. This interdisciplinary engagement enabled a holistic examination of the structural, relational, and cultural influences shaping EoLC for people with dementia. Importantly, the voices of bereaved relatives added emotional and ethical depth to the analysis, while clinical and managerial perspectives helped illuminate systemic constraints and possibilities for change.

My own positionality also served as a strength. Coming from a different cultural and healthcare background, I brought an ‘outsider’ perspective that enabled me to question taken-for-granted assumptions and reflect critically on UK-based EoLC practices. This perspective enhanced my ability to recognise and interpret implicit norms and power dynamics that might otherwise remain invisible (Manzano, 2016). The multidisciplinary expertise of my supervisory team, including clinical and methodological specialists, contributed significantly to the methodological rigour and theoretical development of the study.

In addition, the study’s engagement with complex ethical issues—particularly the exclusion of people with advanced dementia due to consent concerns—demonstrates a commitment to ethical integrity. While their direct voices were absent, I sought to include their perspectives through the accounts of relatives and professionals who had cared for them. This approach, though imperfect, offered valuable insight into the lived experiences of patients nearing the end of life.

In summary, the study’s strengths lie in its use of a critical realist methodology, its iterative and collaborative theory development process, its inclusion of diverse stakeholder voices, and its interdisciplinary and ethical sensitivity. Together, these strengths have contributed to the development of nuanced and practically relevant programme theories to inform future interventions for EoLC for people with dementia in hospitals.

7.7.2 Limitations

Despite the strengths of this study, several limitations must be acknowledged. These limitations do not undermine the study’s contributions but rather help contextualise the findings and guide future research directions.

A key limitation was the absence of direct accounts from individuals with terminal dementia. Due to ethical considerations around consent, I was unable to include participants who were in the later stages of dementia and nearing the end of life. Although I addressed this gap by engaging bereaved relatives and healthcare professionals, I recognise that this approach may not fully capture the subjective experiences of people with dementia themselves. From a critical realist perspective, this limitation reflects the constraints of the empirical domain and reinforces the importance of engaging with multiple stakeholder perspectives to access the real and actual dimensions of experience (Bhaskar, 2008).

Another significant limitation was the small sample size of bereaved relatives. This was largely due to the timing of data collection during the COVID-19 pandemic, which affected recruitment processes and ethical permissions. I had to rely on gatekeepers and intermediaries to contact potential participants, which limited my ability to reach a broader and more diverse group. As a result, the perspectives gathered may not reflect the full range of bereavement experiences, especially those from minority ethnic or culturally diverse backgrounds.

The pandemic also restricted access to hospitals, limiting the depth of data collected from family participants. Many relatives had reduced opportunities to visit loved ones in hospital and were often unaware of the day-to-day care provided. This posed challenges in obtaining rich, detailed accounts of hospital-based EoLC. Furthermore, restrictions in hospital access may have affected staff perspectives and experiences, given the exceptional pressures they faced during the pandemic.

The study’s setting in a single hospital located in a predominantly homogenous community presents another limitation. Although this setting provided valuable insights into EoLC in a specific context, the findings may not be easily generalisable to more diverse urban hospitals or other healthcare systems. From a critical realist standpoint, contextual specificity is essential to understanding how mechanisms are activated under particular conditions (Fletcher, 2017). Nevertheless, I acknowledge the need for future research in more diverse and varied settings to test the transferability of the programme theories developed here.

Resource constraints, including time and funding, also limited the scope of the study. Although I aimed to pilot an intervention based on the refined programme theories, the timeframe of a typical PhD programme did not allow for this. Instead, the study focused on theory development and refinement, laying a foundation for future intervention design and testing.

Finally, I must acknowledge the potential for recall bias, particularly in interviews with bereaved relatives. Participants were often reflecting on events that had occurred weeks or months earlier, and their recollections may have been influenced by grief, time, or the quality of care received. Positive or traumatic experiences may have been more vividly remembered, shaping how participants interpreted and communicated their narratives. While such bias is a common challenge in qualitative research, I attempted to mitigate it by triangulating data across different stakeholder groups and being critically reflexive during analysis (Manzano, 2016).

In conclusion, these limitations reflect the complex realities of conducting research in sensitive and high-stakes settings such as end-of-life care for people with dementia. From a critical realist position, recognising these constraints helps situate the findings within their appropriate social, temporal, and institutional contexts. Future research should aim to build on this foundation by involving more diverse populations, integrating patient voices where ethically possible, and testing the programme theories developed here in applied settings.

7.8. Dissemination and Future Research

7.8.1 Dissemination

The systematic review protocol was registered in PROSPERO (registration number CRD42020169037) (Alhatamleh et al. 2020). Initial findings from the systematic review were shared through a poster presentation at the Annual Postgraduate Research Conference at Bournemouth University (Alhatamleh et al. 2022). A comprehensive update of the systematic review is underway, and the complete findings will be disseminated through publication in a peer-reviewed journal.
Similarly, the CRR is undergoing an update for submission to a peer-reviewed journal, ensuring that the nuanced insights from this evaluation contribute to the academic discourse.

In 2022, I presented the initial findings of the CRE at the Aging and Dementia Research Centre (ADRC), Bournemouth University. The findings derived from the CRE are also being systematically reported to be published in a peer-reviewed journal.
Results will be shared with the participants interested in enhancing transparency and fulfilling participant requests. Furthermore, the participating will offer a concluding presentation to facilitate potential improvements in their practices and knowledge base. Additionally, I will email a succinct summary of the study results to bereaved relatives and interested staff, inviting them to attend a presentation at Bournemouth University to delve deeper into the study's findings. This multi-pronged approach ensures the wide dissemination of valuable insights from the research, fostering knowledge exchange among diverse stakeholders.

7.8.2. Recommendation for Future Research

This study has illuminated several avenues for future research, identifying gaps and unanswered questions that warrant further exploration. These recommendations aim to guide future studies, building upon the findings of this research to continually advance EoLC for individuals with dementia.
1. Development and piloting a holistic intervention informed by this study’s programme theories.
2. Exploration of Cultural Variations

A critical gap remains in understanding how patients’ cultural backgrounds influence decision-making at the end of life. While international literature highlights cultural disparities in healthcare decisions (Nayfeh et al., 2022; Giezendanner et al., 2017), there is a lack of UK-based research examining how diverse cultural values affect preferences around spiritual care, family roles, and treatment escalation. Future studies should explore these cultural dimensions in more diverse settings, contributing to the development of culturally competent EoLC practices (Hinton et al., 2004).

3. Implementation and Evaluation of ACP Interventions
Future research should focus on the practical implementation and evaluation of ACP interventions in hospital settings. Investigating the real-world application of ACP,

including barriers and facilitators, can contribute to developing guidelines and best practices for embedding ACP into routine clinical care (Detering et al., 2010).

4. Multidimensional Assessment of MDT Collaboration

Studies could employ a multidimensional approach to assess the impact of MDT collaboration on EoLC outcomes. This may involve exploring the frequency and depth of MDT meetings and the qualitative aspects of collaboration, team dynamics, and the perceived value of interdisciplinary teamwork.

5. Effectiveness of Person and Family-Centred Interventions

Future research should examine the effectiveness of interventions designed to enhance person and family-centred EoLC. This could involve implementing and evaluating specific strategies, such as shared decision-making tools or communication training, to understand their impact on improving the overall experience of individuals with dementia and their families.

6. Exploration of Technological Solutions

Given the evolving landscape of healthcare technologies, future studies could explore integrating technological solutions in improving EoLC for individuals with dementia. This may include developing and evaluating digital tools that support communication, education, and coordination among healthcare professionals, patients, and families.

7. Inclusive Research Involving Patients with Dementia

Future research should address the ethical challenges associated with including the voices of patients with dementia in research. Exploring innovative and ethical methodologies to incorporate the perspectives of individuals with advanced dementia in shaping EoLC practices could contribute to a more inclusive and patient-centred approach (Chelberg & Swaffer, 2023).

By focusing on these areas, future research can extend and refine the understanding of effective strategies to improve EoLC for individuals with dementia. These recommendations aim to foster a continuous cycle of research and implementation, ultimately contributing to enhancing care practices and outcomes in this critical healthcare domain.

7.9. Reflections

In synthesising research findings and exploring their implications, it is essential to turn the lens inward and engage in a reflective analysis of my journey. This section serves as a critical juncture in the discussion chapter, offering a candid examination of the challenges, growth, and transformative moments experienced throughout this research endeavour.

As the principal investigator, my role extended beyond data collection and interpretation. It encompasses the complex interplay of emotions, adaptability in methodologies, and the perpetual refinement of skills vital for successfully navigating the research landscape. The decision to integrate reflective insights into the discussion chapter arises from recognising the symbiotic relationship between the researcher and the researched, acknowledging that each interaction, setback, and triumph contributes to the nuanced understanding of the phenomena under investigation.

This reflective journey is not merely a personal narrative; instead, it underscores the dynamic and reciprocal nature of the research process. By delving into moments of vulnerability, the refinement of interview and focus group skills, and the imperative need for effective communication adaptation, this section aims to illuminate the intricacies that often remain veiled behind the academic discourse. Furthermore, it aligns with a commitment to transparency, acknowledging the human element within the scientific pursuit and contributing to a richer, more holistic interpretation of the research outcomes.

In essence, these reflections are not mere anecdotes but integral components of the research narrative, providing depth and context to the findings presented in the preceding sections. Through this introspective examination, a bridge is forged between the researcher's experiences and the academic discourse, fostering a deeper understanding of the research process and its broader implications.

7.9.1. Reflection on Researcher Vulnerability

The episodes of vulnerability I encountered during my research journey not only illuminated the sensitivity of the topic of death and dying but also prompted a critical reflection on the inherent challenges researchers face in navigating emotionally charged subjects. These instances underscored the intricate interplay between personal experiences and the research process, shedding light on the complexity of maintaining objectivity when one's own emotions are intricately tied to the subject matter.

Firstly, the convergence of my personal experience with the loss of a family member and the interview on death and dying exposed the depth of researcher vulnerability. The emotional resonance between my recent loss and the interviewee's insights created an unexpected and intense emotional reaction. This emotional convergence not only challenged my ability to remain detached but also raised questions about the broader implications of personal experiences influencing research outcomes. It prompted me to critically examine how my own emotional state might have shaped the nature of the interview, potentially impacting the depth and nuance of the data collected.

The decision to pause the interview and seek emotional support from my clinical supervisor, while deemed appropriate in the context of maintaining ethical research practices, also opens a discourse on the need for researchers to acknowledge and address their vulnerabilities proactively. The critical question raised to me: how can researchers ensure that their personal experiences do not unduly influence the research process? This is a multifaceted challenge that demands ongoing self-awareness, rigorous methodological safeguards, and a supportive research environment.

Furthermore, the emotional impact of transcribing an interview brought to the forefront the ethical responsibility researchers bear. The poignant narrative of a family participant underscored the potential harm that can emanate from a lack of adequate support and palliative care. This realisation not only deepened my emotional connection to the subject matter but also compelled me to critically question the broader ethical implications of my research. How can researchers balance the imperative to illuminate societal issues with the ethical responsibility to protect participants from potential distress, which I thought it happens through ensuring participants are fully aware of the study’s purpose, potential, and the nature of the involvement allowing them to make an informed consent. I also think that as a researcher I should protect participant’s identity and personal information through anonymity.

In conclusion, researcher vulnerability, as revealed through my personal experiences, invites a critical analysis of the intricate dynamics at play when researching emotionally charged topics. It necessitates ongoing scrutiny of one's own biases, emotions, and ethical responsibilities. While vulnerability can be seen as a potential pitfall, it also serves as a catalyst for deeper self-reflection and a commitment to enhancing the rigour and ethical integrity of the research process. By actively engaging with and addressing my own vulnerability, I was able to navigate these challenges, thereby reinforcing the broader societal impact and responsibilities inherent in studying sensitive subjects.

7.9.2. Reflection on the Need for Effective Communication Adaptation

The phase of presenting my initial theories to participants in the second round of data collection marked a pivotal juncture in my PhD research journey. It not only underscored the importance of effective communication but also highlighted the need to bridge the gap between academic jargon and the participants' understanding. This experience provided profound insights into the intricacies of translational communication in research.

Initially, the inclination towards using research-specific jargon was a default mode, reflecting the conventional language of academia. However, the realisation that such terminology posed a significant barrier to communication became evident during the feedback sessions with my supervisor, SP. His guidance to avoid jargon, emphasising that even healthcare staff may not be well-versed in research methodology standards, prompted a crucial shift in my approach.

As advised, I made concerted efforts to replace technical terms with more accessible language. For instance, substituting "mechanisms" with "factors" aimed at demystifying the terminology for participants. This adjustment demonstrated a conscious effort to communicate my research in a manner that resonated with the diverse backgrounds and expertise of the participants.

Despite these adjustments, I encountered a specific challenge with the term "theory." One participant, associating it with physics or mathematical theories, expressed confusion. This instance served as a stark reminder that even seemingly commonplace academic terms might carry diverse interpretations. The need for immediate clarification post-interview prompted a deeper reflection on the nuances of participant comprehension.

The iterative nature of the research process became particularly apparent during this phase. Post the challenging interview, I promptly revised my approach, making additional changes to the terminology for subsequent participants. This adaptive strategy underscored a commitment to enhancing participant understanding and signalled a willingness to learn from each interaction.

This experience highlighted the art of translational communication in research transmuting complex ideas into a language that resonates with the lived experiences and perspectives of participants. It underscored my responsibility not only to collect data but to do so in a manner that respects the diverse knowledge backgrounds of participants, ensuring their meaningful engagement in the research process.

Reflecting on this communication challenge, I recognise the broader implications for research practice. It emphasises the need for researchers to continually assess and adapt their communication strategies, acknowledging the varied educational backgrounds and disciplinary exposures of participants. This approach enriches the participant-researcher dialogue, making research more accessible and inclusive.

In conclusion, the experience of presenting initial theories to participants prompted a profound reflection on the role of communication in research. It reinforced the idea that effective communication is not merely a transmission of information but a dynamic, adaptive process that requires sensitivity to participants' perspectives and a commitment to clarity. This reflective journey serves as a valuable cornerstone in refining not only my communication skills but also the ethos of my research practice.

7.9.3. Reflection on the Development of Interview and Focus Group Skills

The evolution of my interviewing skills during the course of my PhD research represents a critical facet of my research journey, underscoring the iterative nature of skill refinement. The multifaceted development in this area can be dissected into several key components.

One pivotal aspect of skill enhancement involved my ability to ask objective questions. Initially, my inquiries tended to be more exploratory, inadvertently steering participants towards certain perspectives. Recognising this, I worked conscientiously to refine my questioning techniques, ensuring neutrality and openness. This evolution was not only crucial for maintaining the integrity of the data but also contributed to a more nuanced understanding of participants' experiences.

Establishing a conducive and informal environment for interviews was another dimension that underwent substantial refinement. While I initially struggled with balancing professionalism and informality, she gradually learned to set the tone for interviews that encouraged participants to express themselves freely. This transition was essential, particularly when addressing the sensitive topic of death and dying, as it allowed for more authentic and unfiltered responses.

The hospital setting presented unique challenges, primarily related to time management during interviews. Understanding that participants were often sacrificing their work breaks for the interviews necessitated a strategic and considerate approach. This challenge prompted me to develop a meticulous scheduling system, optimising the limited time available while respecting the participants' constraints. This aspect of skill development not only improved the efficiency of the interview process but also highlighted the importance of adaptability in research settings.

With the iterative nature of the programme theories discussion, and where I put across pre-established views that were developed from the literature and previous participants responses, it was easy for me to unintentionally inject my own views with them. That was a significant turning point in my skill development emerged from an early experience in a focus group where I injected my own opinions into the discussion. Recognising the potential impact of bias, my clinical supervisor's feedback was instrumental. Subsequently, she consciously refrained from intervening during discussions, allowing participants to express themselves without external influence. This adjustment not only preserved the integrity of the data but also reflected a commitment to maintaining objectivity throughout the research process.

Encountering misunderstandings, particularly regarding complex concepts like ACP, became a pivotal juncture in my skill development. Instead of immediately clarifying or providing my interpretation, I learned to let these moments unfold organically during interviews. This approach not only yielded richer insights into participant perspectives but also reinforced the importance of allowing the research process to be participant driven.

In essence, the development of my interviewing skills was a dynamic and intricate process. It involved a constant interplay between reflection, feedback, and proactive adjustments. The cumulative effect of these refinements was not merely an improvement in technique but a profound transformation in my ability to navigate the complexities of researching a sensitive topic within a hospital context. This journey stands as a testament to the iterative nature of skill development and the commitment required to uphold the principles of rigorous and ethical research.

7.9.4. Reflection on My Position as an Outsider

One of the most influential aspects of my research journey was my position as an outsider, both culturally and professionally. I did not begin this PhD with experience working in the UK healthcare system. Even when I did eventually work in the UK, my experience was not within the National Health Service (NHS), which is the setting where my study was conducted. Prior to coming to the UK, I worked as an intensive care unit (ICU) nurse in Jordan. While this role involved caring for terminally ill patients, my encounters with individuals living with dementia were rare. As such, my exposure to the nuances of dementia care, especially at the EoL, was limited.

This outsider status proved to be both a challenge and a strength. Initially, I was conscious of my unfamiliarity with the UK context, particularly in terms of policy frameworks, healthcare structures, and cultural expectations related to EoL care. However, over time, I came to see that this detachment allowed me to approach the topic with fresh eyes. Without being embedded in the assumptions, routines, or cultural norms of the UK system, I was able to question practices that might be taken for granted by those working within them. This perspective encouraged me to probe deeper into areas that others might overlook or accept as given, particularly when participants described issues around communication, family involvement, or culturally insensitive care.

Additionally, coming from a clinical background that focused on curative and acute interventions in an ICU environment, I was initially struck by the difference in approach required in dementia care, especially at the EoL. In my prior experience, death often followed aggressive life-sustaining interventions, whereas the context of dementia care in UK hospitals called for a more holistic, person-centred, and sometimes palliative approach. The contrast prompted me to reflect critically on how ideologies and organisational systems shape practice. It also heightened my sensitivity to the emotional, cultural, and ethical challenges that healthcare staff and families navigate when caring for individuals with advanced dementia.

This outsider position also influenced how I engaged with participants. I was transparent about my background and lack of direct NHS experience, which, in some cases, seemed to encourage participants to explain things in more detail or offer additional context. This dynamic may have facilitated richer data collection, as participants were not assuming shared knowledge but instead were actively constructing meaning during our conversations.

In sum, my position as an outsider allowed me to explore the complexities of EoL dementia care from a different vantage point. It helped me ask different questions, see patterns in data that might be less visible to insiders, and remain reflexively aware of my own assumptions. I believe this perspective added depth and nuance to the study and offered a valuable contribution to the way EoL dementia care is researched and understood.

7.9.5 Reflection on My Methodological Positioning as a Critical Realist Researcher

Alongside the emotional dimensions of conducting this research, I continuously engaged with reflexivity through a critical realist lens. CR encouraged me to move beyond observable experiences to examine the deeper mechanisms, structures, and contextual factors shaping for people with dementia. This ontological and epistemological stance meant embracing layered reality, recognising that outcomes are produced through the interaction of intervention mechanisms, internal and external contexts, and human agency, often in unpredictable ways.

As an outsider to the NHS and the UK healthcare system, I approached the field without being embedded in its routines, assumptions, or medical ideologies. This position afforded me a unique lens to detect and question patterns that might otherwise be taken for granted. I was especially attuned to how hidden mechanisms such as unspoken hierarchies, implicit policies, or institutional logics, influenced how care was delivered and experienced. My outsider perspective enabled me to interrogate not just what happened, but why, how, and under what conditions certain outcomes emerged.

Methodologically, I used reflexive journaling, supervisory dialogue, and theory-driven memoing to stay conscious of my positionality and its influence on data collection, interpretation, and theory refinement. I was aware that as a researcher interpreting participant narratives through a critical realist lens, my own conceptual framing could shape which mechanisms I identified as salient. By returning iteratively to the data, my notes, and critical realist theory, I worked to ensure that emerging programme theories were not simply imposed but grounded in participants' lived realities. This process helped me navigate uncertainty, remain open to complexity, and maintain methodological integrity throughout the research journey**.**

In this methodological reflection, I considered how my position as a researcher using CRE shaped the research process. Viewing EoLC for people with dementia through a layered reality enabled me to explore underlying mechanisms, agency, and contextual influences. Through reflexive journaling and iterative engagement with theory, I remained attuned to how my interpretations were shaped by my philosophical stance . This reflective approach strengthened the coherence, transparency, and depth of my evaluation.

7.10. Conclusion

In conclusion, this chapter has provided a comprehensive exploration of the findings, implications, and recommendations stemming from the research on EoLC for individuals with dementia in hospital settings. The study identified key programme theories, including education and training, ACP, MDT collaboration, and person and family-centred care, to address the complex challenges associated with dementia in its final stages.

The programme theories, developed and refined through systematic reviews, interviews, and focus groups, contribute significantly to the academic understanding of EoLC for individuals with dementia. The discussion highlighted the nuanced intervention mechanisms and contextual factors that shape care delivery, providing a foundation for future research and practice.

This research carries profound implications for both the academic and societal realms. Academically, the study advances theoretical frameworks and CRE methodologies, offering a robust foundation for future research endeavours. The multifaceted data collection approach, coupled with the interdisciplinary perspective of the research team, enriches the academic discourse surrounding EoLC and CRE.

On a societal level, the research addresses an urgent need for improved EoLC for individuals with dementia, considering the rapidly increasing prevalence of this life-limiting illness. The refined programme theories provide actionable insights for healthcare professionals, policymakers, and stakeholders involved in caring for individuals with dementia at the EoL.

The potential impact of this research extends to the development of targeted interventions, policy recommendations, and educational strategies that prioritise the dignity, preferences, and holistic needs of individuals with dementia and their families. By fostering a person-centred and collaborative approach to EoLC, the study contributes to the broader societal goal of enhancing the well-being of those affected by dementia during this critical phase of care.

In summary, this research not only adds to the academic knowledge base but also holds the potential to drive positive changes in clinical practice, healthcare policies, and the overall experience of individuals with dementia and their families. As the findings reverberate across academic and societal spheres, the study sets the stage for continued advancements in EoLC for people with dementia, ultimately striving towards a more compassionate and dignified approach to EoL experiences.

References

Afzal, N., Buhagiar, K., Flood, J. and Cosgrave, M., 2010. Quality of end-of-life care for dementia patients during acute hospital admission: a retrospective study in Ireland. *General hospital psychiatry*, 32(2), pp.141-146.

Ahronheim, J. C., Morrison, R. S., Morris, J., Baskin, S. and Meier, D. E., 2000. Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. *Journal of Palliative Medicine*, 3 (3), 265-273.

Aldridge, M. D., & Bradley, E. H., 2017. Epidemiology and patterns of care at the end-of-life: rising complexity, shifts in care patterns and sites of death. *Health Affairs*, 36(7), 1175-1183.

Alford, J., 2019. Patients at risk because NHS hospitals using different record-keeping systems. IMPERIAL, Available at: https://www.imperial.ac.uk/news/194269/patients-risk-because-nhs-hospitals-using/#:~:text=Researchers%20at%20the%20Institute%20of,unable%20to%20effectively%20share%20information., (Accessed: 11 Jan 2024.)

Alhatamleh, H., Porter, S., Board, M., Valentine, J. 2020. How effective are the interventions designed to improve end-of-life care for hospital inpatients with dementia?: a systematic review. PROSPERO Available from: Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020169037

Alhatamleh, H., Porter, S., Board, M., Valentine, J. 2022. How effective are the interventions designed to improve end-of-life care for hospital inpatients with dementia?: a systematic review. [Poster]. the 14th Annual Postgraduate Research Conference, 30 November 2022, Bournemouth University (FG06). Available from: https://issuu.com/bournemouthuniversity/docs/11551_the_14th_annual_postgraduate_research_confer?fr=sMjAzODM4ODEyMDU

Alzheimer's Disease International (ADI), 2019. *World Alzheimer Report 2019: Attitudes to dementia*. [online] London: Alzheimer's Disease International. Available from: https://www.alzint.org/resource/world-alzheimer-report-2019/ [Accessed 11 Jan 2024].

Alzheimer's Research UK, 2021. *Dementia Statistics Hub*. [online] Available from: https://www.dementiastatistics.org [Accessed 31 May 2024].

Alzheimer's Research UK, 2021. *Prevalence and incidence of dementia*. [online] Available from: https://dementiastatistics.org/about-dementia/prevalence-and-incidence/#:~:text=Prevalence%20and%20incidence%20of%20dementia,to%20rise%20to%201.6%20million. [Accessed 11 Jan 2024].

Anandaciva, S., Ward, D., Randhawa, M. and Edge, R., 2018. Leadership in today's NHS: Delivering the impossible. London: The King's Fund. Available at: https://www.kingsfund.org.uk/publications/leadership-todays-nhs [Accessed 1 June 2025].

Araw, M., Kozikowski, A., Sison, C., Mir, T., Saad, M., Corrado, L., Pekmezaris, R. and Wolf-Klein, G., 2015. Does a palliative care consult decrease the cost of caring for hospitalized patients with dementia? Palliative & Supportive Care, 13 (6), 1535-1540.

Archer, M. S., 1995. Realist social theory: The morphogenetic approach. Cambridge: Cambridge University Press.

Aveyard, H., 2023. Doing a Literature Review in Health and Social Care: A Practical Guide. 5th ed. Oxford: McGraw-Hill Education.

Babbie, E., 2016. The Practice of Social Research, 323-334. 15th Ed. Thousands Oaks, CA: Cengage Learning.

Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A. and Kudelka, A.P., 2000. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. The oncologist, 5(4), pp.302-311.

Ballard, C. and Corbett, A., 2013. Agitation and aggression in people with Alzheimer's disease. Current opinion in psychiatry, 26(3), pp.252-259.

Beauchamp, T. and Childress, J., 2019. Principles of biomedical ethics: marking its fortieth anniversary, Vol., 19, pp. 9-12. Taylor & Francis.

Becker, E., 1973. *The Denial of Death*. Free Press.

Bentley, B. and O'Connor, M., 2015. Conducting research interviews with bereaved family carers: when do we ask? Journal of palliative medicine, 18 (3), 241-245.

Berkman, C., Ahronheim, J. C. and Vitale, C. A., 2019. Speech-Language Pathologists' Views About Aspiration Risk and Comfort Feeding in Advanced Dementia.

Bettany-Saltikov, J., 2012. How to do a Systematic Literature Review in Nursing: A Step-by-step Guide. Open University Press.

Bhaskar, R. and Hartwig, M., 2016. *Enlightened common sense: The philosophy of critical realism*. Routledge.

Bhaskar, R., 1975. A Realist Theory of Science with a new introduction. London: Verso.

Bhaskar, R., 1979. The possibility of naturalism. Atlantic Highlands.

Bhaskar, R., 1986. 2009. Scientific Realism and Human Emancipation.

Bhaskar, R., 1989. Reclaiming reality: A critical introduction to contemporary philosophy. London: Routledge.

Bhaskar, R., 2008. *Dialectic: The pulse of freedom*. Routledge.

Blackman, G., Pedersen, J., March, M., Reyes-Fournier, E. and Cumella, E.J., 2019. A comprehensive literature review of online teaching effectiveness: Reconstructing the conceptual framework.

Blakemore, A., Kenning, C., Mirza, N., Daker-White, G., Panagioti, M. and Waheed, W., 2018. Dementia in UK South Asians: a scoping review of the literature. BMJ open, 8 (4), e020290.

Bloor, M., Frankland, J., Thomas, M. and Robson, K., 2001. Focus Groups in Social Research Sage Publications London.

Boateng, W., 2012. Evaluating the Efficacy of Focus Group Discussion (FGD) in Qualitative Social Research. International Journal of Business and Social Science, 3 (7), 54-57.

Bonell, C., Fletcher, A., Morton, M., Lorenc, T. and Moore, L., 2012. Realist randomised controlled trials: a new approach to evaluating complex public health interventions. Social science & medicine, 75 (12), 2299-2306.

Bournemouth University's Code of Good Research Practice, 2024 Code of Good Research Practice [Online], Available from https://intranetsp.bournemouth.ac.uk/pandptest/8a-code-of-practice-for-research-degrees.PDF[Accessed 01/04/2025].

Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2), 77-101.

Brooker, D. and Latham, I., 2015. Person-centred dementia care: Making services better with the VIPS framework. Jessica Kingsley Publishers.

Brooker, D., 2004. What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13(3), pp.215–222.

Bunn, F., Burn, A.-M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J. and Brayne, C., 2014. Comorbidity and dementia: a scoping review of the literature. *BMC medicine* [online], 12 (1), 192. Available from: http://dx.doi.org/10.1186/s12916-014-0192-4.

Calanzani, N., 2013. *Palliative and end-of-life care for black, Asian and minority ethnic groups in the UK. Marie Curie Cancer Care Research Report*.

Campbell, M. L., Dove-Medows, E., Walch, J., Sanna-Gouin, K. and Colomba, S., 2011. The impact of a multidisciplinary educational intervention to reduce PEG tube placement in patients with terminal-stage dementia: A translation of research into practice. Journal of Palliative Medicine, 14 (9), 1017-1021.

Campbell, M. L., Guzman, J. A., 2004. A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia. *Critical Care Medicine*, 32 (9), 1839-1843.

Campbell, P., Torrens, C., Pollock, A. and Maxwell, M., 2018. A scoping review of evidence relating to communication failures that lead to patient harm. Glasglow Caledonia Univeristy, Glasglow.

Centre for Research and Dissemination (CRD), 2009. Systematic Reviews. CRD's Guidance for Undertaking Reviews in Health Care. University of York: CRD.

Chelberg, K. and Swaffer, K., 2023. " Missing Persons": Absent Voices of People with Dementia in the Australian Royal Commission into Aged Care. *Journal of Law & Medicine*, 30(3).

Chen, G.-T., Chen, Y.-H., Chen, P.-J., Chen, Y.-C., Wang, J.-J., Ho, C.-H., Hsu, Y.-W. and Huang, C.-C., 2017. Comparison of healthcare utilisation and life-sustaining interventions between elderly patients with dementia and those with cancer near the end of life: A nationwide, population-based study in Taiwan. *Geriatrics & Gerontology International*, 17 (12), 2545-2551.

CHKS, 2013. Insight report: An economic analysis of the excess costs for acute care for patients with dementia. Available at: http://www.chks.co.uk/userfiles/files/Dementia_an_economic_analysis.pdf, (Accessed:19 Dec 2020)

Clarfield, A. M., Monette, J., Bergman, H., Monette, M., Ben-Israel, Y., Caine, Y., Charles, J., Gordon, M. and Gore, B., 2006. Enteral feeding in end-stage dementia: a comparison of religious, ethnic, and national differences in Canada and Israel. Journals of Gerontology Series A: Biological Sciences & Medical Sciences, 61 (6), 621-627.

Clarke, M., 2004. Doing new research? Don't forget the old. *PLoS medicine*, 1 (2), e35.

Cohen-Mansfield, J. and Billig, N., 2018. Agitated behaviours in the elderly: I. A conceptual review. *Journal of the American Geriatrics Society*, 36(10), pp.711–721

Cooper, H., Findlay, G., Goodwin, A.P.L., Gough, M.J., Lucas, S.B. and Mason, D.G., 2009. Deaths in Acute Hospitals. Caring to the end. National Confidential Enquiry into Patient Outcome and Death (NCEPOD), London.

Cornwell, J., Levenson, R., Sonola, L., Poteliakhoff, E. and Fund, K. s., 2012. Continuity of care for older hospital patients: a call for action. King's Fund.

Creswell, J. W. and Creswell, J. D., 2017. Research design: Qualitative, quantitative, and mixed methods approaches. Thousand Oaks, CA: Sage Publications.

Creswell, J. W., 2014. A Concise Introduction to Mixed Methods Research. Thousand Oaks, CA: SAGE publications.

Critical Appraisal Skills programme (CASP). 2018. CASP Checklists[online]. Available from: https://casp-uk.net/casp-tools-checklists/ [Accessed Dec 2019].

Cunningham, C., McWilliam, G. and O'Sullivan, G., 2008. Why don't they talk to me? Communication between staff and people with dementia in care settings. Age and Ageing, 37(6), pp.627–629.

Danermark, B., Ekstrom, M., Jakobsen, L. and Karlsson, J. C., 2002. *Explaining society: Critical realism in the social sciences*. London: Routledge.

Davies, N., 2014. Barriers to the provision of high-quality palliative care in dementia: A qualitative study. *BMC Palliative Care*, 20 (1), 1–10.

Demanze Laurence, B. and Michel, L., 2017. The fall in older adults: physical and cognitive problems. *Current aging science*, *10*(3), pp.185-200.

Denzin, N.K. and Lincoln, Y.S. (eds.), 2018. *The SAGE handbook of qualitative research*. 5th ed. Los Angeles, CA: Sag.

Department of Health and Social Care (2023). Care workforce pathway: Phase 1 – overview. London: Department of Health and Social Care. Available at: https://www.vodg.org.uk/group/learning-and-development/downloadattachment.html?documentId=24EF5DF0-5951-4847-AF8CAF0438445EC3&groupId=CE10311C-5528-43A7-8F23B41F53E23AD8&version=1 [Accessed 1 Jun. 2025].

Detering, K.M., Hancock, A.D., Reade, M.C. and Silvester, W., 2010. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*, 340.

Dixon, J., King, D. and Knapp, M., 2019. Advance care planning in England: Is there an association with place of death? BMJ Supportive & Palliative Care, 9(3), pp.316–325.

Durepos, P., Kaasalainen, S., Carroll, S. and Papaioannou, A., 2019. Perceptions of a psychoeducation program for caregivers of persons with dementia at end of life: a qualitative study. *Aging and Mental Health*, 23 (2), 263-271.

Edgley, A., Stickley, T., Timmons, S., & Meal, A., 2016. Critical realist review: exploring the real, beyond the empirical. *Journal of Further and Higher Education*, 40(3), 316-330.

Engström, M., Ljunggren, B., Lindqvist, R. and Carlsson, M., 2005. Staff perceptions of job satisfaction and life situation before and 6 and 12 months after increased information technology support in dementia care. *Journal of telemedicine and telecare*, 11(6), pp.304-309.

Ernecoff, N. C., Wessell, K. L., Gabriel, S., Carey, T. S. and Hanson, L. C., 2018. A Novel Screening Method to Identify Late-Stage Dementia Patients for Palliative Care Research and Practice. *Journal of Pain & Symptom Management*, 55 (4), 1152-1158.e1151.

Etters, L., Goodall, D. and Harrison, B.E., 2008. Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), pp.423–428.

Fletcher, A., 2017. Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20 (2), 181–194.

Fossey, E., Harvey, C., McDermott, F. and Davidson, L., 2002. Understanding and evaluating qualitative research. *Australian & New Zealand journal of psychiatry*, 36(6), pp.717-732.

García-Alberca, J.M., 2017. Cognitive-behavioral treatment for depressed patients with Alzheimer’s disease. An open trial. Archives of gerontology and geriatrics, 71, pp.1-8.

Gieniusz, M., Sinvani, L., Kozikowski, A., Patel, V., Nouryan, C., Williams, M.S., Kohn, N., Pekmezaris, R. and Wolf-Klein, G., 2018. Percutaneous feeding tubes in individuals with advanced dementia: are physicians "choosing wisely"?. Journal of the American Geriatrics Society, 66(1), pp.64-69.

Giezendanner, S., Jung, C., Banderet, H.R., Otte, I.C., Gudat, H., Haller, D.M., Elger, B.S., Zemp, E. and Bally, K., 2017. General practitioners' attitudes towards essential competencies in end-of-life care: A cross-sectional survey. *PloS one*, 12(2), p.e0170168.

Gillick, M.R., 2000. Rethinking the role of tube feeding in patients with advanced dementia. New England Journal of Medicine, 342(3), pp.206–210.

Gkioka, M., Schneider, J., Kruse, A., Tsolaki, M., Moraitou, D. and Teichmann, B., 2020b. Evaluation and effectiveness of dementia staff training programs in general hospital settings: a narrative synthesis with holton's three-level model applied. *Journal of Alzheimer's Disease*, 78(3), pp.1089-1108.

Gkioka, M., Teichmann, B., Moraitou, D., Papagiannopoulos, S. and Tsolaki, M., 2020a. Effects of a person centered dementia training program in Greek hospital staff—implementation and evaluation. Brain Sciences, 10(12), p.976.

Gómez-Batiste, X., Murray, S.A., Thomas, K., Blay, C., Boyd, K., Moine, S., Gignon, M., Van den Eynden, B., Leysen, B., Wens, J. and Engels, Y., 2017. Comprehensive and integrated palliative care for people with advanced chronic conditions: an update from several European initiatives and recommendations for policy. *Journal of Pain and Symptom Management*, *53*(3), pp.509-517.

Goodman, C., et al. (2010). End-of-life care for community dwelling older people with dementia: An integrated review. *International Journal of Geriatric Psychiatry, 25*(4), 329–337.

Gorski, P.S., 2013. What is Critical Realism? And why should you care? Contemporary Sociology, 42(5), pp.658–670.

Gough, D., Thomas, J. and Oliver, S., 2012. Clarifying differences between review designs and methods. Systematic reviews, 1 (1), 1-9.

Grant, M.J. and Booth, A., 2009. A typology of reviews: an analysis of 14 review types and associated methodologies. Health information & libraries journal, 26(2), pp.91-108.

Guthrie, B., Payne, K., Alderson, P., McMurdo, M. E. T. and Mercer, S. W., 2012. Adapting clinical guidelines to take account of multimorbidity. *BMJ (Clinical research ed.)* [online], 345 (oct04 1), e6341.

Hallenbeck, J. (2022). *Palliative care perspectives*. Oxford University Press.

Hanson, L. C., Kistler, C. E., Lavin, K., Gabriel, S. L., Ernecoff, N. C., Lin, F.-C., Sachs, G. A. and Mitchell, S. L., 2019. Triggered palliative care for late-stage dementia: a pilot randomized trial. Journal of pain and symptom management, 57 (1), 10-19.

Hanson, L.C., Zimmerman, S., Song, M.K., Lin, F.C., Rosemond, C., Carey, T.S. and Mitchell, S.L., 2017. Effect of the goals of care intervention for advanced dementia: a randomised clinical trial. JAMA internal medicine, 177(1), pp.24-31.

Husebø, B.S., Strand, L.I., Moe-Nilssen, R., Borgehammar, K.H. and Ljunggren, A.E., 2011. Pain in older persons with severe dementia: A review of behavioural pain assessment tools. BMC Geriatrics, 11(1), p.70.

Hayhoe, B. and Howe, A., 2011. Advance care planning: interactive and individualised. *British Journal of General Practice*, 61(582), pp.344–345.

Health Education England, 2018. Facing the Facts, Shaping the Future: A draft health and care workforce strategy for England to 2027. London: Health Education England. Available at: https://www.hee.nhs.uk/our-work/workforce-strategy [Accessed 1 Jun. 2025].

Health Research Authority (HRA), 2019. Informing participants and seeking consent. [Online]. Available from: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/informing-participants-and-seeking-consent/ [Accessed 01/04/2021].

Hickman, S.E., Torke, A.M., Sachs, G.A., Sudore, R., Hougham, G.W. and Slaven, J.E., 2012. Advance care planning for patients with advanced dementia: Meeting the challenge. Journal of Gerontological Nursing, 38(8), pp.44–51.

Hinton, L., Franz, C. and Friend, J., 2004. Pathways to dementia diagnosis: evidence for cross-ethnic differences. Alzheimer Disease & Associated Disorders, 18(3), pp.134-144.

Hossain, M.Z., Tarafdar, S.A., Kingstone, T., Campbell, P. and Chew-Graham, C.A., 2022. From detection to preparing for the end-of-life: A qualitative exploration of the South Asian family carers' experiences of the journey with dementia. Health & Social Care in the Community, 30(6), pp.e5135-e5144.

Hossain, M.Z., Tarafdar, S.A., Kingstone, T., Campbell, P. and Chew-Graham, C.A., 2022. From detection to preparing for the end-of-life: A qualitative exploration of the South Asian family carers' experiences of the journey with dementia. Health & Social Care in the Community, 30(6), pp.e5135-e5144.

Johnson, R.B. and Onwuegbuzie, A.J., 2004. Mixed methods research: A research paradigm whose time has come. Educational researcher, 33(7), pp.14-26.

Kastenbaum, R. and Moreman, C.M., 2024. *Death, society, and human experience*. Routledge.

Kofahi, R., Aljezawi, M.E., Abdalrahim, A., Al Qadire, M., Obiedat, D. and Aqaileh, S., 2021. Annual period prevalence and risk factors of dementia among older Jordanian hospitalized patients. *International Journal of General Medicine*, pp.641-647.

Kübler-Ross, E., 1969. On death and dying. Scribner.

Kupersmith, J., 2005. Quality of care in teaching hospitals: a literature review. Academic Medicine, 80(5), pp.458-466.

Kvale, S. and Brinkmann, S., 2007. Introduction to interview research. Doing interviews, 2-11.

Landry, G. J. and Liu-Ambrose, T., 2014. Buying time: a rationale for examining the use of circadian rhythm and sleep interventions to delay progression of mild cognitive impairment to Alzheimer’s disease. Frontiers in aging neuroscience, 6, 325.

Lawrence, V., Samsi, K., Murray, J., Harari, D. and Banerjee, S., 2011. Dying well with dementia: qualitative examination of end-of-life care. *The British Journal of Psychiatry*, 199(5), pp.417-422.

Leadership Alliance for the Care of Dying People, 2014. *One chance to get it right: Improving people's experience of care in the last few days and hours of life*. London: Department of Health and Social Care.

Leedy, P. D. and Ormrod, J. E., 2014. Practical Research: Planning and Design, England. Pearson International.

Lin, H.-C., Lu, Y.-F., Yeh, C.-H., Wang, J.-J., & Yang, Y.-P. (2025). Hindering factors and perceived needs for the decision making of advanced directives among people with dementia and their families. *Geriatrics*, *10*(1), 19.

Lincoln, Y.S. and Guba, E.G., 1985. Naturalistic inquiry. sage.

Lyketsos, C. G., Carrillo, M. C., Ryan, J. M., Khachaturian, A. S., Trzepacz, P., Amatniek, J., ... & Miller, D. S., 2018. Neuropsychiatric symptoms in Alzheimer's disease. *Alzheimer's & Dementia*, 7(5), 532-539.

Manley, K., Hills, V. and Marriot, S., 2011. Person-centred care: Principle of Nursing Practice D. Nursing Standard, 25(31).

Manzano, A., 2016. The craft of interviewing in realist evaluation. Evaluation, 22(3), pp.342–360.

Marchal, B., Van Belle, S., Van Olmen, J., Hoerée, T. and Kegels, G., 2012. Is realist evaluation keeping its promise? A review of published empirical studies in the field of health systems research. Evaluation, 18 (2), 192-212.

Mason, M., 2010. Sample size and saturation in PhD studies using qualitative interviews (3. Vol11).

Middleton-Green, L., Gadoud, A., Norris, K., Sargeant, A. and Hughes, J., 2017. Advance care planning in the UK: Perspectives from general practice. *Palliative Medicine*, 31(7), pp.683–691.

Miles Matthew, B., Michael, H. A. and Johnny, S., 2014. Qualitative data analysis: A methods sourcebook. Sage Publications.

Mitchell, S. L., Black, B. S., Ersek, M., Hanson, L. C., Miller, S. C., Sachs, G. A., Teno, J. M. and Morrison, R. S., 2012. Advanced dementia: state of the art and priorities for the next decade. *Annals of internal medicine* [online], 156 (1 Pt 1), 45–51. Available from: http://dx.doi.org/10.7326/0003-4819-156-1-201201030-00008.

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., Volicer, L., Givens, J. L. and Hamel, M. B., 2009. The clinical course of advanced dementia. *The New England journal of medicine* [online], 361 (16), 1529–1538.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G. and Group*, P., 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Annals of internal medicine, 151 (4), 264-269.

Moyle, W., Jones, C., Dwan, T. and Petrovich, T., 2018. Effectiveness of a virtual reality forest on people with dementia: A mixed methods pilot study. *The Gerontologist*, 58(3), pp.478–487.

Mukadam, N., Sommerlad, A., Huntley, J. and Livingston, G., 2019. Population attributable fractions for risk factors for dementia in low-income and middle-income countries: an analysis using cross-sectional survey data. The Lancet Global Health, 7 (5), e596-e603.

National Institute for Health and Care Excellence (NICE), 2015. *Care of dying adults in the last days of life*. [online] NICE Guideline NG31. London: National Institute for Health and Care Excellence. Available from: https://www.nice.org.uk/guidance/ng31/resources/care-of-dying-adults-in-the-last-days-of-life-pdf-1837387324357 [Accessed 31 May 2025].

National Institute for Health and Care Excellence (NICE), 2018. *Dementia: assessment, management and support for people living with dementia and their carers*. NICE Guideline NG97. [online] London: National Institute for Health and Care Excellence. Available from: https://www.nice.org.uk/guidance/ng97 [Accessed 31 May 2025].

National Institute for Health and Care Excellence (NICE), 2019. *End of life care for adults: service delivery*. [online] NICE Guideline NG142. London: National Institute for Health and Care Excellence. Available from: https://www.nice.org.uk/guidance/ng142/resources/end-of-life-care-for-adults-service-delivery-pdf-66141776457925 [Accessed 31 May 2025].

National Institute on Aging (NIA), 2020. *End of life: Helping with comfort and care*. [online] Bethesda, MD: U.S. Department of Health and Human Services. Available from: https://www.nia.nih.gov/health/end-life-helping-comfort-and-care [Accessed 31 May 2021].

Nayfeh, A., Kheir, N., Yazbeck, S., Ismail, S., El Hajj, M.S. and Awaisu, A., 2022. Attitudes and practices of palliative and hospice care among healthcare professionals in Middle Eastern countries: a systematic review, *BMC Palliative Care*, 21(1), 100.

NHS (2022) *Advance care planning: Guidance and resources for healthcare professionals*. NHS England. Available from: https://www.england.nhs.uk/publication/advance-care-planning-guidance-and-resources [Accessed 5 Apr. 2025].

Ninkatec, 2022. 5 common comorbidities amongst dementia patients: How to manage & prevent. *Ninkatec* [online]. Available from: https://ninkatec.com/5-common-comorbidities-amongst-dementia-patients-how-to-manage-and-prevent/ [Accessed 1 Jun 2025].

Nowaskie, D., Carvell, C.A., Alder, C.A., LaMantia, M.A., Gao, S., Brown, S., Boustani, M.A. and Austrom, M.G., 2020. Care coordinator assistants: Job satisfaction and the importance of teamwork in delivering person-centered dementia care. *Dementia*, 19(5), pp.1560-1572.

Nursing & Midwifery Council (NMC), 2018. *The code: Professional standards of practice and behaviour for nurses, midwives and nursing associates*. [online] London: NMC. Available from: http://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/revised-new-nmc-code.pdf [Accessed 21 May 2020].

O'Shea, E., Timmons, S., Kennelly, S., Siún, A. d., Gallagher, P. and O'Neill, D., 2015. Symptom assessment for a palliative care approach in people with dementia admitted to acute hospitals: results from a national audit. Journal of Geriatric Psychiatry and Neurology, 28 (4), 255-259.

Office for National Statistics (ONS), 2020. *Leading causes of death, UK: 2020*. [online] London: ONS. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath [Accessed 31 May 2025]

Ouchi, K., Wu, M., Medairos, R., Grudzen, C. R., Balsells, H., Marcus, D., Whitson, M., Ahmad, D., Duprey, K. and Mancherje, N., 2014. Initiating palliative care consults for advanced dementia patients in the emergency department. Journal of palliative medicine, 17 (3), 346-350.

Patton, M. Q., 1990. Qualitative evaluation and research methods. SAGE Publications, inc.

Pawson, R. and Manzano-Santaella, A., 2012. A realist diagnostic workshop. Evaluation, 18 (2), 176-191.

Pawson, R. and Tilley, N., 1997. Realistic Evaluation. Thousand Oaks, California: SAGE Publications.

Pawson, R. and Tilley, N., 2004. Realist evaluation.

Pawson, R., 2013. The science of evaluation: a realist manifesto.

Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K., 2005. Critical realist review--a new method of systematic review designed for complex policy interventions. Journal of Health Services Research & Policy, 10 (1), 21-34.

Polit, D. and Beck, C., 2017. Nursing research: generating and assessing evidence for nursing practice. Philadelphia: Wolters Kluwer.

Porter, S., 2015. The uncritical realism of realist evaluation. Evaluation, 21 (1), 65-82.

Puchalski, C. M., et al. (2009). Improving the quality of spiritual care as a dimension of palliative care. *Journal of Palliative Medicine*, *12*(10), 885–904.

Quill, T.E. and Brody, H., 1996. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. Annals of internal medicine, 125(9), pp.763-769.

Rietjens, J.A.C., Sudore, R.L., Connolly, M., van Delden, J.J.M., Drickamer, M.A., Droger, M., Ling, T., Shi, Y., Simon, J. and Korfage, I.J., 2017. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. The Lancet Oncology, 18(9), pp.e543–e551

Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J. and Exley, C., 2013. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but⋯'. Palliative Medicine, 27 (5), 401-408.

Royal College of Psychiatrists, 2019. *National Audit of Dementia – Third round results*. [online] London: Royal College of Psychiatrists. Available from: https://www.rcpsych.ac.uk/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia [Accessed 31 May 2025].

Sachs, G. A., Shega, J. W. and Cox-Hayley, D., 2004. Barriers to excellent end-of-life care for patients with dementia. *Journal of general internal medicine* [online], 19 (10), 1057–1063

Sampson, E. L., Jones, L., Thune-Boyle, I. C., Kukkastenvehmas, R., King, M., Leurent, B., Tookman, A. and Blanchard, M. R., 2011. Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. Palliative medicine, 25 (3), 197-209.

Sampson, E. L., Lodwick, R., Rait, G., Candy, B., Low, J., King, M. and Petersen, I., 2016. Living with an older person dying from cancer, lung disease, or dementia: Health outcomes from a general practice cohort study. *Journal of pain and symptom management*, 51 (5), 839–848.

Sampson, E.L., Candy, B. and Jones, L., 2006. Enteral tube feeding for older people with advanced dementia. Cochrane Database of Systematic Reviews, (4), CD004030.

Samsi, K. and Manthorpe, J., 2011. 'I live for today': a qualitative study investigating older people's attitudes to advance planning: Older people's attitudes to advance planning. *Health & social care in the community* [online], 19 (1), 52–59.

Sandelowski, M., Voils, C. I. and Barroso, J., 2006. Defining and designing mixed research synthesis studies. Research in the schools: a nationally refereed journal sponsored by the Mid-South Educational Research Association and the University of Alabama, 13 (1), 29.

Sayer, A., 2000. Key features of critical realism in practice: a brief outline. *Realism and social science*, pp.10-28.

Scheltens, P., De Strooper, B., Kivipelto, M., Holstege, H., Chételat, G., Teunissen, C. E., Cummings, J. and van der Flier, W. M., 2021. Alzheimer's disease. *Lancet* [online], 397 (10284), 1577–1590.

Seymour, J., 2011. End-of-life care: Promoting comfort, choice, and well-being for older people. *Age UK*.

Shenton, A.K., 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22(2), pp.63-75.

Simard, J., 2010. *The Namaste Care Program for People with Dementia*. Baltimore: Health Professions Press.

Singer, A.E., Meeker, D., Teno, J.M., Lynn, J., Lunney, J.R., Lorenz, K.A., & Shekelle, P.G., 2015. Symptom trends in the last year of life from 1998 to 2010: a cohort study. Annals of Internal Medicine, 162(3), pp.175–183.

Smith, C. P., Feld, S. C., & Franz, C. E. 1992. Methodological considerations: Steps in research employing content analysis systems. In C. P. Smith, J. W. Atkinson, D. C. McClelland, & J. Veroff (Eds.), *Motivation and Personality: Handbook of Thematic Content Analysis* (pp. 515–536). Cambridge University Press.

Sommerlad, A. and Liu, K.Y., 2023. Air pollution and dementia. *BMJ*, 381.

Spacey, A., Scammell, J., Board, M. and Porter, S., 2018. End-of-life care in UK care homes: a systematic review of the literature. Journal of Research in Nursing, 23(2-3), pp.180-200.

St John, K. and Koffman, J., 2017. Introducing Namaste care to the hospital environment: a pilot study. *Annals of palliative medicine*, 6 (4), 35464-35364.

Stilos, K. and Moore, L., 2020. Nurses’ experiences during COVID-19 and its impact on their practice. *Canadian Oncology Nursing Journal*, 30(4), pp.232–235.

Strike, Kenneth, & Posner, George, 1983. Types of synthesis and their criteria.

Surr, C.A., Gates, C., Irving, D., Oyebode, J., Smith, S.J., Parveen, S., Drury, M. and Dennison, A., 2017. Effective dementia education and training for the health and social care workforce: a systematic review of the literature. *Review of educational research*, 87(5), pp.966-1002.

Tadd, W., Hillman, A., Calnan, S., Calnan, M. and Read, I., 2011. *Dignity in Practice: An exploration of the care of older adults in acute NHS Trusts*. PANICOA.

Tennant, M., 2012. Is learning transferable?. In Understanding learning at work (pp. 165-179). Routledge.

Thacker, P.G., 2008. The power of nursing education in transforming end-of-life care. *Journal of Hospice and Palliative Nursing*, 10(4), pp.227-228.

Thuné-Boyle, I. C. V., Sampson, E. L., Jones, L., King, M., Lee, D. R. and Blanchard, M. R., 2010. Challenges to improving end of life care of people with advanced dementia in the UK. Dementia (14713012), 9 (2), 259-284.

Tible, O. P., Riese, F., Savaskan, E. and von Gunten, A., 2017. Best practice in the management of behavioural and psychological symptoms of dementia. Therapeutic advances in neurological disorders [online], 10 (8), 297–309.

Tongco, M. D. C., 2007. Purposive sampling as a tool for informant selection. *Ethnobotany research and applications* [online], 5, 147-158

Van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., Francke, A. L., Jünger, S., Gove, D. and Firth, P., 2014. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative medicine*, 28 (3), 197-209.

van Teijlingen, E. and Pitchforth, E., 2006. Focus group research in family planning and reproductive health care. *BMJ Sexual & Reproductive Health*, 32 (1), 30.

Webb, C. and Roe, B., 2007. *Reviewing research evidence for nursing practice: Systematic reviews*. Oxford: John Wiley & Sons.

West, M.A., Eckert, R., Collins, B. & Chowla, R., 2017. Caring to change: How compassionate leadership can stimulate innovation in health care. London: The

King’s Fund. Available at: https://www.kingsfund.org.uk/publications/caring-change

Westhorp, G., 2014. Realist impact evaluation: An introduction. London: Overseas Development Institute.

Wilhelmsson, M., Ponzer, S., Dahlgren, L.O., Timpka, T. and Faresjö, T., 2012. Are female students in general and nursing students more ready for teamwork and interprofessional collaboration in healthcare? *BMC Medical Education*, 11(1), p.15.

Williams A., Lavender T., Rickmond H. and Tincello DG., 2005. Women’s experiences after a third-degree obstetric anal sphincter tear: a qualitative study. *Birth*, 32 (2), 129–136.

Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C. and Kingston, A., 2019. The costs of dementia in England. *International journal of geriatric psychiatry*, 34(7), pp.1095-1103.

Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J. and Pawson, R., 2013. RAMESES publication standards: realist syntheses. *BMC medicine*, 11, 1-14.

Wong, K., Camacho, J.H., Dulani, S., Trivedi, K., Camacho, J.H.S.P. and Dulani, S.S., 2022. Honoring Long-Lived Cultural Beliefs for End-of-Life Care: Are We Prepared in the Modern Western Society?. *Cureus*, 14(10).

World Health Organization (WHO), 2023. *Dementia*. [online] Available from: https://www.who.int/news-room/fact-sheets/detail/dementia [Accessed 31 May 2025].

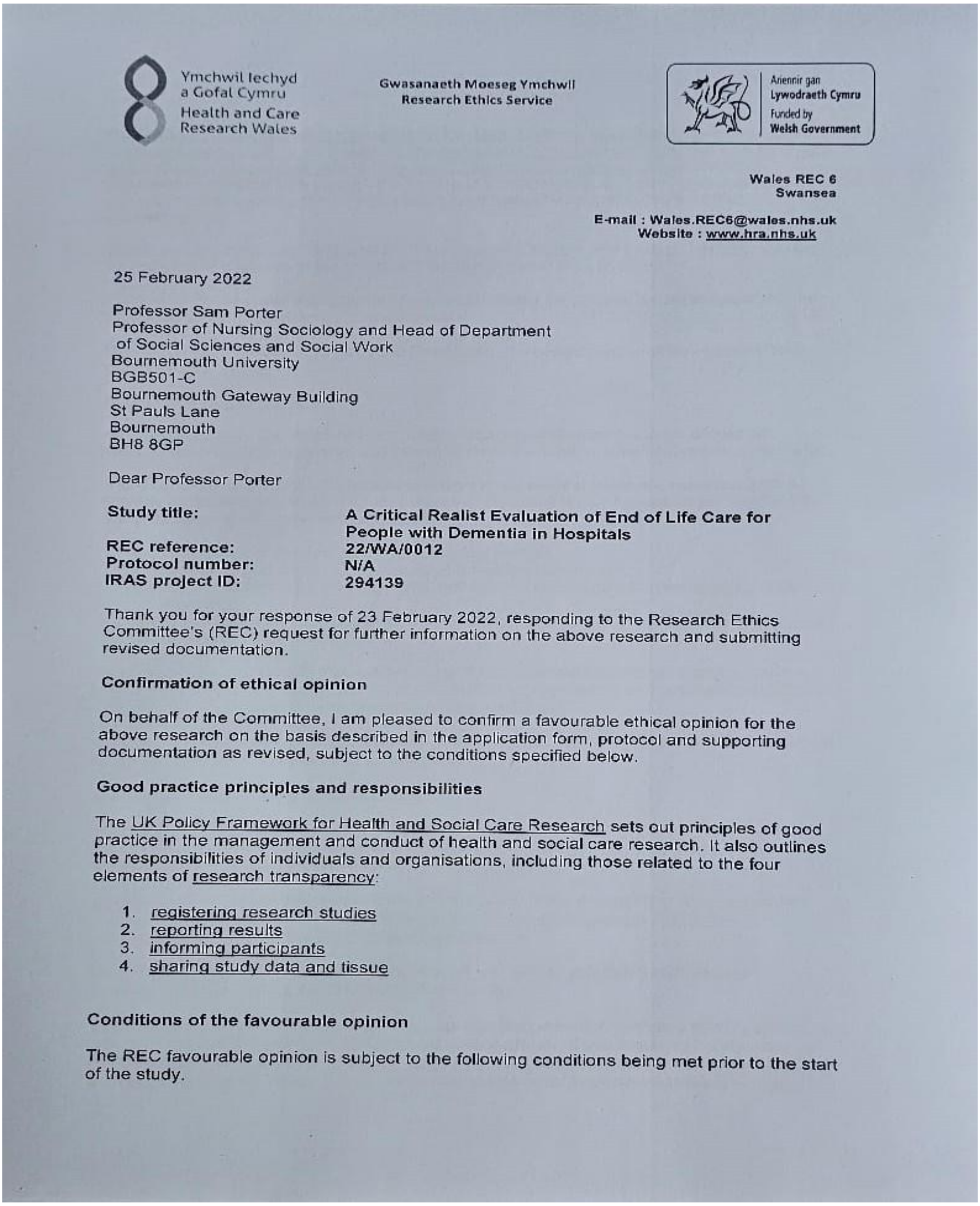
Xiao, L. D., Cheng, A., Xie, C., Chiu, K., Yu, Y., Ullah, S., Wang, J., Hu, R., Xu, D., Pan, X. and Zhang, A. R. Y., 2025. Evaluating an evidence-based iSupport for Dementia programme in routine care services: study protocol for a hybrid type II trial. *BMJ open* [online], 15 (2), e086667.

Yaguchi, A., Truog, R. D., Curtis, J. R., Luce, J. M., Levy, M. M., Mélot, C. and Vincent, J.-L., 2005. International differences in end-of-life attitudes in the intensive care unit: results of a survey. *Archives of internal medicine*, 165 (17), 1970-1975.

Yoshii, A., Plaut, D. A., McGraw, K. A., Anderson, M. J. and Wellik, K. E., 2009. Analysis of the reporting of search strategies in Cochrane systematic reviews. *Journal of the Medical Library Association: JMLA*, 97 (1), 21.

Appendices

Appendix 1 - HRA ethics Approval.



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

Wales REC 6
Swansea

E-mail : Wales.REC6@wales.nhs.uk
Website : www.hra.nhs.uk

25 February 2022

Professor Sam Porter
Professor of Nursing Sociology and Head of Department
of Social Sciences and Social Work
Bournemouth University
BGB501-C
Bournemouth Gateway Building
St Pauls Lane
Bournemouth
BH8 8GP

Dear Professor Porter

Study title:	**A Critical Realist Evaluation of End of Life Care for People with Dementia in Hospitals**
REC reference:	**22/WA/0012**
Protocol number:	**N/A**
IRAS project ID:	**294139**

Thank you for your response of 23 February 2022, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

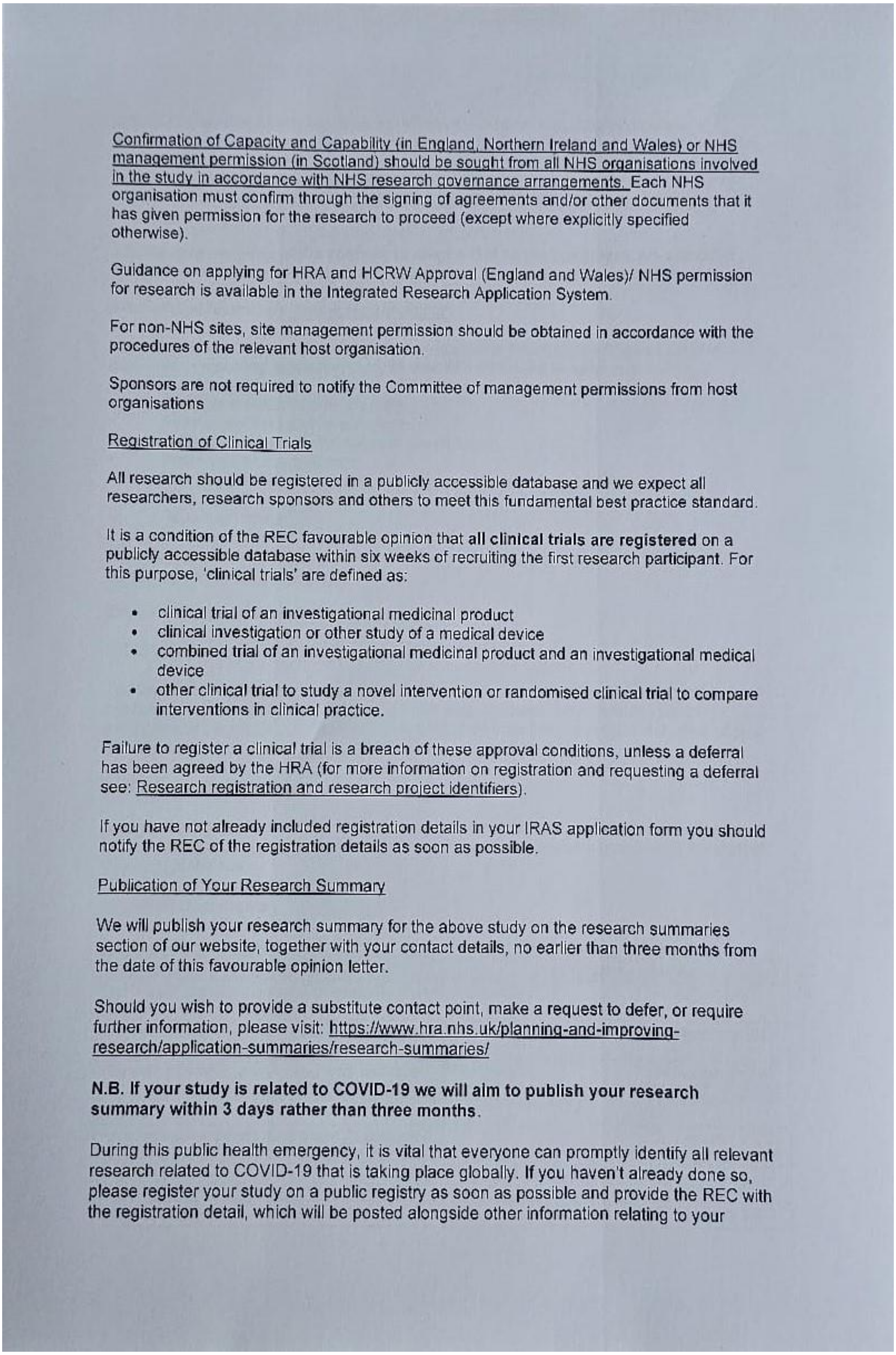
Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.



Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

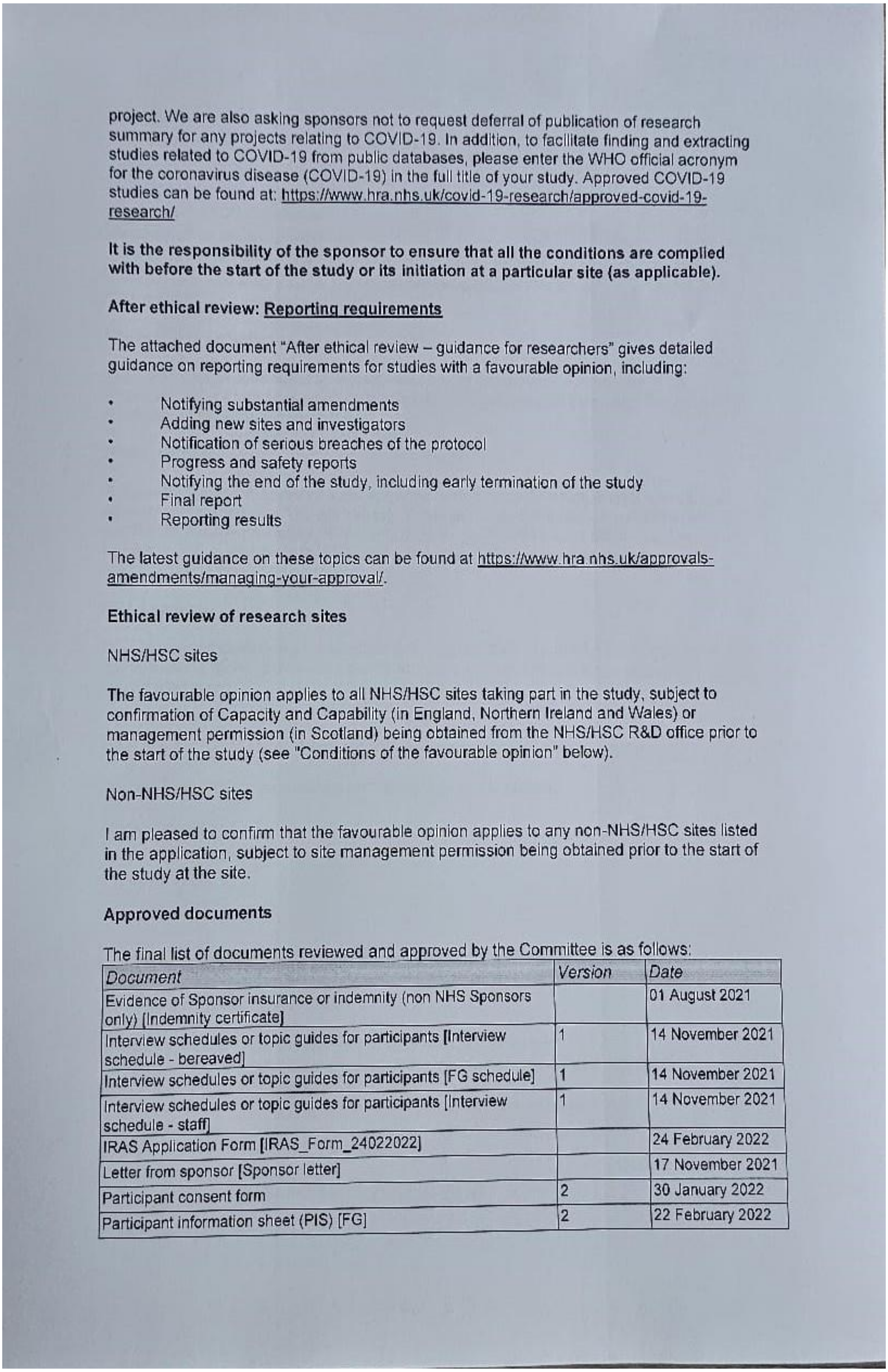
Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your



project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

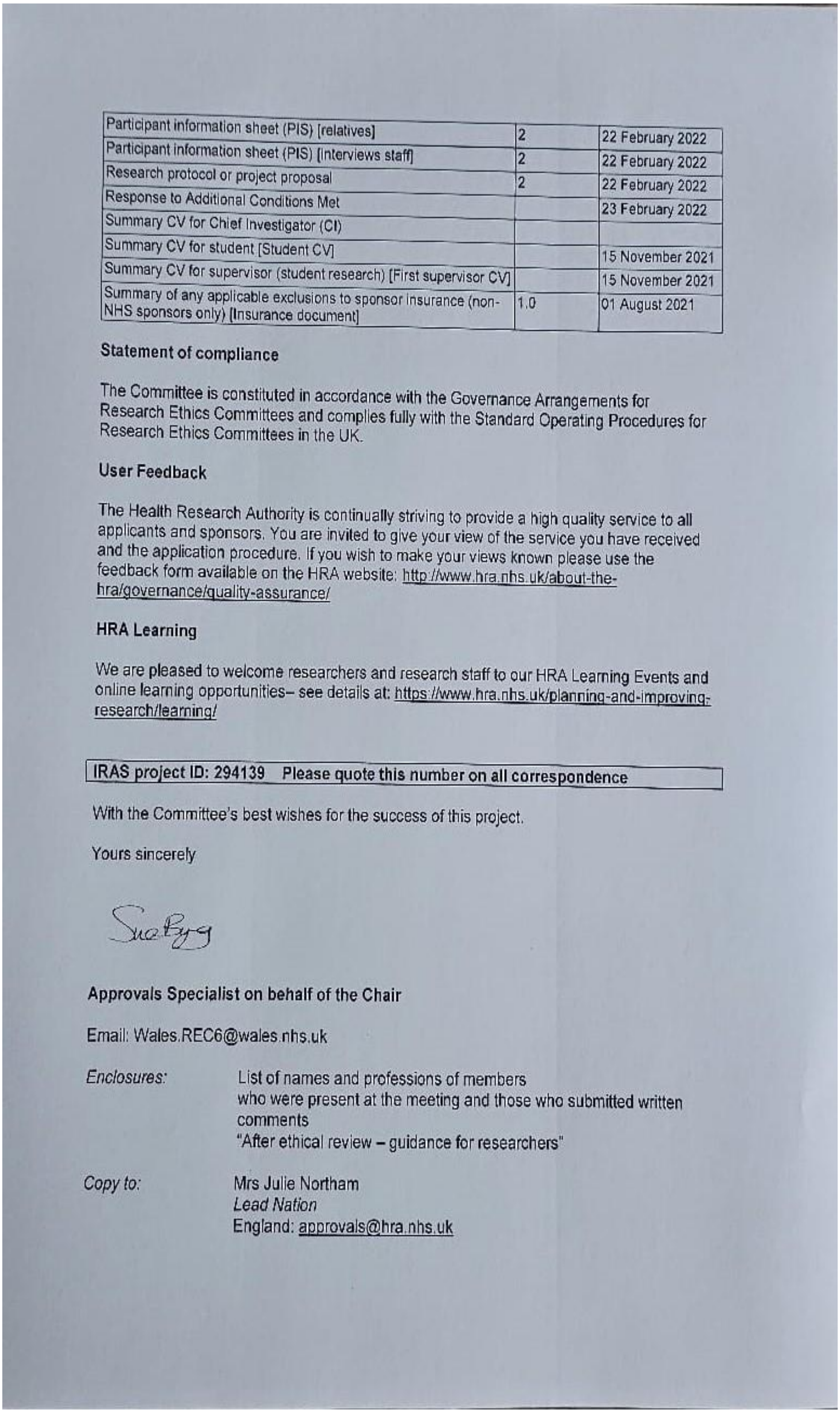
Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity certificate]		01 August 2021
Interview schedules or topic guides for participants [Interview schedule - bereaved]	1	14 November 2021
Interview schedules or topic guides for participants [FG schedule]	1	14 November 2021
Interview schedules or topic guides for participants [Interview schedule - staff]	1	14 November 2021
IRAS Application Form [IRAS_Form_24022022]		24 February 2022
Letter from sponsor [Sponsor letter]		17 November 2021
Participant consent form	2	30 January 2022
Participant information sheet (PIS) [FG]	2	22 February 2022



Participant information sheet (PIS) [relatives]	2	22 February 2022
Participant information sheet (PIS) [interviews staff]	2	22 February 2022
Research protocol or project proposal	2	22 February 2022
Response to Additional Conditions Met		23 February 2022
Summary CV for Chief Investigator (CI)		
Summary CV for student [Student CV]		15 November 2021
Summary CV for supervisor (student research) [First supervisor CV]		15 November 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance document]	1.0	01 August 2021

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 294139 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Approvals Specialist on behalf of the Chair

Email: Wales.REC6@wales.nhs.uk

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"
Copy to:	Mrs Julie Northam *Lead Nation* England: approvals@hra.nhs.uk

Appendix 2 - Participant information Sheet (Family and Close Others)

Date: 22/02/2022

Version number: version 2

IRAS: 294139

[Headed paper]

Title of study: End-of-Life Care for people with dementia in hospitals.

This study is being carried out as part of a PhD degree that the researcher, Hadeel Alhatamleh, is doing. The researcher is being supervised by a team of researchers at Bournemouth University and Yeovil District Hospital. Yeovil District Hospital has invited us to explore care at the end-of-life for people with dementia. Below we have outlined the proposed project in more detail. After reading this, if you are interested in participating, please contact Hadeel Alhatamleh (**email:** *halhatamleh@bournemouth.ac.uk*). Additional contact details can be found at the end of this document.

Title of study:

Title: End-of-Life Care for people with dementia in hospitals.

Who is funding the study?

This research study is match-funded by Bournemouth University and Yeovil District Hospital.

How has this study been reviewed?

Before commencing this study, it has been reviewed by an independent NHS research ethics committee, Wales REC 6.

Purpose of the study

The purpose of this study is to find out how to care best for people who have dementia and are approaching the end of their lives in hospital. We would like to ask you about your experiences of having someone close to you receiving end-of-life care in hospital. We are interested in exploring any aspects of care that you think are good and any aspects of care that you think can be improved. Our aim is to use the information that comes from these discussions to help hospitals to provide excellent end-of-life care for people with dementia.

Why you have been invited

You are invited because you are a family member or a close other of an in-hospital patient who died at their end-of-life stage of dementia, in ‘Yeovil District Hospital’ which has kindly offered to take part in our study. We feel it is important to include the views of family members or close others of patients in our research findings.

Do I have to take part?

You do not have to take part in the study. It is your choice. If you do decide to take part, you will be asked to sign a consent form before you take part. Also, if you do take part, you are free to stop at any point.

What will happen if I decide to take part?

The researcher, Hadeel Alhatamleh will arrange a time to meet you by phone or Skype, or in person in the hospital, your home or a place convenient to you, to discuss your experiences of end-of-life care for people with dementia in hospitals. With your permission, we would like to conduct two interviews, though you can decide to only take part in the first interview should you wish. Each interview will last a maximum of one hour. The interview will be audio recorded with your permission.

The first interview will explore your experiences of end-of-life care for people with dementia from the perspective of patients. There are no right or wrong answers; we are just interested in your views.

The purpose of this second optional interview is to present our findings to you and allow you to comment on the conclusions that we have come to after the first interview, based on personal experiences that were discussed.

Who will pay for my travel expenses (if any)?

If you wish to have a face-to-face interview in the hospital or in any place you prefer, we will pay your travel expenses.

How will my information be managed?

Researchers must make sure they write the reports about the study in a way that no one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data (i.e. recordings and transcripts) for ten years, if they need to check it. Please ask me if you want to know more about this.

Bournemouth University (BU) is the organisation with overall responsibility for this study and is the Data Controller of your personal information. This means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university. Undertaking this research study involves collecting and/or generating anonymised information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws.

BU's Research Participant Privacy Notice [1]sets out more information about how we fulfil our responsibilities as a Data Controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information. Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet.

Publication

We hope to publish the results of our work so that people involved in the care of people with dementia get to hear about our recommendations about the best way to care for them at the end of their lives when they are in hospitals. You will not be able to be identified in any external reports or publications about the research. Your information will only be included in these materials in an anonymous form (i.e., you will not use your name or any other information that might lead to you being identified). Direct quotes of what you said may be used in our publications, but they will be kept anonymised. Research results will be published in a reputable journal or a conference presentation and will be stored by the university in anonymised form for other researchers to use.

In order to contact you with the study results, your contact information will only be kept by Hadeel Alhatamleh. Your data will be held in a password protected Bournemouth University account. After contacting you, the researcher will destroy your personal information by deleting them from the Bournemouth University account it is saved in.

Security and access controls

---

[1] https://intranetsp.bournemouth.ac.uk/documentsrep/Research Participant Privacy Notice.pdf

Bournemouth University will hold the anonymised information we collect about you electronically on a password-protected secure network.

Contact information will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research, or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

Keeping your information if you withdraw from the study

You can stop being part of the study during the interview or afterwards without giving a reason, but we will keep information about you that we already have. This is because once we anonymise the information, we will not be able to tell what information came from you. We need to manage your records in specific ways for the research to be reliable. This means that we will not let you see or change the data we hold about you.

Retention of research data

Participant consent form

We will keep the signed consent form for a period of 10 years. This is the only document **can I find out more about how my information is used?**

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- the following leaflet from http://www.hra.nhs.uk/patientdataandresearch
- our Research Participant Privacy notice from https://intranetsp.bournemouth.ac.uk/documentsrep/Research Participant Privacy Notice.pdf
- by asking one of the research team
- by sending an email to DPO@bournemouth.ac.uk

What will happen to the results?

They will be compiled in a thesis and may be published in academic journals. All information presented in these documents will be non-identifiable.

How the results/findings of the study would be fed back to you?

If you are interested in receiving the results of the study, we will send you a summary of the results and invite you to attend a presentation at Bournemouth University. The summary of the results and the invitations will be sent to you via the email you provided us in the consent form. Hadeel Alhatamleh will present the results.

Will my data be used in another research?

The findings may be used to help the hospital staff care better for people with dementia.

Are there any benefits or disadvantages to taking part?

You might get upset, anxious, or stressed out during the interview as we will be discussing the sensitive topic of end-of-life care for people with dementia and their family and close others. If you become distressed, the interview will be paused or stopped. You also might be offered hospital chaplaincy end-of-life Care and will be suggested to go online for Cruse Bereavement Care on https://www.cruse.org.uk/ or contact them via phone on: 0808 808 1677. If needed, I might call the GP or the emergency.

We hope that findings from the study will help improve end-of-life care for people with dementia in hospitals across the country and internationally.

The Researchers

Hadeel Alhatamleh, Bournemouth University: PhD student

Professor Samuel Porter, Bournemouth University: Chief Investigator and Supervisor

Dr Michele Board, Bournemouth University: Supervisor

Janine Valentine, Yeovil District Hospital: Clinical Supervisor

If you have any concerns regarding this study, you can contact: Professor Sam Porter, at: *porters@bournemouth.ac.uk*

If you remain unhappy and wish to complain formally, you can contact:

Professor Vanora Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Sciences on *researchgovernance@bournemouth.ac.uk*

In respect of the Hospital, please direct your complaints to:

Yeovil District Hospital, Patient Advice and Liaison Services (PALS), Higher Kingston, Yeovil, Somerset, BA21 4AT, Tel: 01935 384706, pals@ydh.nhs.uk

Finally

A copy of this information sheet will be given to you to keep at the start of the study. You will also be given the chance to read this again and ask questions before you then sign a consent form to participate in the interviews.

Thank you for considering taking part in this research project.

Research Team Contact Details:

Hadeel Alhatamleh
PhD Student
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth University
Bournemouth
BH8 8AJ
Tel: 07479472744
Email: halhatamleh@bournemouth.ac.uk

Professor Sam Porter
Professor of Nursing Sociology
Head of Department of Social Sciences and Social Work
Bournemouth University
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth
BH8 8AJ
Email: porters@bournemouth.ac.uk

Appendix 3 - Participant information Sheet (Staff/ Focus Group).

Date: 22/02/2022

Version number: version 2

IRAS: 294139

[Headed paper]

Title of study: End-of-Life Care for people with dementia in hospitals.

This study is being carried out as part of a PhD degree that the researcher, Hadeel Alhatamleh, is doing. The researcher is being supervised by a team of researchers at Bournemouth University and Yeovil District Hospital. Yeovil District Hospital has invited us to explore care at the end-of-life for people with dementia. Below we have outlined the proposed project in more detail. After reading this, if you are interested in participating, please contact Hadeel Alhatamleh (**email:** *halhatamleh@bournemouth.ac.uk*). Additional contact details can be found at the end of this document.

Additional contact details can be found at the end of this document.

Who is funding the study?

This research study is match-funded by Bournemouth University and Yeovil District Hospital.

How has this study been reviewed?

Before commencing this study, it has been reviewed by an independent NHS research ethics committee, Wales REC 6.

Purpose of the study

The purpose of this study is to find out how to care best for people who have dementia and are approaching the end of their lives in hospital. We would like to ask you about your experiences of providing end-of-life care for people with dementia in hospital. We are interested in exploring any aspects of care that you think are good and any aspects of care that you think can be improved. Our aim is to use the information that comes from these discussions to help hospitals to provide excellent end-of-life care for people with dementia.

Why you have been invited

You are invited because you work in 'Yeovil District Hospital' which has kindly offered to take part in our study. We feel it is important to include the views of staff in our research.

Do I have to take part?

You do not have to take part in the study. It is your choice. If you decide to take part, you will be asked to sign a consent form before you take part. Also, if you take part, you are free to stop at any point. However, your information cannot be removed following commencement due to the nature of focus groups.

What will happen if I decide to take part?

The researcher, Hadeel Alhatamleh will arrange a time to visit you in the hospital to discuss your experiences of end-of-life care for people with dementia in hospitals. With your permission, we would like to conduct two focus group discussions, though you can decide to only take part in the first interview should you wish. Each interview will last a maximum of one hour. The interview will be audio recorded with your permission.

The first focus group discussion will explore your experiences of end-of-life care from the perspective of staff. There are no right or wrong answers; we are just interested in your views.

The purpose of this second optional focus group discussion is to present our findings to you and allow you to comment on the conclusions that we have come to after the first interview, based on personal experiences that were discussed.

How will my information be managed?

Researchers must make sure they write the reports about the study so that no one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data (i.e. recordings and transcripts) for ten years if they need to check it. Please ask me if you want to know more about this.

Bournemouth University (BU) is the organisation with overall responsibility for this study and is the Data Controller of your personal information. This means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university. Undertaking this research study involves collecting and/or generating anonymised information about you. We manage research data strictly in accordance with:

- Ethical requirements; and

Current data protection laws.

BU's Research Participant Privacy Notice [2]sets out more information about how we fulfil our responsibilities as a Data Controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice to fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet.

Publication

We hope to publish the results of our work so that people involved in the care of people with dementia get to hear about our recommendations about the best way to care for them at the end of their lives when they are in hospitals. You will not be able to be identified in any external reports or publications about the research. Your information will only be included in these materials in an anonymous form (i.e., you will not use your name or any other information that might lead to you being identified). Direct quotes of what you said may be used in our publications, but they will be kept anonymised. Research results will be published in a reputable journal or a conference presentation and will be stored by the university in anonymised form for other researchers to use.

In order to contact you with the study results, your contact information will only be kept by Hadeel Alhatamleh. Your data will be held in a password protected Bournemouth University account. After contacting you, the researcher will destroy your personal information by deleting them from the Bournemouth University account it is saved in.

Security and access controls

Bournemouth University will hold the anonymised information we collect about you electronically on a password-protected secure network.

Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include

---

[2] https://intranetsp.bournemouth.ac.uk/documentsrep/Research Participant Privacy Notice.pdf

giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

Keeping your information if you withdraw from the study

You can stop being part of the study during the focus group or afterwards without giving a reason, but we will keep information about you that we already have. This is because once we anonymise the information, we will not be able to tell what information came from you. We need to manage your records in specific ways for the research to be reliable. This means that we will not be able to let you see or change the data we hold about you.**Retention of research data**

Participant consent form

We will keep the signed consent form for a period of 10 years. This is the only document that has your name and signature on it. Your anonymised information and samples cannot be linked to your name on this form.

Where can I find out more about how my information is used?

You can find out more about how we use your information

- the following leaflet from http://www.hra.nhs.uk/patientdataandresearch
- our Research Participant Privacy notice from https://intranetsp.bournemouth.ac.uk/documentsrep/Research Participant Privacy Notice.pdf
- by asking one of the research team
- by sending an email to DPO@bournemouth.ac.uk

What will happen to the results?

They will be compiled in a thesis and may be published in academic journals; all information presented in these documents will be non-identifiable.

How the results/findings of the study would be fed back to you?

If you are interested in receiving the results of the study, we will send you a summary of the results and invite you to attend a presentation at Bournemouth University. The summary of the results and the invitations will be sent to you via the email you provided us in the consent form. Hadeel Alhatamleh will present the results.

Will my data be used in another research?

The findings may be used to help the hospital staff care better for people with dementia.

Are there any benefits or disadvantages to taking part?

There is the potential to get upset because the focus groups will be discussing the sensitive topic of end-of-life care for people with dementia and their family and close others. If you become distressed or upset during the project, you will have the opportunity to stop or pause the focus group. Furthermore, if you become distressed in the hospital and you still need support, the researcher will direct you to the wide range of available resources within the trust accessible online. E.g., To find support for emotional wellbeing, please go to *https://yeovilhospital.co.uk/health-and-wellbeing/*.

We hope that findings from the study will help improve end-of-life care for people with dementia in hospitals across the country and internationally.

The Researchers

Hadeel Alhatamleh, Bournemouth University: PhD student

Professor Samuel Porter, Bournemouth University: Chief Investigator and Supervisor

Dr Michele Board, Bournemouth University: Supervisor

Janine Valentine, Yeovil District Hospital: Clinical Supervisor

If you have any concerns regarding this study, you can contact: Professor Sam Porter, Chief Investigator for this study at: *porters@bournemouth.ac.uk*

If you remain unhappy and wish to complain formally, you can contact: *Professor Vanora Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Sciences on researchgovernance@bournemouth.ac.uk*

In respect of the Hospital, please direct your complaints to:

Yeovil District Hospital, Patient Advice and Liaison Services (PALS), Higher Kingston, Yeovil, Somerset, BA21 4AT, Tel: 01935 384706, pals@ydh.nhs.uk

Finally

A copy of this information sheet will be given to you to keep at the start of the study. You will also be given a chance to reread this and ask questions before signing a consent form to participate in the focus group.

Thank you for considering taking part in this research project.

Research Team Contact Details:

Hadeel Alhatamleh
PhD Student
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth University
Bournemouth
BH8 8AJ
Tel: 07479472744
Email: halhatamleh@bournemouth.ac.uk

Professor Sam Porter
Professor of Nursing Sociology
Head of Department of Social Sciences and Social Work
Bournemouth University
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth
BH8 8AJ
Email: porters@bournemouth.ac.uk

Appendix 4 - Participant information Sheet (Staff/ Semi-structured Interviews)

Date: 22/02/2022

Version number: version 2

[Headed paper]

Title of study: End-of-life Care for people with dementia in hospitals.

This study is being carried out as part of a PhD degree that the researcher, Hadeel Alhatamleh, is doing. The researcher is being supervised by a team of researchers at Bournemouth University and Yeovil District Hospital. Yeovil District Hospital has invited us to explore care at the end-of-life for people with dementia. Below we have outlined the proposed project in more detail. After reading this, if you are interested in participating, please contact Hadeel Alhatamleh (**email:** *halhatamleh@bournemouth.ac.uk*. Additional contact details can be found at the end of this document.

Who is funding the study?

This research study is match-funded by Bournemouth University and Yeovil District Hospital.

How has this study been reviewed?

Before commencing this study, it has been reviewed by an independent NHS research ethics committee, Wales REC 6.

Purpose of the study

The purpose of this study is to find out how to care best for people who have dementia and are approaching the end of their lives in hospital. We would like to ask you about your experiences of providing care for people with dementia in hospital. We are interested in exploring any aspects of care that you think are good and any aspects of care that you think can be improved. Our aim is to use the information that comes from these discussions to help hospitals to provide excellent end-of-life care for people with dementia.

Why you have been invited

You are invited because you work in ‘Yeovil District Hospital’ which has kindly offered to take part in our study. We feel it is important to include the views of staff/managers in our study of end-of-life care for people with dementia because your experiences can help impact and shape our research findings.

Do I have to take part?

You do not have to take part in the study. It is your choice. If you do decide to take part, you will be asked to sign a consent form before you take part. Also, if you do take part you are free to stop at any point.

What will happen if I decide to take part?

The researcher, Hadeel Alhatamleh will arrange a time to visit you in the hospital to discuss your experiences of end-of-life care for people with dementia in a hospital. With your permission, we would like to conduct two interviews, though you can decide to only take part in the first interview should you wish. Each interview will last a maximum of one hour. The interview will be audio recorded with your permission.

The first interview will explore your experiences of end-of-life care for people with dementia from the perspective of a member of staff/manager. There are no right or wrong answers; we are just interested in your views.

The purpose of this second optional interview discussion is to present our findings to you, allowing you to refine what we conclude based on your personal experiences of end-of-life care for people with dementia in the hospital.

How will my information be managed?

Researchers must make sure they write the reports about the study in a way that no one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data (i.e. recordings and transcripts) for ten years, in case they need to check it. Please ask me if you want to know more about this.

Bournemouth University (BU) is the organisation with overall responsibility for this study and is the Data Controller of your personal information. This means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and/or generating anonymised information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws.

BU's Research Participant Privacy Notice [3]sets out more information about how we

---

[3] https://intranetsp.bournemouth.ac.uk/documentsrep/Research Participant Privacy Notice.pdf

> fulfil our responsibilities as a Data Controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet.

Publication

We hope to publish the results of our work so that people involved in the care of people with dementia get to hear about our recommendations about the best way to care for them at the end of their lives when they are in hospitals. You will not be able to be identified in any external reports or publications about the research. Your information will only be included in these materials in an anonymous form (i.e., you will not use your name or any other information that might lead to you being identified). Direct quotes of what you said may be used in our publications, but they will be kept anonymised. Research results will be published in a reputable journal or a conference presentation and will be stored by the university in anonymised form for other researchers to use.

In order to contact you with the study results, your contact information will only be kept by Hadeel Alhatamleh. Your data will be held in a password protected Bournemouth University account. After contacting you, the researcher will destroy your personal information by deleting them from the Bournemouth University account it is saved in.

Security and access controls

Bournemouth University will hold the anonymised information we collect about you electronically on a password-protected secure network.

Contact information will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research, or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

Keeping your information if you withdraw from the study

You can stop being part of the study during the interviews or afterwards, without giving a reason, but we will keep information about you that we already have. This is because once we anonymise the information, we will not be able to tell what information came from you. We need to manage your records in specific ways for the research to be reliable. This means that we will not be able to let you see or change the data we hold about you.

Retention of research data

Participant consent form

We will keep the signed consent form for a period of 10 years. This is the only document that has your name and signature on it. Your anonymised information and samples cannot be linked to your name on this form.

Where can I find out more about how my information is used?

You can find out more about how we use your information

- the following leaflet from http://www.hra.nhs.uk/patientdataandresearch
- our Research Participant Privacy notice from https://intranetsp.bournemouth.ac.uk/documentsrep/Research Participant Privacy Notice.pdf
- by asking one of the research team
- by sending an email to DPO@bournemouth.ac.uk

What will happen to the results?

They will be compiled in a thesis and may be published in academic journals, all information presented in these documents will be non-identifiable.

How the results/findings of the study would be fed back to you?

If you are interested in receiving the results of the study, we will send you a summary of the results and invite you to attend a presentation at Bournemouth University. The summary of the results and the invitations will be sent to you via the email you provided us in the consent form. Hadeel Alhatamleh will present the results.

Will my data be used in another research?

The findings may be used to help the hospital staff care better for people with dementia.

Are there any benefits or disadvantages to taking part?

You might get upset, anxious, or stressed out during the interview as we will be discussing the sensitive topic of end-of-life care for people with dementia and their family and close others. If you become distressed, the interview will be paused or stopped. Furthermore, if you become distressed in the hospital and you still need support, the researcher will direct you to the wide range of available resources within the trust accessible online. E.g., To find support for emotional wellbeing, please go to *https://yeovilhospital.co.uk/health-and-wellbeing/*.

We hope that findings from the study will help improve end-of-life care for people with dementia in hospitals across the country and internationally.

The Researchers

Hadeel Alhatamleh, Bournemouth University: PhD student

Professor Samuel Porter, Bournemouth University: Chief Investigator and Supervisor

Dr Michele Board, Bournemouth University: Supervisor

Janine Valentine, Yeovil District Hospital: Clinical Supervisor

If you have any concerns regarding this study, you can contact: Professor Sam Porter, Chief Investigator for this study at: *porters@bournemouth.ac.uk*

If you remain unhappy and wish to complain formally, you can contact: *Professor Vanora Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Sciences on researchgovernance@bournemouth.ac.uk*

In respect of the Hospital, please direct your complaints to:

Yeovil District Hospital, Patient Advice and Liaison Services (PALS), Higher Kingston, Yeovil, Somerset, BA21 4AT, Tel: 01935 384706, pals@ydh.nhs.uk

Finally

A copy of this information sheet will be given to you to keep at the start of the study. You will also be given the chance to read this again and ask questions before you then sign a consent form to participate in the interviews.

Thank you for considering taking part in this research project.

Research Team Contact Details:

Hadeel Alhatamleh
PhD Student
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth University
Bournemouth
BH8 8AJ
Tel: 07479472744
Email: halhatamleh@bournemouth.ac.uk

Professor Sam Porter
Professor of Nursing Sociology
Head of Department of Social Sciences and Social Work
Bournemouth University
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth
BH8 8AJ
Email: porters@bournemouth.ac.uk

Appendix 5 – Consent Form

IRAS ID: 294139

Participant Identification Number for this project:

CONSENT FORM

Title of Project: A Critical Realist Evaluation of End-of-life for People with Dementia in Hospitals.

Name of Researcher: Hadeel Alhatamleh

Details of Researcher: Hadeel Alhatamleh, Post Graduate Research student (PhD), Bournemouth University, Bournemouth Gateway Building, 10 St Paul's Ln, Boscombe, Bournemouth BH8 8AJ, Email: halhatamleh@bournemouth.ac.uk

Please initial box

1. I confirm that I have read the information sheet dated................... (version...........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand and consent that I will be audio recorded during the data collection. ☐
4. I understand and consent that direct quotes of what I told the researcher would be used in the publications. ☐
5. (If appropriate) I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐
6. I agree to take part in the above study. ☐

   '1 copy for the participant, 1 copy for the file'

Name of Participant	Date	Signature
Name of Person	Date	Signature

Appendix 6 - Interview schedule – Bereaved relatives

Date: 14/11/2021

Version number: version 1

IRAS: 294139

Study title: A Critical Realist Evaluation of End-of-life for People with Dementia in Hospitals.

Details of Researcher: Hadeel Alhatamleh, Post Graduate Research student (PhD), Bournemouth University, Bournemouth Gateway Building, 10 St Paul's Ln, Boscombe, Bournemouth BH8 8AJ

Email: halhatamleh@bournemouth.ac.uk

1. Introduction

- Introduce self
- Explain the purpose of the study and this interview.
- No right or wrong answers – not a test of your knowledge, and answers are voluntary
- Consent – written because this is extra to standard care.
- Explain interview recorded, but details will be confidential. If the interview raises concerns regarding health and safety, these will be raised with senior ward staff and the research supervisory team.
- I also want to reassure you that your privacy and confidentiality will be respected in this research as your names, or any identifiable data will not be used in any publication that uses the data. However, you are the only person in a particular post there is a possibility that you could be identified even though your name will not be used.
- Questions or concerns?
- Each interview should only take 30-45 minutes. However, the interview may go on as long as you want.
- If you feel you need to stop or pause the interview, just let me know.
- Questions or concerns?
- Can you tell me about yourself? (e.g. age, sex, nature and length of relationship with the deceased)

2. Understanding of Palliative Care and End-of-life Care

- Can you tell me your understanding of End-of-Life and palliative care?

- Would you think the patients receive appropriate End-of-Life or palliative care at their last months of life during hospitalisation?

3. Needs of the patients and their close others:

- What do you think of the experience you/your relative/close other have/has had in the hospital regarding the intervention/ care provided?
- What aspects of care were important to you and your close other? What do you think were the needs of you and your close other?
- What was done appropriately in response to those needs?
- What was not done or could have been done better from your perspective? Did hospital staff involve you in eol care? If so, how?

4. Factors that may support or inhibit good practice:

- What do you think are the factors inhibited providing good End-of-Life care for you and your relative/close other in the hospital? Example…
- What do you think are the factors supported providing good End-of-Life care for you and your relative/close other in the hospital? Example…
- How do you feel the staff in the hospital responded to your and your relative/close other while providing End-of-life care for him/her?
- What do you feel should be done to improve/inhibit End-of-life care for your relative/close other?
- What things in the hospital environment, policies, facilities improved/inhibited the care for your relative/close other?
- What things in the hospital environment, policies, facilities improved/inhibited the care for you?
- What should be done in the hospital setting to improve the quality of care provided for the patients?

5. Any further questions/comments and conclude the interview

- Thank participant for the contribution.
- Check there is anything else relating to the topic that we have not covered they want to talk about.
- Check they are still happy for their information to be used in the study.

Research Team Contact Details:

Hadeel Alhatamleh
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth University
Bournemouth
BH8 8AJ
Tel: 07479472744
Email: halhatamleh@bournemouth.ac.uk

Sam Porter
Professor of Nursing Sociology
Head of Department of Social Sciences and Social Work
Bournemouth University
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth
BH8 8AJ
Tel: (0044) 1202 964107
Email: porters@bournemouth.ac.uk

Appendix 7 - Focus Groups Schedule – Staff and Managers

Date: 14/11/2021

Version number: version 1

IRAS: 294139

focus groups schedule – Staff and Managers

Study title: A Critical Realist Evaluation of End-of-life for People with Dementia in Hospitals.

Details of Researcher: Hadeel Alhatamleh, Post Graduate Research student (PhD), Bournemouth University, Bournemouth Gateway Building, 10 St Paul's Ln, Boscombe, Bournemouth BH8 8AJ

Email: halhatamleh@bournemouth.ac.uk

1. Introduction • Introduce self

- • Explain the purpose of the study and this interview.
- • No right or wrong answers – not a test of your knowledge, and answers are voluntary
- • Consent – written because this is extra to standard care.
- • Explain interview recorded, but details will be confidential. If the interview raises any concerns regarding health and safety, these will be raised with senior ward staff and the supervisory research team.
- • Questions or concerns?
- • Each focus group meeting should take no more than one hour. However, the interview may go on as long as you want.
- • You will be asked to respect your fellow interviewees privacy and not to share what is said in the interview please.
- • I also want to reassure you that your privacy and confidentiality will be respected in this research as your names, or any identifiable data will not be used in any publication that uses the data. However, you are the only person in a particular post there is a possibility that you could be identified even though your name will not be used.
- • If you feel you need to stop or pause the interview, just let me know.
- • Questions or concerns?
- • Can you tell me about yourself? (e.g., age, sex, job title, experience)

2. Understanding of Palliative Care and End-of-life Care

- Can you tell me your understanding of End-of-Life and palliative care?
- Would you think the patients receive appropriate End-of-Life or palliative care at their last months of life during hospitalisation?

3. Needs of the patients and their close others:

- What do you think of the experience of providing care for people with dementia at their End-of-Life in the hospital?
- Can you tell me about the experiences of patients with dementia and their close others of receiving end-of-life care in the hospital?
- What aspects of care do you feel are important while providing End-of-Life care for the patient?
- What do you think are the most important needs of the patients and their close others?
- How could these needs be met during hospitalisation?
- What is usually done appropriately in response to those needs?
- Are there any current practices that you think are not appropriate, concerning, or could be done better from your perspective?

4. Factors that may support or inhibit good practice:

- What do you think are the factors inhibited providing good End-of-Life care for the patients and their close others in the hospital? Example…
- What do you think are the factors that support providing good End-of-Life care for patients and their close others in the hospital? Example…
- How do you feel about how you responded to patients and their close others while providing End-of-life care?
- What do you feel should improve/inhibit you as staff from providing and sustainable End-of-life care?
- What things in the hospital environment, policies, facilities do you think improve /inhibit providing quality palliative and End-of-life care?
- How do you respond to the policy of the hospital?
- How do you personally feel about initiating conversations about End-of-Life within the team or with the patients and their close others? And what do you feel as a professional or health care provider about the need for those conversations? (if there are tensions between the answers, I will explore them further).

- What should be done in the hospital setting to improve the care provided for the patients?
- How do you feel about the communication between the staff about the patients and the care provided to them?

5. Any further questions/comments and conclude the interview

- Thank participant for the contribution.
- Check there is anything else relating to the topic that we have not covered they want to talk about.
- Check they are still happy for their information to be used in the study.

Research Team Contact Details:

Hadeel Alhatamleh
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth University
Bournemouth quality
BH8 8AJ
Tel: 07479472744
Email: halhatamleh@bournemouth.ac.uk

Sam Porter
Professor of Nursing Sociology
Head of Department of Social Sciences and Social Work
Bournemouth University
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth
BH8 8AJ
Tel: (0044) 1202 964107
Email: porters@bournemouth.ac.uk

Appendix 8 – Interview schedule – Staff and Managers

Date: 14/11/2021

Version number: version 1

IRAS: 294139

Interview schedule – Staff and Managers

Study title: A Critical Realist Evaluation of End-of-life for People with Dementia in Hospitals.

Details of Researcher: Hadeel Alhatamleh, Post Graduate Research student (PhD), Bournemouth University, Bournemouth Gateway Building, 10 St Paul's Ln, Boscombe, Bournemouth BH8 8AJ

Email: halhatamleh@bournemouth.ac.uk

1. Introduction • Introduce self

- Explain the purpose of the study and this interview.
- No right or wrong answers – not a test of your knowledge, and answers are voluntary
- Consent – written because this is extra to standard care.
- Explain interview recorded, but details will be confidential. If the interview raises any concerns regarding health and safety, these will be raised with senior ward staff and the supervisory research team.
- Questions or concerns?
- Each interview should only take 30-45 minutes. However, the interview may go on as long as you want.
- I also want to reassure you that your privacy and confidentiality will be respected in this research as your names or any identifiable data will not be used in any publication that uses the data. However, you are the only person in a particular post there is a possibility that you could be identified even though your name will not be used.
- If you feel you need to stop or pause the interview, just let me know.
- Questions or concerns?
- Can you tell me about yourself? (e.g. age, sex, job title, experience)

2. Understanding of Palliative Care and End-of-life Care

- Can you tell me your understanding of End-of-Life and palliative care?
- Would you think the patients receive appropriate End-of-Life or palliative care at their last months of life during hospitalisation?

3. Needs of the patients and their close others: • What do you think of your experience of providing care for people with dementia at their End-of-Life in the hospital?

- Can you tell me about the experiences of patients with dementia and their close others of receiving end-of-life care in the hospital?
- What aspects of care do you feel are important while providing End-of-Life care for the patient?
- What do you think are the most important needs of the patients and their close others?
- How could these needs be met during hospitalisation?
- What is usually done appropriately in response to those needs?
- Are there any current practices that you think are not appropriate, concerning, or could be done better from your perspective?

4. Factors that may support or inhibit good practice:

- What do you think are the factors inhibited providing good End-of-Life care for the patients and their close others in the hospital? Example…
- What do you think are the factors that support providing good End-of-Life care for patients and their close others in the hospital? Example…
- How do you feel about how you responded to patients and their close others while providing End-of-life care?
- What do you feel should improve/inhibit you as staff from providing quality and sustainable End-of-life care?
- What things in the hospital environment, policies, facilities do you think improve /inhibit providing quality palliative and End-of-life care?
- How do you respond to the policy of the hospital?
- How do you personally feel about initiating conversations about End-of-Life within the team or with the patients and their close others? And what do you feel as a professional or health care provider about the need for those conversations? (if there are tensions between the answers, I will explore them further).
- What should be done in the hospital setting to improve the care provided for the patients?

- How do you feel about the communication between the staff about the patients and the care provided to them?

5. Any further questions/comments and conclude the interview

- Thank participant for the contribution.
- Check there is anything else relating to the topic that we have not covered they want to talk about.
- Check they are still happy for their information to be used in the study.

Research Team Contact Details:

Hadeel Alhatamleh
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth University
Bournemouth
BH8 8AJ
Tel: 07479472744
Email: halhatamleh@bournemouth.ac.uk

Sam Porter
Professor of Nursing Sociology
Head of Department of Social Sciences and Social Work
Bournemouth University
Bournemouth Gateway building, 10 St Paul's Ln
Bournemouth
BH8 8AJ
Tel: (0044) 1202 964107
Email: porters@bournemouth.ac.uk

Appendix 9- Lone working policy

Title: Lone Working Policy

Keywords: Alone, Remote, Unaccompanied, Health and Safety

Description: Guidance on Lone Working

Publish Date: 1st July 2015

Policy Owner: Karen Parker

Audience: Staff

10.1.1 Lone Working Policy – Bournemouth University

It is the University's responsibility under the Health & Safety at Work Act 1974 to ensure, so far as is reasonably practicable, the Health and Safety if its employees and individuals undertaking activities when working alone.

This policy deals both with individuals who may be required to work by themselves on or off campus or who work outside normal working hours on campus unaccompanied or without immediate access to another person/s for assistance. Also, any individual (e.g. student) undertaking fieldwork, or practical projects without direct supervision and who are exposed to a significant risk of the hazards associated with lone working.

'Normal Working Hours' are defined as the University's core working hours 08:30 – 17:00 Monday to Friday, with 'Out of Hours' defined as anytime outside of the University's normal working hours, including weekends and all public holidays.

In most instances the University considers the carrying out of normal office work to be low risk, especially where there is ready access to either a land phone or mobile phone which an individual can use to summon assistance – either using the '222' emergency number, or the equivalent external line number (01202) 9 62222.

Working alone by definition means there will be no direct supervision and/or contact. As with other health and safety risks, BU policy therefore requires this to be proactively managed by carrying out a risk assessment of activities (particularly where there are identified risks) and adopting safe working arrangements to control risks.

Apart from ensuring individuals are sure that they are capable of doing the job/activity safely on their own, it is also important that managers ensure:

- That lone working is considered in all risk assessments carried out in their area of responsibility, and that appropriate formal records are kept.
- Lone working is avoided wherever possible.

- The lone worker knows about the hazards & risks present in the work to be undertaken, and the controls to be followed to reduce the risk.
- The lone worker knows what to do if something goes wrong.
- The lone worker is instructed to formally report any incident.
- Someone else knows the whereabouts of a lone worker and what he or she is doing.
- Consideration is given to the need for effective communication systems for assistance to be summoned.

Individual responsibilities include.

- Avoiding lone working wherever possible (outside of a normal working environment).
- Comply with all control measures as identified through the risk assessment.
- Ensure that agreed control measures are adhered to, and that plans are not deviated upon without prior agreement, or the knowledge of a manager.

Risk Assessments

The assessment of the risks to which a lone worker may be exposed must take into account and consider:

- An individual's ability to carry out their activities safely on their own.
- The potential for the individual to be subject to violence or allegations of inappropriate behaviour.
- The individual's ability to request assistance or to withdraw safely from a volatile situation.
- The individual's fitness or ability to work alone.
- Sudden illness or emergency (e.g., accidents, ability to raise the alarm).
- Effects of social isolation
- Fire safety and/or access to fire protection
- Any existing precautionary measures and emergency arrangements.

This list is not intended to be exhaustive; every situation is different and individual controls for those situations must be considered based on their own merits.

Examples of control measures for lone working include:

- Prevention of lone working wherever possible.
- 'Buddy' systems
- Suitable training

- Suitable emergency equipment and emergency arrangements
- Adequate supervision
- Defined work activities and working processes, including written safe systems of work

Abbreviations

ACP - Advance Care Planning

CR - Critical Realism

CRR- Critical Realist Review

CRE - Critical Realist Evaluation

DNACPR – Do Not Attempt Cardiopulmonary Resuscitation

EHR - Electronic Health Records

EoL - End-of-life.

EoLC - End-of-life Care.