How nurses manage the transition to comfort-focused care for dying people in the acute hospital setting – A focused ethnography

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

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Abstract

Background

Comfort-focused care refers to when all treatment and interventions prioritise the comfort of the dying person instead of the focus being on investigations and interventions to prolong life. A delayed transition to comfort-focused care may leave little time to plan and implement high quality end-of-life care in line with the dying person's wishes and values. As well as increased suffering experienced by the dying person, a delay in transition to comfort-focused care is associated with moral distress in nurses.

In many countries around the world the majority of people die in hospital. Nurses spend more time directly caring for dying people than other healthcare professionals. However, little is known about how nurses manage the transition to comfort-focused care for dying people in acute settings.

To begin this study, I conducted a systematically constructed literature review. The review question was: *How do clinicians recognise people who are dying and what are the factors that influence this recognition?* Recognising dying is an essential step in the transition to comfort-focused care. I selected an integrative review methodology to guide the literature review. This enabled the inclusion of a range of research designs, including both qualitative and quantitative research. The analysis and synthesis produced three main categories: 'Clues and signals', 'Recognition by others', and 'Culture, system and practice'. There were also three sub-categories: 'Knowing the patient over time', 'Intuition and experience', and 'Uncertainty'. The findings of this review informed and guided the empirical research that followed.

Aim

To understand how the culture of the acute setting shapes how nurses manage transitions to comfort-focused care for dying people.

Methodology and methods

A focused ethnography design guided the research. The setting was two acute medical wards in a UK National Health Service hospital. Registered nurses were the focus of the research. Data collection methods included observation and interviews. Observation focused on general ward activity, individual participants and ward events such as handover meetings and ward rounds. The combination of observation and interviews meant I could study the experiences and perceptions of participants alongside examining their practice in the particular cultural context. I purposively sampled observational episodes and individual participants. Individual participants were required to give formal consent, otherwise there was an opt-out process in place for all others in the setting. I carried out 144 hours of observation, over 32 episodes, and 20 participant interviews. To analyse the data, I adopted an inductive approach. The analytical steps included: coding for descriptive labels, sorting for patterns, identification of outliers or negative cases, generalising with constructs and theories, memoing and making note of insights and ideas. Throughout the research process I was consciously reflexive and took account of my own positionality.

Findings

I constructed six themes to explain how nurses manage the transition to comfort-focused care for dying people within the culture of an acute setting. I named these themes: Denial, Competing priorities, Discomfort, Moral dissonance, Nurse agency and Delay. The transition to comfort-focused care occurred within a culture where dying was not openly talked about. There was a tension between curative care and end-of-life care, and dying people were deprioritised. There was also a conflict between a task-oriented approach and person-centred care, with the task-oriented approach dominating. The transition to comfort-focused care was emotionally burdensome for nurses, especially when care conflicted with their beliefs and values. Nurses were disempowered in the transition process, and their ability to influence the transition was limited. These factors contributed to a delay in a change to a comfort-focused approach, which often occurred very close to the time of death.

Conclusion

The transition to comfort-focused care was often a fraught and stressful process until the official recognition of dying by a doctor. It was a complex process with many influencing factors. The change to comfort-focused care often happened abruptly and close to the time of death.

Glossary

- **Acute medical ward**: wards that admit acutely unwell patients over the age of 16 years with non-surgical conditions.
- **Active treatment**: medical treatments and interventions with the aim of prolonging life.
- **Comfort-focused care**: refers to where the care and all treatment prioritise the comfort of the patient at the end of life, rather than the primary aim of care being to prolong life (Meeker et al., 2019).
- **Dying**: in the context of this research dying refers to the last days or hours of life.
- **End-of-life care**: in the context of this research end-of-life care refers to the care of dying people in the last days or hours of life.
- **Internationally educated nurses**: nurses who have trained outside the UK and have registered with the Nursing and Midwifery Council in the UK.
- **National Early Warning Score (NEWS):** a system for identifying acutely ill patients by scoring physiological measurements at the patient's bedside (Royal College of Physicians, n.d).
- **Palliative care**: an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (World Health Organization, 2020).
- **Registered Nurses**: nurses who have undergone an approved educational programme and are regulated by the Nursing and Midwifery Council in the UK as Registered Nurses. This title is protected in UK law.

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Chapter 1. Introduction

1.1 Background

Defining comfort-focused care

Comfort-focused care refers to when all treatment and interventions are intended to prioritise the comfort of the dying person instead of the focus being on interventions and investigations that are potentially burdensome with the goal of prolonging life (Meeker & White, 2021). Transition to comfort-focused care involves a realisation that deterioration is irreversible and dying is inevitable. This realisation allows important conversations between clinicians, patients and families so that appropriate care can be planned in line with the patient's wishes and values. A timely and successful transition to comfort-focused care for dying patients can enable high-quality end-of-life care (Meeker et al., 2019). This is not only important for the dying person but also for families, as their experiences of end-of-life care can impact their bereavement (Mason et al., 2020).

Dying in hospital

In many countries around the world more people die in hospital than in any other setting (Cohen et al., 2015; Koyama et al., 2020; Seitz et al., 2022). In the UK 43% of all deaths occur in hospital (Office for Health Improvement and Disparities, 2024). In 2022, data from the UK revealed 69% of individuals who died spent time in hospital during the six months prior to their death, and 61% experienced an emergency admission to hospital in the last three months of life. Additionally, 50% of people over the age of 85 years in hospital were in the last year of life (Office for Health Improvement and Disparities, 2024). These statistics highlight the importance of hospital care at the end of life. Despite the drive to reduce deaths in hospitals there will always be a place for end-of-life care in hospital, for example, for people with acute exacerbations of chronic conditions and complications of advanced illness, or where there is a lack of suitable care at home or in care homes (Gott et al., 2011; Marie Curie, 2019; Reid et al., 2015). Therefore, there is a continuing imperative for high quality end-of-life care, both to minimise suffering and to ensure the best possible quality of life until the moment of death.

In recent years, end-of-life care in hospitals has been the subject of much criticism and is also a major theme in healthcare complaints (Care Quality Commission, 2016; Committee on Approaching Death: Addressing Key End of Life Issue, 2015; Neuberger et al., 2013; Parliamentary and Health Service Ombudsmen, 2015). End-of-life care in hospitals presents challenges, including the competing priorities of curative care with its accompanying investigations and interventions, alongside the needs of dying patients (Chan et al., 2018). Organisational constraints can impact the quality of end-of-life care. These constraints include lack of continuity of care due to factors such as shift systems and doctors' rotations, and lack of time. Environmental constraints, such as lack of space and privacy, and noise, also negatively impact the quality of end-of-life care and can increase suffering (Bakken et al., 2023; Gagnon & Duggleby, 2014; Green et al., 2023).

Recognising dying

Acknowledging recovery is uncertain and death is a possibility is an integral part of the process of transition to comfort-focused care. Recognising dying is known to be challenging even for experienced clinicians (Gibbins et al., 2009; Qureshi et al., 2018). However, it is an essential step in the transition to comfort-focused care (Department of Health, 2008; Leadership Alliance for the Care of Dying People, 2014). Recognising dying is complex, and there is a limited evidence base to support the decision-making process (Taylor et al., 2017). It is an iterative process of information gathering rather than a decision which is made at a particular point in time (Taylor et al., 2017). When dying is recognised it is often close to the time of death. Contributing to the difficulty is that signs of dying may be attributed to other causes, and clinicians may have difficulty differentiating between acute deterioration and dying (Bloomer et al., 2013). A patient's diagnosis is an important factor influencing the recognition of dying. Recognising dying in patients with non-malignant conditions, for example, heart failure or respiratory disease, can present additional challenges as the disease trajectories are often less predictable than in cancer (Flierman et al., 2019; Taylor & Johnson, 2011). Late recognition of dying may result in the continuation of interventions and treatments that can increase or prolong suffering (Gibbins et al., 2009; Green et al., 2023; Gunasekaran et al., 2019). This can result in a delayed transition to comfort-focused care and reduced quality of the remaining life.

Ethical and moral challenges

End-of-life care is known to cause ethical challenges for healthcare professionals, for example in decisions about artificial hydration, terminal sedation and the withdrawal or withholding of treatments (Akdeniz et al., 2021). Ethical challenges can be exacerbated by poor communication, lack of resources, differences in opinion and patient distress (Georges & Grypdonck, 2002; Rittenmeyer & Huffman, 2009; Young et al., 2017). There may be tensions between doctors and nurses around decisions about the goals of care. Nurses can experience frustration and moral challenges if they are required to carry out active treatments when they feel a palliative approach is required (Glaser & Strauss, 1968; Long-Sutehall et al., 2011; Thompson et al., 2006). This can cause nurses moral or ethical distress in their efforts to do what they believe is right. Moral distress is described as arising when an individual recognises the morally correct course of action but is prevented from following it due to institutional constraints (Jameton, 2013). A recent study found levels of moral distress are higher when the quality of end-of-life care provided is perceived as poor by clinicians (Spence et al., 2023). End-of-life care is known to be a major cause of moral distress for nurses, and the continuation of futile interventions and the witnessing of suffering as a result of these are important contributory factors (Wiegand & Funk, 2012).

Doctor-nurse relationship

The cultural and historical subordination of nurses still impacts the doctor-nurse dynamic today. This presents as a power differential between doctors and nurses, which has consequences for patient care (Bloomer et al., 2013; Lupton, 2012). Poor collaboration between doctors and nurses can impede the quality of end-of-life care, whereas when the relationship is more collegial, this positively influences nurses' experiences of caring for dying people (Gagnon & Duggleby, 2014). Studies have also shown there can be uncertainty as to which profession is responsible for recognising dying, with nurses believing it is not their responsibility and therefore being reluctant to inform doctors when they think a patient is dying (Flierman et al., 2019; Reid et al., 2015). Nurses may instead use strategies such as indirectly and subtly negotiating with doctors in order to influence end-of-life care (Coombs et al., 2012; Long-Sutehall et al., 2011; McMillen, 2008). This reflects the doctor-nurse game described by Stein (1967). In this 'game', nurses make recommendations or plant ideas in such a way they appear to come from the doctor. Over fifty years on, this is still relevant. It is important to recognise and understand this interplay, as ineffective communication between doctors and nurses contributes to the delay in transition to comfort-focused care.

In order for there to be a shift in focus from active treatment to comfort-focused care, there needs to be consensus within the multi-disciplinary team that the patient is dying (Meeker et al., 2019; Thompson et al., 2006). Research in intensive care units has highlighted issues and difficulties around achieving consensus (Coombs et al., 2012). Consensus requires negotiation of complex decision-making processes as well as time, which also may contribute to delay in the transition to comfort-focused care. Recognising dying involves recognising the futility of active treatment. However, research has shown nurses are more likely to link futility with dying than doctors (Coombs et al., 2012).

Uncertainty

A cultural fear of uncertainty is known to impact appropriate decision-making and timely transitions to comfort-focused care (Pattison et al., 2018). Medical conditions that have more unpredictable trajectories are associated with more uncertainty, as it is more challenging to identify irreversibility. Clinicians use a strategy of ‘buying time’ in order to gather cues and information to support clinical decision-making and to determine whether a condition is reversible (Pattison et al., 2018). However, this can result in limited time and opportunity for end-of-life care planning and for focusing on quality of life. Uncertainty is intrinsic and inevitable in navigating the complexities of clinical medicine and healthcare. Indeed, some have argued uncertainty in recognising dying should be explicitly acknowledged, and rather than aiming to remove uncertainty, focus should be given to incorporating it into decision-making (Kennedy et al., 2014; Malterud et al., 2017). Indeed, Fox (2000), who first wrote about uncertainty in the 1950’s, argues that even with scientific and clinical advancements, uncertainty will always remain integral to the practice of medicine.

Cultural context and impact

Dying is a normal part of the life continuum. However, in westernised countries, it has largely become medicalised and positioned within a biomedical model. It is defined as a problem (Kaufman, 2005). Medicalisation removes the social and cultural aspects of dying (Helman, 2007). The concept of person-centred care continues to be prominent within healthcare, meaning treatment is not only based on biomedical factors but also on other considerations such as patient choice and benefits balanced against over-treatment (Mackintosh & Armstrong, 2020). However, advancements in medical technology and treatments have continued alongside, meaning it is increasingly possible to contain and control illnesses, delay dying and, to some extent, determine the timing of death (Kaufman, 2005). This creates a tension between what is possible, what should be done (a moral or value judgement) and patient choice. Friedrichsen et al. (2021) suggest there is a clash between the curative culture of the acute setting and palliative care and that this brings challenges in balancing the different needs of patients within a biomedical culture.

Hospitals reflect the values, perspectives and beliefs of the wider culture they are situated within (Van der Geest & Finkler, 2004). However, inevitably individual clinicians will bring their own cultural influences and perspectives into the hospital. There is an iterative and dynamic cultural relationship between wider society and the hospital (Chapple, 2010). Hospitals are themselves microsocieties with their own cultures, which include expected behaviours, hierarchies, gender roles, rituals and even their own ‘dialect’, for example terminology, jargon and acronyms, all within their own historical contexts (Helman, 2007). Indeed, there are cultures within different professions, and each ward will have its own culture influenced by the leadership and speciality (Braithwaite et al., 2017; Nelson et al., 2020).

Transition to comfort-focused care – a developmental transition

The transition to comfort-focused care is complex and often difficult. However, a timely and successful transition can mean treatments which have little benefit and increase suffering are avoided. The time when a person moves to the last stage of life has been described as a developmental transition or status passage, from one life stage to another (Glaser & Strauss, 1968; Meeker et al., 2019; Meleis et al., 2000). Meeker et al. (2019) suggest reframing the transition to comfort-focused care as a developmental transition where goals are refocused and quality of life is prioritised, rather than as medical failure.

1.2 Focus of empirical research

The purpose of my research was to explore how nurses manage the transition to comfort-focused care for dying patients in acute hospital settings. In the context of this research, ‘dying’ refers to the last days or hours of life, and the term ‘nurse’ refers to registered nurses. I chose to focus on registered nurses as they spend more time directly caring for dying people than other healthcare professions. Therefore, the role of nurses in recognising dying and the subsequent shift in approach and goals of care is likely to be highly influential (Bloomer et al., 2013). To improve end-of-life care in acute settings, further research is needed to understand the nurse’s role in navigating the transition to comfort-focused care in the culture of the acute hospital setting.

1.3 Research question

The research question underpinning this study was:

How does the culture of the acute hospital setting shape how nurses manage the transition to comfort-focused care for dying people?

My objective was to explore the roles, perceptions and attitudes of nurses’ working within acute hospital settings regarding the transition to comfort-focused care for people who are dying.

1.4 Underpinning philosophical position

A constructionist paradigm underpinned the research. Constructionism challenges ‘taken for granted’ assumptions about how we categorise the world (Burr, 2015). Indeed, the concept of transition to comfort-focused care is itself a social construction. From a constructionist perspective, all knowledge is produced through interaction with the world and does not assume one reality. This research aligns with constructionism, as my interaction as researcher with the participants, and within the context of the setting, was central to the construction of knowledge (Braun & Clarke, 2013; Guba & Lincoln, 1994). For this reason, it was essential to recognise and acknowledge my own positionality in this research and to adopt a reflexive approach throughout the research process.

1.5 My background and positionality in the research

I am a palliative care nurse by professional background, currently working as a consultant nurse in a district general hospital with many similarities to the hospital where I carried out my research. I lead a hospital specialist palliative care team which has a supportive and advisory role across all adult inpatient areas. In my hospital, there are doctors and nurses who are highly motivated and skilled in caring for dying people. However, factors such as high turnover of staff, lack of staff and the intensity of the workload present challenges to consistently maintaining a workforce that is both confident and skilled in end-of-life care. Despite the good intentions and care and compassion of most nurses, my experience is that end-of-life care can be problematic and not always of the high standard we would wish it to be.

I witness the stress and difficulties encountered by the doctors and nurses when there is uncertainty about whether a patient will recover, and there are often different, conflicting opinions about the correct course of action. Witnessing the stress, tension and sometimes distress of nurses before a comfort-focused approach is initiated has motivated me to undertake this research to unpack and understand the process.

In my experience, nurses receive little, if any, formal education in end-of life care during their pre-registration education and many are very uncomfortable when they encounter dying patients on the wards. My role, and the role of the palliative care team I lead, is to empower clinicians through role modelling, support and advice, and education. However, in order to meet their needs, it is necessary to understand their experiences and perspectives. This was part of my motivation to carry out this research.

The usual response and 'go to' solution for dealing with issues and required improvements is to provide additional training and education. This approach appears to identify the individual clinician or clinicians as the root of the problem, with the solution entirely in their hands. However, it is clear to me there are other organisational and cultural factors contributing to the challenges of end-of-life care in hospitals. Therefore, alternative strategies may need to be explored.

Within the hospital walls and in the lives of the clinicians, including myself, who work within them, life-or-death situations and the range of human experience from birth to death are our everyday, our 'taken for granted' norm. Hence, we become part of the culture. However, as a palliative care nurse, I am only transiently present on the wards. This separates my experience from that of the ward nurses, who are a more constant presence. They do not have my specialist status, or that of the rest of the palliative care team, with the authority and agency this specialist status brings. A factor in my choice of an ethnographic approach was to see and experience the process of transition to comfort-focused care with 'fresh eyes', to better understand the perspectives and experiences of the ward nurses.

1.6 Structure of thesis

Including this introduction, this thesis consists of five chapters. Chapter 2 is a systematically constructed integrative review of the literature (Whittemore & Knafl, 2005). This method facilitated the inclusion of evidence from a range of methodologies so that a breadth of perspectives could be gained. This helped situate this research by highlighting gaps and contextual factors that impact and influence the recognition of dying, an essential stage in the transition to comfort-focused care. In Chapter 3, I begin by examining the philosophical underpinnings of the research and the rationale for the chosen methodology – focused ethnography. I then describe research methods in detail. In Chapter 4, I present the findings, which include six themes that explain how nurses manage the transition to comfort-focused care and the factors that influence this: Denial, Competing priorities, Discomfort, Moral dissonance, Nurse agency and Delay. In Chapter 5, I discuss my research findings within a broader context and in relation to existing research. Next, I discuss the research’s strengths and limitations, followed by the contributions to knowledge and my recommendations for policy, practice and future research. The discussion ends with my final thesis conclusion.

Chapter 2. How clinicians recognise people who are dying: An integrative review

2.1 Introduction

This literature review was published in the International Journal of Nursing Studies. The published version is reproduced in Appendix 1:

Colquhoun-Flannery, E., Goodwin, D., & Walshe, C. (2024). How clinicians recognise people who are dying: An integrative review. *International Journal of Nursing Studies*, *151*, 104666–104666. https://doi.org/10.1016/j.ijnurstu.2023.104666

The version I present here is largely identical but has some additional explanatory and justificatory content.

The main aim of the literature review was to explore how clinicians caring for dying people recognise they are in the last days or hours of life and the factors that influence this recognition. Recognising dying is an integral and essential step in the transition to comfort-focused care. I decided to include all clinicians and all settings in order to explore the wider context influencing the recognition of dying. A secondary aim was to identify any gaps in the literature. The findings of this literature review helped to situate the focus, methodology and methods of the empirical research that followed.

2.2 Methods

2.2.1 Review question

How do clinicians recognise people are dying and what are the factors that influence this recognition?

2.2.2 Design

I wanted to answer the review question by paying particular attention to the breadth and depth of clinicians' perspectives. This required a review design that could accommodate a range of study designs, including qualitative and quantitative studies, to enable a comprehensive and holistic understanding. I was interested in the knowledge, perceptions and behaviours of clinicians as well as measurable factors.

I ruled out designs such as meta-ethnography and thematic synthesis as they do not accommodate quantitative research (Noblit & Hare, 1988; Thomas & Harden, 2008). I considered a critical interpretive synthesis design as it can incorporate different study designs. However, I also ruled this out as the aim of critical interpretive synthesis reviews is theory development (Depraetere et al., 2021; Dixon-Woods et al., 2006). I chose an integrative review design as it can accommodate diverse designs and can enable capturing the complexity and breadth of perspectives (Hopia et al., 2016). The wide sampling frame of integrative reviews enables a more complete picture that can have applicability to policy and practice (Hopia et al., 2016; Whittemore & Knafl, 2005). I selected the integrative review design developed by Whittemore and Knafl (2005), which outlines explicit and systematic methods for each stage of the review to enhance the rigour and transparency of combining diverse designs. It has five stages: problem identification; literature search; data evaluation; data analysis and presentation of findings.

Given the aims of this review, I adopted a constructionist approach to the synthesis. In the context of this literature review, knowledge is constructed in particular social and cultural contexts, and static and complete knowledge is not possible, aligning well with constructionism (Burr, 2015). The review protocol is published with PROSPERO (CRD42022360900), registered September 2022. I used the Enhancing Transparency in Reporting the Synthesis of Qualitative Research checklist as a guide to help ensure the review is comprehensively and transparently reported (Tong et al., 2012).

2.2.3 Search strategy

Predefined inclusion and exclusion criteria enabled the identification of relevant literature. See Table 2.1

Table 2.1. Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Population of interest: Clinicians – paid staff who provide direct health and social care including doctors, nurses, allied health professionals, healthcare assistants and care workers. Dying refers to when a person is thought to be in the last days or hours of life.	Papers exploring the recognition of dying of persons under the age of 18 years.
Phenomenon of interest: How clinicians recognise that a person is dying, and what influences this recognition.	Papers focusing on the transition from curative treatment to palliative care. Studies about development of prognostication tools unless include data about how clinicians recognise dying.
Any setting	
Dates of publication: from 2012 to July 2022.	
Empirical studies of any design	Systematic reviews, review articles and opinion articles. The reference lists of any such papers identified in the search were interrogated to identify papers that met the inclusion criteria.
Full text available	
Papers written in English or translation available	

A literature review exploring how clinicians diagnose dying was published in 2014 (Kennedy et al., 2014). It included papers published between the years 2001 and 2011. This informed my decision to only include literature published from 2012 in this review.

The aim of the search was to identify all relevant papers. I used subject or MeSH headings when available, enhanced by free text terms related to end-of-life care. The search strategy was adapted from the search filters developed by Rietjens et al. (2019) and tailored to each database. Guidance was given by Lancaster University information specialists. Search strings combined variations of the following search terms and subject headings. See Table 2.2.

Table 2.2. Search terms

Search terms		
Palliative Care Terms		Decision making terms
(MH "Palliative Care" OR MH "Terminal Care" OR MH "Hospice and Palliative Care Nursing" OR MH "Palliative Medicine" OR MH "Terminally Ill" OR MH "Hospice Care") OR "end of life care" OR "end-of-life care"	AND	(recogni* OR diagnos* N4 "end of life" OR end-of-life OR death OR dying) OR (MH "Decision Making" OR MH "Clinical Decision-Making" OR MH "Prognosis" OR MH "Diagnosis" OR MH "Attitude to Death")

I searched five databases: Medline, Scopus, Cumulative Index to Nursing and Allied Health Literature, PsycInfo and Allied and Complementary Medicine Database. I selected these databases as together they incorporate nursing, medical, psychological and sociological literature. I performed the searches in July 2022. Detailed search strings are presented in Appendix 2. I also examined the reference lists of included papers to check for further potential papers. In addition, while reviews identified in the search did not form part of the included papers, I examined the reference lists of such reviews for potentially relevant papers (Bruun et al., 2022; Eychmüller et al., 2013; Kennedy et al., 2014). I also performed backward citation tracking (Zwakman et al., 2018).

2.2.4 Data evaluation

I imported search results to Endnote to assist in managing the large number of references and to record where and when database references had been found. I used Rayyan software to remove duplicates and to manage screening and selection of papers. Firstly, I screened titles and abstracts to exclude papers that obviously did not meet the inclusion criteria. A second reviewer screened 10% of the papers. Petticrew and Roberts (2008) suggest a second reviewer screens 10% of papers to help ensure papers are not missed and inclusion/exclusion criteria are not misapplied. There was 100% agreement between the reviewer and me on the papers to be included, excluded and those where there was uncertainty. I obtained full text of papers that were not excluded through screening of titles and abstracts and examined them to confirm their relevance to the review question. A proportion (10%) of full text articles were also screened by the second reviewer. I performed the appraisals and analysis of included papers with oversight and discussion with my supervisors. I discussed any uncertainties with my supervisors to reach consensus.

2.2.5 Quality appraisal

Quality appraisal of diverse designs introduces greater complexity as different designs use different criteria that indicate quality (Whittemore & Knafl, 2005). I selected the Hawker tool to appraise the quality of included papers as it is suitable for use in methodologically diverse studies (Hawker et al., 2016). Tools can help guide the assessment of quality and the relevance of papers; the Hawker tool enabled this sufficiently (Booth et al., 2016). I used the Hawker tool to appraise each paper fairly and consistently using nine criteria. I assigned a quality score to each criterion with an overall maximum score of 36 points. No paper was excluded based on methodological quality or assigned scores, I did, however, consider the impact of the strength or weaknesses of studies on my analysis and synthesis (Aveyard et al., 2021). l appraised all papers, bar two, as high quality. I appraised the remaining two as medium quality. However, these papers had no major flaws that would negatively affect the review findings and I judged them to be of sufficient quality to include in the review. See Appendix 3 for details of appraisal of included papers.

2.2.6 Data analysis

I adopted a constant comparison approach to convert data into categories and to identify patterns, themes, relationships and variations (Charmaz, 2006; Whittemore & Knafl, 2005). This method is recommended by Whittemore and Knafl (2005) as it enables analysis of a variety of data from diverse methodologies. It consists of four phases:

Data reduction: I mainly extracted data from the finding sections of papers. However, presentation of findings can vary; hence, I also found relevant data in abstracts and discussion sections. Some articles presented data pertaining to non-clinicians and different timeframes, but I only extracted data that met the inclusion criteria. I coded papers line by line using NVIVO. Initially, I coded qualitative and quantitative data separately. As the majority of the data were qualitative, I coded qualitative data first, followed by quantitative data. Qualitative data explained and confirmed quantitative data. I used NVIVO for the organisation and structure of developing concepts and categories.

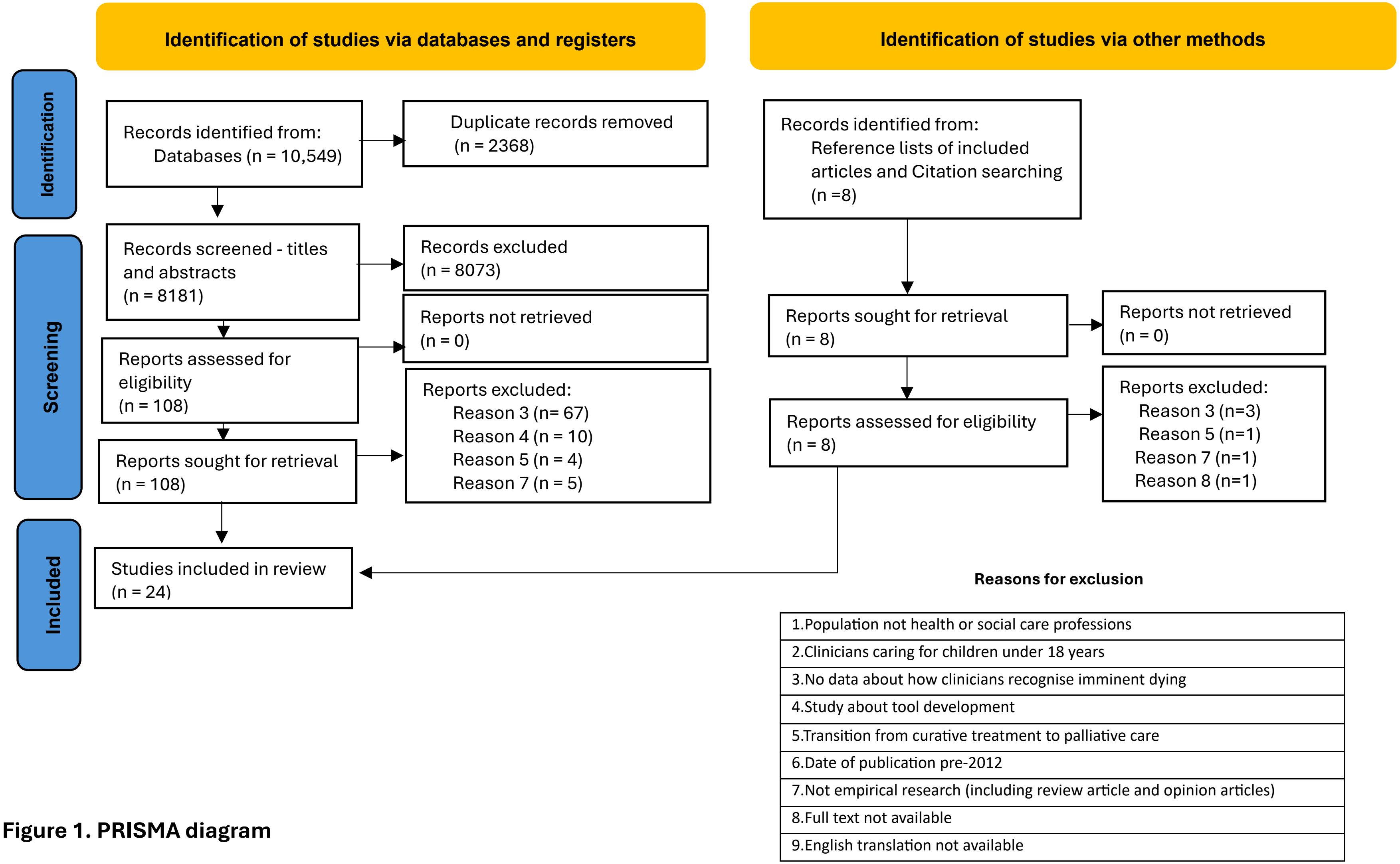
Data display: I displayed data extracts in tables to indicate how I developed categories and sub-categories across sources and designs. I interrogated data to understand if there were patterns depending on setting and clinician type. However, the heterogeneity across studies precluded meaningful within-setting or clinician type analysis.

Data comparison: An iterative process of data comparison to identify patterns, themes or relationships to develop a conceptual map. I compared and integrated codes from quantitative data with codes from qualitative data. See Appendix 4. To enable quantitative data to be incorporated into a synthesis with the qualitative data, I coded relevant data from the narratives in findings sections of quantitative papers (and other sections as applicable). Data comparison was an iterative process that involved categorising and grouping and going back and forth through the data as codes, categories and concepts were developed and refined (Charmaz, 2006). Pearson et al. (2015) suggest converting quantitative data into qualitative data is more reliable and less subject to errors than assigning numerical values to qualitative data. I discussed developing concepts and categories with my supervisors and checked them for accuracy against the original papers.

Conclusion drawing and verification: An inductive process of moving from description of patterns, themes and relationships to a higher level of abstraction. I verified all patterns, categories and concepts with the primary data sources to ensure accuracy (Miles et al., 2018). I discussed interpretations with my supervisors, and any differences were explored until consensus was reached.

2.3 Results

Twenty-four papers met the inclusion criteria and were included in the synthesis. The review process is illustrated in the Prisma diagram below. See Figure 1.



Reasons for exclusion

1.Population not health or social care professions
2.Clinicians caring for children under 18 years
3.No data about how clinicians recognise imminent dying
4.Study about tool development
5.Transition from curative treatment to palliative care
6.Date of publication pre-2012
7.Not empirical research (including review article and opinion articles)
8.Full text not available
9.English translation not available

Figure 1. PRISMA diagram

2.3.1 Data summary of selected papers

Details of the 24 papers that met the inclusion criteria are summarised in Appendix 5. There were six quantitative papers, three mixed methods papers and 15 qualitative papers. Of the 15 qualitative papers, most involved some form of individual or group interview approach; only two involved observation. The quantitative papers included one Delphi study, four retrospective surveys and one prospective observational study. The main focus of 10 papers was how clinicians recognise dying. The remaining papers were partly about how clinicians recognise dying or about end-of-life care more generally. Relevant data only were extracted.

Terms used to describe dying varied, for example, dying state, impending death and imminent dying. Only four papers specifically gave a timeframe for dying, however, a timeframe of the last few days or hours of life was clearly inferred by the remaining papers.

All studies were based in western countries: UK (n=10), Australia (n=3), Canada (n=2), New Zealand (n=1), European countries (n=6), USA (n=1), multi-country study (n=1). Study participants ranged from doctor only (n=6), nurse only (n=2), allied health professionals only (n=1), assistant nurses only (n=1), to mixed professional groups (n=14). Of the 14 mixed professional groups all included nurses, ten included doctors, five included healthcare/care assistants and five included various allied health professionals. Participants in four studies also involved volunteers, residents and family members. Only data pertaining to clinicians were extracted. There were 13 studies in the acute setting, five in long-term care facilities, one in a geriatric rehabilitation setting and four were survey studies which included participants from multiple types of settings.

2.3.2 Findings

The analysis and synthesis produced three main categories: Clues and signals; Recognition by others; and Culture, system and practice.

2.3.2.1 Clues and signals

Clues and signals refer to the prompts and signs that lead a clinician to suspect or believe a person is dying. These include physical signs, as well as psychological signs and changes in behaviour. There was considerable variation in the range of signs, symptoms, tests and observations that prompted clinicians to recognise dying (Domeisen Benedetti et al., 2013; Taylor et al., 2017; Vrijmoeth, Christians, Festen, Groot, Tonino, et al., 2016), and the evidence associating these signs with the time of death is sparse (Taylor et al., 2017). Clues and signals of dying that featured prominently across studies included breathing changes, reducing consciousness, reduced oral intake, skin changes and 'general deterioration' which includes reducing mobility and general function. See Table 2.3 for a presentation of the clues and signals a clinician perceives via sensory information - mainly visual, auditory, or tactile.

Table 2.3. Sensory signals and clues

	Participants profession	Breathing changes	Levels of consciousness	Reduced/no oral intake	General deterioration/ function	Skin changes	Agitation/restlessness/emotional changes	Fatigue/ lethargy
Signals and clues from quantitative data								
Domeisen Benedetti et al. (2013)	1,2,4		✓	✓	✓	✓	✓	
Vrijmoeth et al. (2016)	1		✓	✓	✓		✓	✓
Waldrop et al. (2022)	3	✓				✓		
White et al. (2018)	1	✓			✓ (Palliative performance scale)	✓	✓	
Signals and clues from qualitative data								
Åvik Persson et al. (2018)	2,3,4	✓	✓	✓		✓	✓	
Cable-Williams and Wilson (2014)	2,3,4	✓	✓	✓		✓		✓
Cowey et al. (2015)	1,2,4	✓	✓					
Gerber et al. (2022)	1,2,3	✓	✓	✓	✓	✓	✓	
Sahlberg-Blom et al. (2013)	2	✓		✓	✓	✓	✓	✓
Taylor et al. (2017)	1,2	✓	✓	✓	✓	✓		
Van Der Werff et al. (2012)	2	✓	✓	✓	✓	✓	✓	✓

Key: Doctors =1, Nurses =2, Allied Health professionals =3, Psycho-social professionals =4

Many studies identified breathing changes as a strong sign of dying (Åvik Persson et al., 2018; Domeisen Benedetti et al., 2013; Gerber et al., 2022; Van Der Werff et al., 2012). Clinical measurements such as oxygen saturation, blood pressure and blood tests were not widely used in recognising dying and were only found to be influential in three studies (Cowey et al., 2015; Taylor et al., 2017; Van Der Werff et al., 2012). Across papers many different terms were used to describe similar clues or signals, for example breathing change descriptions included Cheyne Stokes or irregular breathing (Åvik Persson et al., 2018; Domeisen Benedetti et al., 2013; White et al., 2018), noisy secretions (Domeisen Benedetti et al., 2013; Sahlberg-Blom et al., 2013; White et al., 2018) and shortness of breath (Gerber et al., 2022; Waldrop et al., 2015). Skin changes were variously described as mottling (Cable-Williams & Wilson, 2014; Waldrop et al., 2015), peripheral cyanosis (White et al., 2018) and cold extremities (Domeisen Benedetti et al., 2013).

Behavioural and psychological changes such as fatigue, withdrawal, existential distress, restlessness and agitation were also commonly described (Cable-Williams & Wilson, 2014; Domeisen Benedetti et al., 2013; Sahlberg-Blom et al., 2013; White et al., 2018). There is no definitive list of visible signs that inevitably indicate dying, as often such signs also arise in reversible illnesses, have low specificity for dying within hours or days, and their observation can depend on context and the experience, knowledge and role of the clinician (Taylor et al., 2017).

One study found the palliative performance scale, which measures functional status and decline, was the most influential factor in how palliative medicine doctors recognised dying (White et al., 2018). However, prognostic tools and prompting questions were not generally considered helpful and were rarely used (Cable-Williams & Wilson, 2014; Gerber et al., 2022). Although most clinicians knew about the 'surprise question', "Would you be surprised if this patient died within the next 12 months/ 6 months/ this admission?", only geriatricians found it useful. Nurses and allied health professionals did not use it due to lack of confidence (Gerber et al., 2022). Also indicative of differences between professional groups, was that doctors were more likely to use clinical information such as trajectory, diagnosis and changes in clinical measurements, for example observations and blood tests, in recognising dying. However, nurses and other clinicians relied on more visual clues, such as skin changes, but struggled to describe these (Gerber et al., 2022).

Context, such as care setting and type of clinician, was also a factor found to influence the clues and signals that alerted clinicians to the possibility a person may be dying. For example, one study found learning disability physicians identified more signs compared to general practitioners. However, the learning disability physicians had received more palliative care education and were generally caring for people with more severe learning disability (Vrijmoeth, Christians, Festen, Groot, van der Heide, et al., 2016). Another example of contextual differences is in a study involving emergency pre-hospital clinicians. It was found the most common signs indicating imminent dying were apnoea, shortness of breath and skin mottling (Waldrop et al., 2015). However, breathing difficulty, which is closely associated with apnoea and shortness of breath, is a prompt for emergency interventions, and the training and focus of emergency care clinicians are the management and stabilisation of acute illness and resuscitative measures. These factors may account for differences in the importance of reported signs.

Knowing the person over time

A sub-category of clues and signals is *knowing the person over time*. Unfamiliarity with a person contributes to late recognition of dying (Reid et al., 2015) and knowing the person over a period of time, in both acute settings and long-term care settings, is a supporting factor (Bloomer et al., 2018; Cable-Williams & Wilson, 2014; Lee et al., 2017; Taylor et al., 2017). See Table 1, Appendix 6, for excerpts illustrating this sub-category. In long-term care settings 'knowing' the person was as a result of close relationships built over time, meaning staff recognise small changes in behaviour that differ from the person's norm (Åvik Persson et al., 2018; Fryer et al., 2016; Lee et al., 2017; Sahlberg-Blom et al., 2013). These changes could be subtle and multifaceted and include physical, social, psychological and existential changes, requiring close attention and knowledge of the person in order to be noticed (Åvik Persson et al., 2018). However, one study found that in long-term care settings, daily contact with residents may make recognising incremental changes more difficult compared to clinicians with more occasional contact (Cable-Williams & Wilson, 2014). Subtle signs could be vague and harder to define, such as facial changes, an expression, or a different smell (Sahlberg-Blom et al., 2013; Van Der Werff et al., 2012). Similarly, a positive association was found between more frequent physician visits and recognition of dying in people living in long-term care settings (Oosterveld-Vlug et al., 2019). This suggests increased frequency of visits, and by implication, knowing the patient over time, is conducive to recognition of dying. The amount of time spent with patients is related to seniority and profession, often with nurses, healthcare assistants and junior doctors spending most time with patients (Reid et al., 2015; Sahlberg-Blom et al., 2013; Taylor et al., 2017). However, paradoxically, as discussed in the next category, it is the senior doctors who are expected to confirm a patient is dying (Bloomer et al., 2013).

Recognising dying is an iterative process of seeking more information (Gerber et al., 2022; Taylor et al., 2017; Taylor et al., 2020). It occurs over time rather than being a decision at one particular point in time (Taylor et al., 2017). Information used, especially by experienced clinicians, includes response to treatment, manner and rate of change, clinical deterioration and reversibility (Cowey et al., 2015; Taylor et al., 2017). This suggests recognising dying and patient management are not separate processes or mutually exclusive (Taylor et al., 2020). However, in one study in nursing home settings, dying was not seen as a process but rather as an event or a ‘happening’, and this could result in recognition of dying being delayed (Åvik Persson et al., 2018). In another study in long-term care settings, recognition of dying was described as a two-stage process, the first characterised by generalised awareness of mortality in old age and the inevitability of death and the second being when clinicians noticed changes indicating imminent death. Generalised awareness was not associated with dying and was not accompanied by active seeking of information to inform decision-making (Cable-Williams & Wilson, 2014).

Intuition and experience

Recognition of subtle signs is associated with a further subcategory of *intuition and experience*, see Table 2, Appendix 6. Intuition plays a prominent role in recognising dying (Domeisen Benedetti et al., 2013; Gerber et al., 2022; Taylor et al., 2017). It is described as a ‘gut feeling’ and is presented as participants not being able to describe what they are seeing and how they came to know (Bloomer et al., 2013; Sahlberg-Blom et al., 2013; Taylor et al., 2017; Van Der Werff et al., 2012). In hospital settings, clinicians described recognition of dying as being predominantly an intuitive process which they found difficult to communicate to others in the team (Gerber et al., 2022; Taylor et al., 2017). Clinicians were aware of their intuition being founded on experience (Gerber et al., 2022; Johnson et al., 2014). This included recognising patterns which they could match to their experience of previous patients (Morrison & Forbes, 2012; Taylor et al., 2017). Junior doctors who had undertaken a dedicated palliative care post found this experience increased their expertise in recognising dying (Morrison & Forbes, 2012).

However, lack of feedback on the accuracy of their assessment after a patient had been discharged limited the opportunity to learn from experience (Gerber et al., 2022).

2.3.2.2 Recognition by others

In addition to dying being recognised by individual clinicians, to enable clarity of goals and a change in focus of care, a consensus is needed by the team involved in the patient's care (Bloomer et al., 2018; Cowey et al., 2015; Morrison & Forbes, 2012; Vrijmoeth, Christians, Festen, Groot, Tonino, et al., 2016). See Table 3, Appendix 6, for excerpts illustrating this category. Recognition of dying by others can be a consequence of a cascade effect. This could be described as secondary recognition, as someone has already recognised the patient is dying. For example, an individual clinician who recognises dying will communicate their assessment in some way and, in doing so, alert other clinicians to the possibility a patient is dying. A study of emergency pre-hospital clinicians' perceptions of end-of-life care illustrates how clinicians come to recognise someone is dying through the context of care. It was found they were prompted in their awareness of dying by hospice involvement (Waldrop et al., 2015). Use of tools, such as care pathways or treatment limitation forms, was how some clinicians were made aware a patient was dying (Bloomer et al., 2018; Cable-Williams & Wilson, 2017; Lee et al., 2017; Taylor et al., 2017). Opioid administration, a care plan, or a symbol outside the room to indicate a dying patient are also examples of contextual changes in care prompting others to recognise dying (Cable-Williams & Wilson, 2014; Cable-Williams & Wilson, 2017; Johnson et al., 2014; White et al., 2018).

> *In the absence of clear information to inform their understanding, participants described other ways in which they could ascertain when a patient might be deteriorating towards death, or what other members of the treating team, such as medical staff, might think,*

> *including relying on documents (such as treatment limitation form) in the medical record that were not intended to be the first indicator that a patient was dying (Bloomer et al., 2018, p.1621)*

As well as recognition being prompted by other clinicians and changes in context of care, patients themselves may purposefully signal they think they are dying (Gerber et al., 2022; Sahlberg-Blom et al., 2013; Taylor et al., 2017; Van Der Werff et al., 2012). At times this was explicitly verbalised by patients expressing their readiness to die (Cable-Williams & Wilson, 2014; Sahlberg-Blom et al., 2013; Van Der Werff et al., 2012). Gerber et al. (2022) found clinicians were also influenced in their recognition of dying by the views of families.

Effective communication within the team is essential for recognition of dying patients, though this can be challenging (Bloomer et al., 2018). Opportunities for communication include discussion with the larger team, for example in handover meetings, as well as with individual colleagues (Lee et al., 2017; Morrison & Forbes, 2012; Redman et al., 2017; Taylor et al., 2017). Newly qualified doctors perceived handover meetings and 'accurate and specific' documentation in the clinical records as being particularly helpful (Redman et al., 2017). Written documentation was an important means of communicating between teams when a patient is dying (Gerber et al., 2022; Lee et al., 2017; Redman et al., 2017; Reid et al., 2015). However, poor documentation can be a barrier with unclear and ambiguous language leading to uncertainty and reluctance to make decisions (Bloomer et al., 2018; Gerber et al., 2022; Reid et al., 2015).

Nurses in acute settings can find it difficult to differentiate between deteriorating patients, where there is potential for reversibility, and patients who are dying. Nurses frequently recognise dying first but depend on doctors for confirmation. This can contribute to curative management continuing until dying is confirmed (Bloomer et al., 2013; Gerber et al., 2022), with senior doctors making the final decision despite knowing the patient less well (Cable-Williams & Wilson, 2014; Reid et al., 2015; Taylor et al., 2017). However, Reid et al. (2015) found doctors believed it was a nurse's role to recognise dying as nurses spend more time with patients, revealing a lack of clarity and uncertainty as to whose role it is. Similarly, in long-term care settings palliative measures could also be delayed until a doctor confirms dying (Cable-Williams & Wilson, 2014; Johnson et al., 2014).

Nurses used several strategies to inform other clinicians when they felt dying was not being recognised by the treating team. These strategies ranged from seeking support from senior nurses, writing their assessments and opinions in notes, as well as escalating to medical emergency teams (Bloomer et al., 2018). This reveals intrinsic challenges nurses have in communicating a person may be dying and implies cultural influences, which are explored in the next category. However, doctors also rely on nurses and other clinicians to identify dying, and senior doctors consult with other members of the clinical team to gain the information needed (Cowey et al., 2015; Gerber et al., 2022; Morrison & Forbes, 2012; Vrijmoeth, Christians, Festen, Groot, Tonino, et al., 2016). This suggests a co-dependency between members of the team for dying to be recognised, but with doctors being the author of the final decision.

2.3.2.3 Culture, system and practice

Underpinning the process of recognising dying by both individual clinicians and by the clinical team are the culture, system and practice of the care setting; see Table 4, Appendix 6 for data excerpts illustrating this category. Cultural beliefs influence awareness of dying, including deeply held beliefs that some settings, such as long-term care settings, are for living and not dying (Cable-Williams & Wilson, 2017). This leads to resistance to acknowledging a person is dying. Clinicians found it challenging to unambiguously name dying, using words such as ‘decline’ as a way of softening the impact (Cable-Williams & Wilson, 2014; Cable-Williams & Wilson, 2017; Johnson et al., 2014). There is also a strong belief in the importance of recognising dying so people do not die alone or in pain, so someone can be with the dying person and palliative measures implemented (Cable-Williams & Wilson, 2017). This reveals an inherent conflict between a culture of denial of dying and death as a possibility and the high value placed on attentive, high-quality end-of-life care.

In acute settings, a culture of denial was particularly apparent. This led to an avoidance of directly referencing death and dying, with the use of euphemisms such as ‘guarded prognosis’ and ‘not appropriate for escalation’ (Gerber et al., 2022). Medical and nursing staff across a range of grades perceived there was a culture of active management in which dying was rarely openly discussed. This led to the avoidance of explicitly acknowledging dying. Some doctors referred to requiring courage to openly declare someone is dying, and not actively managing a patient was seen by some as ‘letting them die’ (Reid et al., 2015). Higginbotham et al. (2021) found some doctors perceived to recognise dying was failure and therefore this justified continuing curative treatment.

> *Staff explained that the hospital culture was rarely to discuss or acknowledge death or dying and to treat all patients actively, assuming that active treatments and investigations are always in a patient’s best interest. Some spoke of the ‘bravery’ required to state that a patient was dying (Reid et al., 2015, p.492)*

Cultural differences between different specialities within acute settings were found to influence the decision-making process of recognising dying (Redman et al., 2017; Reid et al., 2015; Taylor et al., 2017). Junior doctors perceived surgical specialities as being particularly poor for recognising dying (Redman et al., 2017). In addition, it was found senior doctors' attitudes towards end-of-life care varied, which junior doctors found challenging and influenced their decision-making as they felt obliged to concur with the senior doctor's decisions (Reid et al., 2015).

System and practice in acute settings were found to impact the recognition of dying. This included the intensity and pace of the work (Bloomer et al., 2013), the need to vacate beds for new admissions and the movement of patients to different wards (Gerber et al., 2022; Reid et al., 2015). These factors could result in staff being unfamiliar with patients, consequently impacting their ability to recognise dying.

> *System pressures also played a role, especially in hospital settings where there is often a perceived mantra of active treatment and high pressure to vacate beds to free up space for new admissions (Gerber et al., 2022, p.13)*

Shift systems also meant doctors could be unfamiliar with patients, resulting in doctors not having the confidence or information needed to recognise dying. Frequency and timing of senior doctors' reviews and ward rounds were found to contribute to delayed recognition of dying as both nurses and doctors looked for confirmation by senior doctors (Bloomer et al., 2013; Reid et al., 2015). Senior doctors could feel they were not familiar enough with patients to be confident in recognising dying, which meant it may not happen at all (Reid et al., 2015). This often resulted in the continuation of futile treatment, sometimes despite nurses' distress or discomfort. An absence of attempts to influence the focus of care revealed a culture of passivity amongst nurses (Bloomer et al., 2013), though Reid et al. (2015) found nurses continued to request patient reviews.

In one study, nurses and allied health professionals made surreptitious attempts to influence a better outcome for the patient by being deliberately slow to assess patients for residential care so they could remain in hospital rather than be transferred only to survive for a short time (Gerber et al., 2022). Indirect and circuitous ways of communicating with other clinicians point to a hierarchy that was seen across settings. Hierarchy was also apparent by the contributions of healthcare assistants being undervalued, leading to negative consequences for the recognition of dying (Fryer et al., 2016). In one study, junior doctors found their role in recognising dying to be unclear and at times this part of their role was not recognised by others (Redman et al., 2017). A hierarchical dynamic was present between doctors, allied health professionals and nurses but also between different grades of nursing staff and between nurses and healthcare assistants (Bloomer et al., 2018; Fryer et al., 2016; Gerber et al., 2022; Redman et al., 2017).

Uncertainty

Uncertainty and the impact it has on recognition of dying and subsequent care is threaded throughout the findings of this review, see Table 5, Appendix 6. In several studies and across different settings, the need to be certain and the absence of the possibility of reversibility was found to be a contributary factor in late recognition of dying (Cable-Williams & Wilson, 2014; Higginbotham et al., 2021; Reid et al., 2015; Taylor et al., 2017).

> *In heart failure patients this lack of certainty in recognizing dying and referring them for palliative care often delayed the patient's transfer and consequently the patient died unnecessarily in a hospital bed. The cardiology doctors often referred to this as being the 'vicious cycle' (Higginbotham et al., 2021, p.3148)*

In long-term care settings, although clues and signals of dying were viewed as 'ominous', they were not seen as predictors of dying (Cable-Williams & Wilson, 2014). This was explained by having prior experience of witnessing residents who 'rallied to life' when death had seemed certain. Johnson et al. (2014) described unpredictability in long-term care facility residents as 'bounce back' – where they are thought to be near to certain death one day only to improve significantly on other days. Dying was not acknowledged if there was any possibility of a 'rally', however, this often resulted in late recognition.

In acute settings, as well as uncertainty around whose role it is to recognise dying, several studies found lack of confidence was a barrier to openly voicing recognition of dying (Gerber et al., 2022; Higginbotham et al., 2021; Reid et al., 2015). In the UK, a care plan for dying people known as the Liverpool Care Pathway was discontinued following controversy and concerns about its use (Neuberger et al., 2013). In one study, it was found a lack of clear guidance following the discontinuation of the Liverpool Care Pathway had contributed to a lack of confidence in recognising dying (Higginbotham et al., 2021). When a patient had been fit and well prior to admission to hospital, clinicians found it particularly hard to acknowledge a patient was dying (Reid et al., 2015). As well as the difficulty in differentiating between reversible deterioration and dying (Bloomer et al., 2018; Bloomer et al., 2013), contributing to uncertainty is the variability of signs and symptoms indicating dying and the varying trajectories of different conditions (Higginbotham et al., 2021; Johnson et al., 2014; Lee et al., 2017; Taylor et al., 2017).

> *Several of the nurses noted that marking 'the turning point' is difficult and that the combination of signs and symptoms may differ from patient to patient. Hence, nurses may feel uncertain about how to diagnose the onset of the dying phase (Van Der Werff et al., 2012, p.148)*

Clinicians use multiple strategies in order to recognise dying (Cowey et al., 2015; Gerber et al., 2022; Lee et al., 2017; Taylor et al., 2017). This can, however, be challenging, especially when there are conflicting messages received from patient documentation, other team members and from the patient themselves (Gerber et al., 2022).

2.4 Discussion

The findings of this synthesis are that timely recognition of dying matters as it enables the focus of care to be adjusted, meaning futile and potentially burdensome interventions are avoided. Despite similarities in clues and signals associated with dying across studies, there is no definitive list that indicates, or is exclusive, to the last few days or hours of life. In addition, they may also be associated with signs of reversible illness and the absence of these clues and signals does not rule out dying (Chu et al., 2019). These factors contribute to uncertainty. Further prospective studies are needed to validate the accuracy of clinicians' perceptions of the clues and signals indicating the last days or hours of life. However, uncertainty is intrinsic to recognising dying and should be incorporated into decision-making.

Potentially, tools can support the nuanced and subtle ways clinicians predict the onset of dying with more objective measures. A UK report into the Liverpool Care Pathway recommended more use of evidence-based tools for recognising dying and further research into their development (Neuberger et al., 2013). A number of validated prognostic tools have been developed; however, few have been shown to be better than clinical prediction alone in determining when death will occur. This is despite research showing clinicians' predictions tend to be inaccurate and overestimate survival (Chu et al., 2019). Many of these tools have been developed for prognostication in advanced cancer and therefore may have less applicability to patients with non-malignant conditions. However, it is suggested the palliative performance scale is the most suitable for predicting the last days of life (Chu et al., 2019). The iterative nature of recognising dying over time has implications for the use of tools which are used at a particular point in time (Taylor et al., 2017). Whereas Kennedy et al. (2014) recommended acknowledging the inherent uncertainty associated with recognising dying, a new finding is that repeated measures whilst acknowledging uncertainty may improve their use in practice. In long-term care settings, staff may not recognise dying until very late and view dying as an event rather than a process. However, on questioning, it was found staff were able to report earlier clues and signals that could be indicative of dying (Åvik Persson et al., 2018), therefore, using tools at repeated time points may be helpful to support staff in recognising dying. In addition, prospectively designed studies are required in order to develop tools to provide objective methods for the recognition of dying, used alongside intuition and clinical judgement.

Intuition is an important contributor to how clinicians recognise dying, and this was evident in all settings. Intuition is known to increase with experience (Melin-Johansson et al., 2017). Knowing the patient over time and the quality of the relationship between the clinician and patient is also an important factor in making intuitive judgements and has been found to enable identification of changes in patients' conditions (Melin-Johansson et al., 2017; Smith et al., 2004). In acute settings, it was found clinicians used a combination of intuition and more methodical and analytical reasoning, reflecting dual process theory (Pelaccia et al., 2011; Reid et al., 2015; Taylor et al., 2017). These two components of decision-making are not competing but are both integral and parallel parts of a holistic process (Sicora et al., 2021). Uncertainty, lack of confidence and beliefs about whose role it is to recognise dying may also undermine intuition and prevent it from being used to its full potential. However, in the included papers, intuition was not validated by the actual death of the patient. In retrospective studies clinicians would have been aware of the outcome (death), and therefore confirmation bias may have influenced their perceptions and views. Further prospective longitudinal studies are also required to investigate the accuracy of clinicians' intuition.

As well as recognition of dying by individual clinicians, there must be recognition and consensus by the team looking after the patient to enable a change in the approach to care. Effective communication is essential in facilitating the process of recognising dying. However, it is evident in the findings of this review that there are inherent challenges to this. Though Kennedy et al. (2014) allude to cultural influences on recognising dying, this review gives further depth and insight into how cultural, organisational and system factors impact recognising dying. Dying is not openly talked about, and euphemisms and ambiguous language are used to describe it (Cable-Williams & Wilson, 2014; Cable-Williams & Wilson, 2017; Gerber et al., 2022). In addition to dying not always being directly referred to in documentation (Bloomer et al., 2018; Gerber et al., 2022; Reid et al., 2015), challenges included inadequate opportunities for face-to-face communication and organisational factors such as timing of senior ward rounds (Bloomer et al., 2013; Reid et al., 2015). Written documentation has an important role in communication between clinicians that a patient is dying (Gerber et al., 2022; Lee et al., 2017; Redman et al., 2017; Reid et al., 2015). Using standardised documentation and terminology may help improve this. Nurses' difficulty in differentiating between acute deterioration and dying means they wait for doctors to confirm dying (Bloomer et al., 2013; Reid et al., 2015). Generally, confirming dying is not within nurses' scope of practice. Along with lack of confidence, uncertainty and a knowledge deficit, this may contribute to nurses not attempting to influence the focus of care until confirmation by a doctor. In addition, the contributions of clinicians who have lower status within health and care settings are not listened to, suggesting a hierarchical culture (Bloomer et al., 2018; Fryer et al., 2016; Gerber et al., 2022; Redman et al., 2017). This is important because it can lead to futile treatment and interventions and delay a change in the focus of care. Despite this, a co-dependency exists in recognising dying between different professional groups and different levels of seniority within professions; for example, senior doctors rely on nurses and junior doctors as they are more familiar with patients (Cowey et al., 2015; Gerber et al., 2022; Morrison & Forbes, 2012; Vrijmoeth, Christians, Festen, Groot, Tonino, et al., 2016).

The cultural context and beliefs of the setting also impact the individual clinician, for example, doctors can feel they are somehow responsible for the death of a patient by recognising dying or believe to recognise dying equals failure (Higginbotham et al., 2021; Reid et al., 2015). Nurses can feel distressed when treatment and interventions continue despite their belief a person is dying (Bloomer et al., 2013; Reid et al., 2015). These factors suggest that support for clinicians in recognising dying needs to extend beyond learning how to do it or tool development. Clinicians need to be empowered in a supportive cultural climate that acknowledges dying as a possibility.

Kennedy et al. (2014) found contextual factors such as diagnosis and experience of the clinician influence the recognition of dying. However, this review gives further insight into contextual factors such as profession and seniority of the clinician, type of setting and knowing the patient over time. System pressures and organisational factors, and the subsequent effects on end-of-life care, are an inherent problem for recognition of dying. Contributing to this problem is that end-of-life care is not the main focus and may not be openly acknowledged as a role of the setting at all, despite patients commonly dying in these settings. These factors contribute to the intrinsic uncertainty in recognising dying. Subsequent to the review by Kennedy et al. (2014), acknowledging uncertainty and incorporating it into decision-making remains an issue. Reflecting the findings of Kennedy et al. (2014), this suggests rather than placing emphasis on recognising dying, recognising the possibility of dying is likely to be more helpful. This switch in emphasis embraces the possibility of recovery and allows for uncertainty.

2.5 Strengths and Limitations

This review has several strengths. The search strategy was comprehensive, and methods have been recorded in detail, which will allow replicability. The inclusion of diverse designs allowed the review question to be comprehensively explored. The findings from the qualitative and quantitative papers reflect each other and consistent patterns were found in the data.

There are also some limitations, including the varying definitions of terms such as ‘end of life’ and ‘imminent dying’ that do not consistently refer to the same timeframe (Hui et al., 2014). Inconsistent terminology added a challenge to searching the literature and determining relevance to the review question. However, where it was not possible to determine this from the title and abstract, the full text was obtained. Although there was 100% congruence between the reviewers in the screening of papers, a greater proportion reviewed by the second reviewer may potentially have reduced any bias. Most qualitative studies involved either interviews or a combination of interviews and focus groups. More studies involving observation would add more depth and perspective to the understanding of how clinicians recognise dying. Furthermore, prospective longitudinal studies are needed to investigate the accuracy of clinicians’ intuition and their perceptions of clues and signals indicating dying.

All studies were based in developed westernised countries meaning perspectives of clinicians in other cultures and countries may not be represented.

2.6 Conclusion

Through undertaking an integrative review and synthesis of the literature, I have gathered evidence on how clinicians recognise dying, including influencing factors. Clinicians recognise dying using a combination of intuition and an analytical, objective process over time. Other factors include communication within the team and various contextual influences. However, further research is needed to validate clinicians' intuition and perceptions of the clues and signals indicating dying with the eventual outcome (death). A cultural landscape where dying is not acknowledged or talked openly about contributes to late recognition of dying. Further research is also needed into how clinicians recognise dying in different contexts such as care setting, profession and diagnosis.

Organisational changes are required to support recognition of dying, such as improving opportunities for senior review of patients thought to be dying. Written documentation has an important role in communication between clinicians that a patient is dying and using standardised terminology to talk about dying may help with this. There is an imperative for consistent terminology to be used when referring to the last days and hours of life - not only in the clinical and care settings but also by researchers and in study reports so the findings can be more easily assessed by the reader.

Further research is needed into the development and use of prognostic tools that use measurable and objective parameters to support clinicians' intuition, as well as research into the use of tools in varying trajectories associated with different conditions. Tools that assist with specifically determining the likelihood of the last few days or hours of life are also needed. However, a focus on the possibility of dying that acknowledges and tolerates inevitable uncertainty would be more helpful to clinicians in recognising dying than the seeking of absolute certainty.

Recognising the role of clinicians in different professions and levels of seniority and formally acknowledging their role in recognising dying would help to empower staff. Nurses spend more time directly caring for patients than other healthcare professionals and so are well positioned to recognise dying. Therefore, acknowledging their role and supporting them to do this is vital.

The findings from this review shaped my chosen methodology and the methods used in the subsequent empirical research. The complexity and challenges clinicians face in recognising when a patient is dying, with multiple influencing factors at play, were highlighted in the review. Since recognising dying is a critical step in the transition to comfort-focused care, I sought to explore this process further within the broader context of the transition to such care. This focus guided my approach during data collection, both in the development of my interview topic guide and my observations, with an emphasis on understanding the role of nurses within the culture of the acute care setting.

Additionally, the importance of interactions and professional dynamics between clinicians and different professional groups as key factors influencing the recognition of dying was highlighted in this review. In light of this, I focused on examining how nurses interacted with one another and with other members of the clinical team. The influence of the culture of the setting on both beliefs and practices was also revealed in the review. This reinforced and justified my decision to adopt an ethnographic approach.

Chapter 3. Philosophical approach, methodology and methods

3.1 Introduction

In this research, I explore how nurses working in acute hospital settings manage the transition to comfort-focused care for people who are dying. In this context I aimed to unpack the challenges nurses face in shifting away from an interventionist approach and towards comfort-focused care. In this chapter, I outline the philosophical underpinnings of the design of this research and my rationale for selecting focused ethnography as the methodological approach. I describe the population, sample and recruitment methods, data collection and data analysis methods. I also discuss the role of reflexivity and my positionality as researcher, ethical considerations and risk, as well as data management. Finally, I address research quality and measures I took to ensure the quality and integrity of the research.

3.2 Philosophical approach

Consistency and congruency of the philosophical underpinnings of the research and throughout the research process is essential, from the research question through to methodology and methods. This research was guided by an overarching constructionist position. This means the world is viewed through a critical lens at 'taken for granted' ways of understanding, rather than from a position that knowledge is based on objective and unbiased understanding of the world (Burr, 2015). From a constructionist perspective, the world is understood within social, cultural and historical contexts, meaning all knowledge is tied to a particular, time, place, context and people (Braun & Clarke, 2013; Guba & Lincoln, 1994). Knowledge is not therefore viewed as fixed and instead it is constantly revised (Bryman, 2016). Knowledge is constructed as human beings engage with the world (Crotty, 1998). I carried out this research in alignment with a constructionist world view, and therefore central to the research was the premise that participants formed their own interpretations within the sociocultural context of the acute hospital setting.

From a constructionist perspective, knowledge is constructed from a given position, and therefore the positionality of the researcher needs to be acknowledged and made explicit, and reflexivity is essential. Reflexivity refers to the awareness of the researcher of how their own perspective, including background and values, informs and shapes the research (Burr, 2015). My own positionality inevitably shaped this research as I brought my own knowledge and experience to the research process. Reflexivity required me to be consciously aware of my own responses and position (Roper & Shapira, 1999). I explore this throughout the thesis, but specifically in the following sections:1.4, 3.5 and 5.10.

3.3 Methodology

To address the research question, I needed an approach that enabled the phenomenon to be explored in-depth to gain deep understanding from multiple perspectives (Braun & Clarke, 2013; Creswell, 2014). I aimed to generate descriptions and explanations rather than to test a hypothesis. This required a flexible design in a natural setting, rather than in a controlled environment with a predetermined plan to be followed (Hammersley, 2013). For these reasons, I selected a qualitative approach to guide the research.

I was interested in the perceptions, beliefs and experiences of nurses. However, I was also interested in nurses' practice and behaviour within the culture of the acute setting. My main focus was how the observable cultural context shapes nurses' understandings. An ethnographic approach aligned well with this. However, I also considered several other qualitative approaches, including phenomenology and grounded theory. Though these methodologies may share data collection methods, where they diverge from an ethnographic approach are in their main goals.

The aim of phenomenology is to gain an in depth understanding of the essence of the lived experience of participants, whereas in grounded theory it is theory development (Charmaz, 2006; Murray & Wilde, 2020). My focus was on the cultural context of the acute setting. ’Culture’ is defined by a particular group’s beliefs and knowledge, in addition to patterns of behaviour and customs (Fetterman, 2019). In ethnography, it is considered inevitable that the researcher will bring their prior knowledge and experience to their research; therefore, a researcher’s positionality is explicitly acknowledged and accounted for, rather than attempting to eliminate it (Hammersley & Atkinson, 2019). This is where phenomenology and grounded theory again differ from ethnography. In phenomenology the researcher ‘sets aside’ prior knowledge, and in grounded theory the researcher approaches their study with their mind as a ‘blank canvas’ (Baines, 2020; Murray & Wilde, 2020). I also considered a case study approach, as case study methodology shares some attributes of ethnography, such as exploring a phenomenon in a specific context and using several data collection methods (Yin, 2014). However, it was my interest in exploring the research question within a specific cultural context that steered me towards ethnography.

Ethnography essentially describes culture and is where researchers carry out their research within a natural setting in real time in order to gain in-depth insights. (Edwards, 2020; Roper & Shapira, 1999). Observation of interactions, events and behaviours is examined alongside the meanings held by the members of the culture (Roper & Shapira, 1999). The aim of ethnographic research is to understand why people act as they do within a particular cultural context (Roper

& Shapira, 1999). Ethnography therefore had particular features I was looking for to conduct my research. I was looking for more than one data collection method with a particular emphasis on observation. The combination of observation and interviews meant I could study the experiences and perceptions of participants alongside examining their practice in the particular cultural context. In alignment with constructionism, the aim of ethnographic research is to gain knowledge through interaction between the researcher and participants over an extended period of time. An ethnographic approach enables, through a process of participant observation and immersion in the setting, an emic, or insider, perspective. The researcher also brings an etic, or outsider, perspective by their attempt to make sense of what they observe. In ethnography, it is the unique combination of the emic and etic lenses, participation in the field to varying degrees, and then stepping back to reflect and analyse the data, which enables the deep insights (Roper & Shapira, 1999).

Ethnography differs from other qualitative methodologies in that the connection between the micro and the macro is examined – that is between everyday activity and the culture within which it is situated, with an emphasis on context (Savage, 2006). Ethnographies examine specific phenomena in their social context, uncovering hidden features and characteristics, and enabling a depth of understanding (Edwards, 2020; Higginbottom et al., 2013).

I specifically selected a focused ethnographic approach to guide this research. This is a form of ethnography particularly suited to research exploring the cultural perspectives of sub-groups of people in a specific cultural context, where the intention is to focus on a particular phenomenon in the setting (Edwards, 2020; Hammersley & Atkinson, 2019). As my research examined a specific phenomenon in the acute hospital environment, an environment with its own social, historical and cultural contexts, it was well aligned with focused ethnography. In addition, focused ethnography is considered particularly suitable for healthcare research where the intention is to examine a phenomenon within a specific professional culture and where there is an intention to apply the findings to improve practice (Roper & Shapira, 1999). When, as with my research, the research question is highly specific, focused ethnography makes it possible to undertake and complete the research in a shorter timeframe than ethnography in general (Roper & Shapira, 1999). By focusing this ethnographic study on a specific phenomenon and purposively sampling specific events, I was able to conduct the research within a relatively short timeframe without compromising the quality.

Fundamental to ethnographic research is the relationship between the researcher and the researched, incorporating both the emic and etic perspectives, thus taking account of multiple realities (Higginbottom et al., 2013). In focused ethnography, the knowledge and experience of the researcher expedite their becoming an insider, or gaining emic insight, which is the primary aim of ethnographic research. It is also a pragmatic option where unlimited time in the field might not be possible (Edwards, 2020; Higginbottom et al., 2013; Roper & Shapira, 1999). My own familiarity and knowledge of the setting, nursing profession and phenomenon in question enabled me to fast-track emic insight. For example, I understood much of the terminology, acronyms, roles, medical conditions and routine. This insider/outsider position required me to exercise reflexivity with respect to my own attitudes, preconceived ideas and values, and the impact of these on my interpretations and my influence on the people I was observing.

3.4 Methods

A focused ethnographic approach is suitable to investigate a specific aspect of a field, which is often informed by the background of the researcher, making it well suited to this research (Higginbottom et al., 2013). Characteristics of focused ethnography, as with ethnography in general, include examination of social phenomena, a large quantity of unstructured data, an inductive approach and narrative description. In focused ethnography, time spent in the field tends to be more purposeful and episodic, with particular events and timeframes being selected. It also tends to be very context specific (Roper & Shapira, 1999). The depth of understanding sought with ethnographies often requires more than one data collection method, with observation usually integral. The focus of data collection often becomes more funnelled as initial insights are examined (Hammersley & Atkinson, 2019). The Consolidated Criteria for Reporting Qualitative Research (COREQ), adapted to be relevant to the reporting of ethnography, was used to guide the reporting of this research (Tong et al., 2007).

3.4.1 Research setting

My research took place on two acute medical wards in a medium sized National Health Service hospital in the southeast of England, broadly typical of district general hospitals in the United Kingdom. The hospital had approximately 450 beds and provided planned and emergency services and some regional services. It was part of a Trust that consisted of two acute hospitals and served over half a million people. The hospital served people from a predominantly white British ethnic background. The hospital had a multi-disciplinary specialist palliative care team that supported and advised the ward clinicians. The hospital and wards were subject to the same statutory standards and regulations as all other National Health Service acute settings in the United Kingdom. I chose this setting as the wards had the features needed to address the research question, such as admitting acutely unwell patients. They included a gastroenterology ward, where patients with gastrointestinal and liver diseases were admitted, and a respiratory ward which admitted patients with chest diseases. Both wards also admitted patients with a range of medical conditions, such as frailty, cancer and exacerbations of chronic conditions, providing a diverse range of disease trajectories. Some of the conditions these wards specialised in, such as liver disease and chronic respiratory diseases, have unpredictable trajectories, making it particularly challenging to recognise when a patient may be approaching the end of life. An additional reason for selecting these wards was that, given the types of conditions treated, it was common for patients to die, and end-of life care was a key component of care on these wards. The wards experienced a high turnover of patients, with beds rarely staying empty for long, reflecting the rapid pace at which acutely ill patients were admitted and discharged. The decision to select these wards was also a pragmatic one, as access to suitable settings can be challenging in ethnographic research (Hammersley & Atkinson, 2019). However, the matrons (senior ward managers) on these wards were supportive and enthusiastic about the research. See Table 3.1 for full inclusion and exclusion criteria for the ward settings.

There were two 12 hour nursing shifts starting at 7.30 and 19.30. The day started with a handover from the nurse in charge of the outgoing shift, followed by a more detailed handover from the nurse responsible for patients in the bay or side room. On a typical shift, there was a nurse in charge (sister/deputy sister), three to four staff nurses on the gastroenterology ward, and four to five staff nurses on the respiratory ward. In addition, there were healthcare assistants and student nurses. A matron was present on the ward who oversaw care and had managerial responsibilities. Generally, a staff nurse and a healthcare assistant were allocated to look after a bay of four to six patients, as well as those in side rooms. The respiratory ward had 28 beds, including five bays and two side rooms, while the gastrointestinal ward had 22 beds, comprising four bays and four side rooms.

The doctors typically arrived on the ward at 8.30. A multidisciplinary team meeting was held three times a week, attended by the consultant, the nurse in charge, junior doctors, physician associates, physiotherapists, students and the discharge coordinator. Following the multidisciplinary team meeting there was a consultant ward round.

After handover on the day shift, the nurses began by administering any medication due to patients. During the day shift, there was a bustle of activity as different staff began their shifts, including the ward clerk, housekeeper, pharmacists, domestics, therapists and doctors. Nurses started their day by giving breakfasts to patients, checking observations, and providing personal care. Nurses balanced many tasks including preparing patients for investigations, coordinating discharges, managing medication rounds, updating documentation, and speaking to families. They also monitored patients' conditions and responded to deteriorating patients and emergencies as they arose. The nurses typically did not join the ward round with the doctors, as they were busy engaged in other tasks. Instead, they would read the patients' notes afterward to stay informed about treatment decisions and plans. On the night shift, following handover, the nurses began their medication rounds and worked to settle the patients for the night. Throughout the night nurses remained vigilant, closely monitoring patients and responding to patient calls. If concerns arose about a patient's condition, the night team would request the on-call medical team or night practitioners (nurses) to review the patient.

Although my aim was not to achieve generalisability, similarities to other settings are likely to mean the findings are relevant to other settings. Clearly describing the sampling methods and characteristics of the research setting enables the relevance to other settings to be judged (Higginbottom et al., 2013).

Table 3.1. Inclusion/Exclusion criteria - Setting

Inclusion criteria	Exclusion criteria
Acute Medical Wards – wards that admit acutely unwell patients over the age of 16 years with non-surgical conditions.	- Admission/assessment wards as patients are generally treated for a shorter time and ongoing care takes place elsewhere in the hospital. - Intensive Care Units/high dependency wards as transition to comfort-focused care typically involves the active withdrawal of more invasive and technologically advanced treatments. - Paediatric wards.

3.4.2 Population

Registered nurses who work within the acute medical ward setting were the focus of this research. See Table 3.2 for inclusion and exclusion criteria.

Table 3.2. Inclusion/Exclusion criteria - Population

Inclusion Criteria	Exclusion Criteria
Registered nurses who work on the two selected acute medical wards, including bank and agency staff.	Non-registered nursing staff including health care assistants, student nurses and assistant practitioners.

3.4.3 Sample

The combination of methods and my intention to observe interactions, events and behaviours alongside the meanings held by the members of the culture meant I needed to make several sampling decisions. Firstly, I made decisions about the setting, selecting the hospital and wards (see 3.4.1). Then, in line with the focused ethnographic approach, I made decisions about which type of activities or events to observe and which people to invite to participate. I purposively sampled opportunities for observation. I also made sampling decisions about the time spent in the field, including length of time spent visiting the field overall, how many visits, what time of day they occurred and how long each visit would last (Hammersley & Atkinson, 2019). When selecting timing of visits, I considered potential variations in activity, including differences during days and nights, weekdays and weekends. Sampling different times of day allowed me to compare similarities and differences. I purposively sampled times and events when there was discussion and decision-making involving patients, such as ward rounds and multidisciplinary team meetings. On most occasions, I attended the nursing handover between the night and day staff which assisted me in identifying opportunities for relevant observation. As I spent more time in the setting and staff became familiar with me and the focus of my research, staff would tell me about events I might be interested in or experiences they had had. This provided useful accounts of perspectives and practices, and information about the setting.

I purposefully sampled individual participants from the nursing staff in the setting (see Table 3.2). Purposive sampling is a form of non-probability sampling to allow selection of participants who have the experience and features that enable the research question to be answered (Bryman, 2016; DeJonckheere & Vaughn, 2019; Higginbottom, 2004). I sampled participants to represent variations in gender, experience and seniority and to provide a range of experiences and perspectives. I identified ‘key informants’. This is a term used to describe people who are willing to share their time and knowledge and who can often relate what is happening currently in relation to the history of the group (Roper & Shapira, 1999). Senior nurses on the wards were my key informants. These included the matrons and ward managers who had worked for several years in the setting and who were able to share detailed contextual information. I also used a snowballing approach to recruitment, where individuals suggested other potential participants I could approach who they thought would provide interesting and relevant information. As I became known in the setting, this became increasingly the most frequent means of recruitment.

There is much debate and little consensus on the subject of sample size in qualitative research (Blaikie, 2018; Sandelowski, 1995). In fact, stating a sample size in advance, although conventional and usually expected, is arguably not aligned with research in which knowledge is co-constructed between researcher and participants and is constructed through an iterative process (Blaikie, 2018; Hammersley, 2015).

The concept of data saturation is often used to determine when enough data has been collected in qualitative research, including ethnography (Higginbottom et al., 2013; Roper & Shapira, 1999; Saunders et al., 2018). However, there is no one definition of data saturation, and its relevance is hotly contested (Braun & Clarke, 2021; Saunders et al., 2018). I decided on the final sample size, including number of individual participants and time in the field, when the research question had been answered and no new information was being obtained, and no new interpretations generated (Guest et al., 2006; Higginbottom et al., 2013; Roper & Shapira, 1999). This point is often referred to as data saturation. This is not to say I assumed knowledge was complete or no new interpretations were possible, but in the context of this particular research, there were no new analytical threads to explore. This is in alignment with constructionism, where knowledge is regarded as context specific, rather than as definitive (Bryman, 2016; Lincoln & Guba, 2013). By comparing the findings of the different data collection methods, I explored similarities and differences, and this assisted me in decisions around the eventual sample size

3.4.4 Recruitment

I approached the hospital's Research and Development department to seek their support in undertaking the research. I was introduced to senior hospital managers for permission for hospital access and for help identifying wards that fitted the inclusion criteria. I then approached and met with relevant ward matrons to seek their agreement and support to carry out the research. I made introductory ward visits to meet staff to discuss the purpose of the research and methods and how this might affect them.

I emailed a letter of invitation to take part in the research to the ward matrons, asking them to forward this to all registered nurses who worked on the ward (Appendix 7). This invitation made it clear individual participants would need to give formal consent. In practice, potential participants indicated their interest in taking part in the research when I was on the wards. I either emailed an information pack to potential participants who had expressed an interest or handed a pack to them directly. This pack included a participant information sheet and a consent form (Appendices 8 and 9). The informed consent requirement meant participants needed to have all the necessary information to decide whether to participate. Consent forms were returned as an attachment via email or handed directly to me. The participant information gave full details about the research purpose and its design. I gave sufficient time for the participants to ask questions and consider their decision to participate between information and consent being given and the observation or interview taking place. I was careful not to, in any way, coerce potential participants to participate. Participation in the research was entirely voluntary and no incentives were offered. Participants were informed of their right to withdraw, without reason, until one month after the interview or observation had taken place. After this, up until thesis submission and publication, effort would be made to exclude their data.

Information strategy/ opt-out process.

Posters informing anyone entering the wards that research would be taking place were prominently displayed for two weeks in advance of the research commencing (Appendix 10). The posters clearly stated observation would be taking place in the ward environment. My details and contact information were given in case any person wished to opt out of observation or wanted more information about the research. Posters were positioned in prominent places, including staff rooms and ward entrances. Individual participants gave formal consent for observation, and an opt-out consent process was in place for others in the observed setting, such as patients, families, and other staff members. These people were aware the research was occurring both through advance information and information at the time. Posters indicating when observation was in progress were also displayed (Appendix 10). Any individual within the field of observation wishing to opt out was advised to inform the nurse-in-charge of the ward or to contact me. The right to opt out was made explicit, at no point during the research did anyone elect to opt out. A leaflet providing further information and detail on the research was available in staff areas (Appendix 11). I wore a badge stating my name and role as a researcher so I could be easily recognised.

During ethnographic research, informal interviews, ‘ad hoc’ comments or ‘unsolicited oral accounts’ during observation and the presence of the researcher in the setting are to be expected (Higginbottom et al., 2013). As I became better known in the setting these occurred more frequently. Nurses would update me on patients and tell me about situations they had experienced and they thought relevant to my research. I was transparent about the collection of data via this method and asked for verbal consent for its use. I ensured participants were aware what they shared and discussed with me would be considered data, and if they declined consent, this data would not be used.

3.4.5 Data collection

In ethnographic research, different data collection methods are selected to gain the deep insights needed to answer the research question (Edwards, 2020; Higginbottom et al., 2013; Roper & Shapira, 1999), with observation usually the primary data collection method (Barbour, 2014). The data collection methods I used were interviews and observation.

Ethnography is by nature 'messy', reflecting the real world, and even though the design should be carefully planned, flexibility is required. Indeed, it is argued attempts to control ethnography or 'clean it up' would not be ethnography (Edwards, 2020). Where observation begins and ends, and what the focus is, is not always clearly defined (Hammersley & Atkinson, 2019).

Negotiating access was ongoing throughout the field work. It involved continually introducing myself to staff and explaining the purpose of the research (Bryman, 2016). Initially, I conducted what Roper and Shapira (1999) termed a general survey, where I made initial decisions about which type of activities or events to observe and identified people who may wish to participate. This also included beginning to build relationships with staff in the setting.

In the early stages of field work, my approach was to gain an overview of the environment and to learn how best to assimilate myself into the setting, for example, where to position myself for observations and the timing and location of regular meetings and events. I made notes of my initial impressions and thoughts. I was transparent about my role as a researcher and the purpose of my research. I wore navy trousers and a scrub top that did not denote any particular profession or seniority and wore a badge clearly stating my name and researcher role.

I collected personal details from individual participants, which included name, the country in which the nurse had undertook their initial nurse education and their level of seniority. This helped give further context to the research and enhanced the richness of the description in the findings.

The findings from the literature review (Chapter 2) played an important role in informing both the development of the interview topic guide and the focus of my observations. Key organisational factors influencing how nurses manage the transition to comfort-focused care, as well as essential aspects of how nurses recognise dying and how they interact with other professional groups, were highlighted in the review. Additionally, clinicians' beliefs and views regarding end-of-life care were revealed. These insights guided the focus of my interview questions and informed the areas of focus for my observations. In sum, the findings of the literature review provided both theoretical and empirical insights into the subject matter, helped align the data collection process with existing research, whilst allowing space for new insights.

3.4.5.1 Observation

Observation can be particularly useful when researching potentially sensitive topics in healthcare settings and is considered suitable when roles, behaviours and social processes are the focus of the research (Walshe et al., 2011). Observational data supported and further enlightened interview data (Hammersley & Atkinson, 2019). It also guided the focus of interview questions. Higginbottom et al. (2013) describe how the role of observer can vary on a continuum from that of observer only to full participation (Schwartz & Schwartz, 1955). They suggest in focused ethnography 'observer as participant' is most usual, as it allows for specific and focused observation when time is not open-ended and full participation is not possible. This was the role I mostly adopted. At certain times, such as handover meetings, I was more exclusively an observer. I was not able to participate as a nurse or in any other professional role. However, the longer I spent in the setting, the more I started to interact naturally with staff and to do small non-clinical tasks, such as passing personal belongings to patients and removing meal trays. Participation is not necessarily doing what the observed are doing. It does, however, involve interaction with those observed whilst they are carrying out their roles and activities (Delamont, 2004). As data gathering progressed, my observation became more focused, such as where nurses were caring for patients approaching the last days or hours of life (Roper & Shapira, 1999). Observation allows the researcher to gain a deeper understanding of more subtle aspects of the social and cultural context (Edwards, 2020). I was, however, mindful of the potential impact of my presence on behaviour (Walshe et al., 2011). I was aware that, as well as observing, I was being observed (Roper & Shapira, 1999). Observation initially felt very unnatural, but I was prepared for this as this is well recognised (Roper & Shapira, 1999). It was difficult to know where to position myself. I carried a notebook to capture details such as environment, time of day, persons present and other contextual details, plus my own reflections, to illustrate and contextualise my observations. After a couple of observational episodes, a nurse told me some staff had thought I was doing a hand washing audit and so were self-consciously washing their hands in my presence! This emphasised I was also being observed and my potential to affect behaviours in the setting. I bought a smaller, less obtrusive notebook that fitted in my pocket. As soon as possible after observational episodes, I recorded and expanded observations using Microsoft OneNote.

I undertook three forms of observation, see Table 3.3. The focus of my observation was the registered nurse. Observation took place over twenty-three weeks from January to June 2023, over a range of times of the day and night, including weekends and bank holidays. Observational episodes lasted between three and six hours. There were several concentrated periods of observation of around three days, particularly in the early stages of fieldwork.

Table 3.3. Data collection methods

Type of data collection	Focus of data collection	Type of consent	Comment
Observation of meetings and events such as ward rounds and handover meetings	Nurses' roles and actions	Opt-out consent	All present were aware that observation was happening at the time through advance and in the moment information.
General observation in ward environment	Nurses' roles and actions	Opt-out consent	As above.
Observation of individual nurses	Nurses' roles and actions	Written consent	Others present in the field of observation, including patients and families, were not the focus of observation. They were aware that observation was happening at the time through advance and in the moment information.
Interviews	Nurses' experiences, perceptions and attitudes	Written consent	

Observation of individual participants

I observed individual participants by shadowing nurses who met the inclusion criteria. Whereas initially I envisaged observation would be for several hours, I quickly realised this was impractical for several reasons, including the pace of their work and a relatively small proportion of this time was spent with relevant patients. More general observation and observation of individual nurses undertaking specific activities provided richer data. I mostly observed individual nurses for short periods of specific activity when they were directly caring for patients who were thought to be approaching the end of life. I collected no patient identifying data. I introduced myself to patients and families before individual observation periods and sought verbal consent for my presence.

Observation of meetings or events

I also observed specific events such as handover meetings, ward rounds and multidisciplinary team meetings. I took no active part in discussions. An opt-out process was in place for attendees during observation of meetings and events, as not all present could be known in advance. This meant that if any person had indicated they did not wish their data to be used or to participate in the research, I would have removed their data from notes and transcripts. In practice, this did not happen.

General observation in ward environment

I carried out general observation by positioning myself in an area of the ward, for example by the nurses' station or in a bay, from which nurses could be observed carrying out activities relevant to the research, such as looking after patients whose recovery was uncertain. I also observed interactions between staff. My focus of observation was nurses' actions and behaviours. I recorded no patient identifying details. The nature of an acute ward is that those present and who enter the area cannot be completely controlled or predicted, hence, consent for observation was assumed unless individuals opted out, other than for observation of individual participants who were required to formally consent (See 3.4.4).

A typical observation day

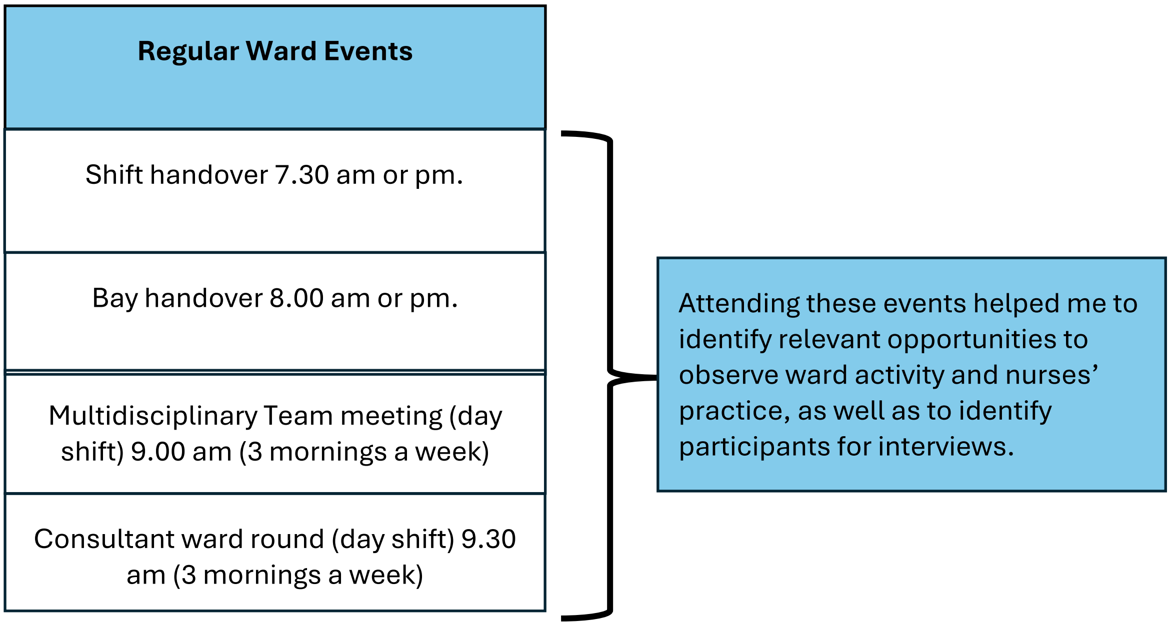
On a typical observational day, I began by attending the nursing handover between the night and day staff. During the handover, the nurse in charge of the outgoing shift shared essential patient information, including clinical status, ongoing treatment, and any concerns or changes in condition. This provided valuable insight into patients who were nearing the end of life or those where their recovery was uncertain, guiding me on where to focus my observations. The handover also highlighted where there were complexities of care, as well as how nurses communicated between shifts.

Next, I would observe the handover between the nurse responsible for a bay or side rooms, where patients relevant to my research were located, and the nurse taking over the care of those patients. This gave me deeper understanding of their care and offered insight into the nurses' concerns, such as how they managed symptoms or emotional challenges in patient care. Afterward, I observed the nurses carrying out their duties, such as monitoring patients, administering medication, liaising with doctors, talking to families and preparing patients for investigations. During this time, I would ask questions about what I observed, which helped me gain a clearer understanding of nursing practices and decision-making. Occasionally, patients would interact with me, and I carried out small non-clinical tasks such as removing meal trays or passing belongings to patients.

If there was a relevant episode of patient care occurring, such as care of a dying patient in a side room, I would request to shadow the nurse. Three times a week, at 9am, I usually attended the multidisciplinary team meeting, which not only allowed me to observe interactions between different professional groups but also revealed further opportunities for observation. I sometimes attended the consultant ward round which followed the multidisciplinary team meeting.

Throughout my observations, I had to make decisions about where there was the most valuable and relevant activity to my research taking place. As I spent more time in the setting, staff became more familiar with me and the focus of my research. Nurses would often volunteer information and direct me to situations they thought valuable to my research. Making these decisions about what to observe and where to position myself on the ward required me to be vigilant.

After two to three hours of observation, I typically took a break away from the ward to write up my field notes and to reflect on the observations I had made. I would return to the ward for a further period observation later in the shift and to conduct interviews with nurses. The observational data I collected helped guide my decisions on which nurses to invite to be interviewed, enabling me to explore their meanings and perspectives related to what I observed. As my time in the field progressed, I increasingly adapted my interview questions in response to the observations I made. Similarly, the insights gained from the interviews informed my decisions on who to observe, what to focus on, and where to direct my attention. See figure 2.



Regular Ward Events
Shift handover 7.30 am or pm.
Bay handover 8.00 am or pm.
Multidisciplinary Team meeting (day shift) 9.00 am (3 mornings a week)
Consultant ward round (day shift) 9.30 am (3 mornings a week)

Attending these events helped me to identify relevant opportunities to observe ward activity and nurses' practice, as well as to identify participants for interviews.

Figure 2. Regular ward meetings schedule

3.4.5.2 Interviews

In ethnographic research, interviews allow the researcher to examine what is observed alongside the meanings held by the researched and in the sociocultural context (Roper & Shapira, 1999). They also offer an opportunity to delve deeper into issues, such as nurses' feelings and opinions (Roper & Shapira, 1999). The integration of both interview and observational data enriched the findings, with each helping to clarify or add depth to the other. In some instances, contradictions arose between what was observed and what was shared in interviews, providing important opportunities for reflection and further exploration. The combination of these methods allowed for a more comprehensive and nuanced understanding of the nurses' practices and the complexities they navigated in their daily work.

The combination of interviews and observations allowed for a dynamic, evolving approach to data collection. As I gathered observational data, I adapted my interview questioning to explore the nurses' feelings, beliefs, and insights regarding what I had observed. By questioning nurses about the behaviours and interactions I observed, I was able to gain a deeper understanding of their experiences, uncovering the explanations behind their actions and their perspectives on issues. An interview topic guide (Appendix 12) formed the basis of interviews, whilst allowing me flexibility to respond to the participants' responses and accounts (Braun & Clarke, 2013; Bryman, 2016). I reviewed the topic guide as data collection progressed, both to check the research question was being addressed and in response to data already collected. As patterns in the data became evident and my analytical ideas formed, I adapted my questions in response, for example, I explored the differences in nurses' experiences of end-of-life care in this setting compared to the country in which they trained. In addition to allowing me to explore data from observational episodes, interviews helped guide the focus of future observations (Higginbottom et al., 2013).

I conducted semi-structured interviews with nurses who met the inclusion criteria. I conducted a single interview with each participant. The timing of interviews varied. They took place either later in the day or night following observation, or at a prearranged time. I often conducted interviews with nurses after observing them, whether during the day or night. However, I also interviewed nurses whom I had not previously observed. These interviews were valuable because subsequent observations could either confirm or explain what they told me, or at times, reveal contradictions. I anticipated interviews to last around an hour, but generally they lasted 45 to 55 minutes. Initially, I carried out most interviews during the nurses' work time with the consent of the ward manager or matron. However, it became apparent that, despite my initial assumption nurses would not want to be interviewed in their own time, many preferred this. Interviews were either in-person or virtual via Microsoft Teams. Virtual interviews offered more flexibility and addressed issues such as the geographical distance between myself and the participants and the lack of availability of a suitable interview room. I carried out in-person interviews in a quiet private area, although finding a suitable location was challenging at times. I recorded in-person interviews with a portable audio device.

3.4.6 Data analysis

In ethnography, data analysis involves interpretation of human behaviour, beliefs and practices and generally generates descriptions, explanations and theories. It is not a separate stage and occurs even as the research question is being formulated and data is collected (Coffey, 2018; Hammersley & Atkinson, 2019). There is no single approach advocated for ethnographic data analysis, however, different approaches have features in common (Angrosino, 2007). Ethnography is characterised by increasingly focused data collection as the research progresses and analytical ideas form (Coffey, 2018; Hammersley & Atkinson, 2019). Essentially data analysis requires deep immersion in the data and involves organising the data and then making sense of it through induction (Roper & Shapira, 1999).

I selected an inductive approach to analysing ethnographic data described by Roper and Shapira (1999). This approach amalgamates features used by different ethnographic researchers. The analytical steps include: coding for descriptive labels, sorting for patterns, identification of outliers or negative cases, generalising with constructs and theories, and memoing and making note of insights and ideas. These are not sequential steps and there was movement back and forth between them, with the exception of memoing which continued throughout the process. This approach is suited to problem-focused research questions and making specific recommendations for practice (Higginbottom et al., 2013). I used NVIVO qualitative data analysis software to assist in organising, sorting and storing the data. I kept a reflective diary to record how ideas and concepts developed.

Adopting an iterative and cyclical approach meant as the research progressed I used developing ideas to make sense of the data and the data then informed the developing explanations (Hammersley & Atkinson, 2019). This ‘to and fro’ approach was essential in developing ideas and connecting them with theories and concepts of others. The narrowing of focus as my research progressed enabled a movement from description of social processes towards developing theory and explanations (Hammersley & Atkinson, 2019).

Fundamental to ethnographic data analysis is familiarity with the data and immersion in it. This requires repeated reading of the data (Hammersley & Atkinson, 2019). I wrote up my field notes the same day in Microsoft OneNote and I transcribed the interviews verbatim soon after the interview had taken place, or for those conducted virtually, I reviewed and corrected the automatic transcripts. This allowed me to immerse myself in the data immediately and helped to guide future observations and line of questioning in later interviews (Bryman, 2016). For an overview of the analytical process for the theme 'Discomfort,' see Appendix 19.

3.5 Reflexivity

Reflexivity is the conscious awareness of the influence of the researcher on their research (Bryman, 2016). It involved self-awareness of my own internal and external responses (Dowling, 2006). Reflexivity is required throughout every aspect of the researcher’s relationship with the phenomenon, including their knowledge, professional background, relationships in the field and how these influence the research (Shelton & Goodwin, 2022). As a palliative care nurse consultant within an acute trust, I was consciously aware I brought to my research in-depth knowledge and experience of the phenomenon being investigated, along with my own views and opinions. This required me to be reflexive on these influences throughout the research process.

I experienced a few situations where, in my opinion, symptoms were not being optimally managed. In these situations, I felt ethically obliged to subtly intervene, for example, on one occasion, I asked whether the palliative care team were involved, which prompted a referral. On another occasion, when I noticed a dying patient appeared agitated, I asked the nurse whether a certain medication had been prescribed. I was very aware my intervention influenced what happened; this was accounted for in my interpretations. There were also occasions when I was aware I felt empathy with the nurses when they were under pressure or in challenging situations. As a nurse, I had been in situations where the expectations and workload felt overwhelming and unachievable. At times my response was to feel an allegiance and loyalty to the nurses and to offer some supportive words. I was aware of the potential for this to influence my interpretations. After each episode of observation and each interview, I reflected and recorded in my reflexive diary factors that may have influenced my response or that of the participant. I referred to this during analysis.

Although I was present on the wards in the role of researcher, I did not seek to hide my professional background. If asked, I said I was a nurse at a neighbouring NHS Trust. My familiarity and prior enculturation in the acute hospital environment influenced, to some extent, my behaviours and level of comfort on the wards. Although I was never directly asked about my specific role and seniority, it was likely this was known as the matrons on both wards were aware. This potentially provided a power discrepancy, whether I was aware of it or not. However, there were many occasions, when in conversation with nurses, both in interviews and informally, nurses described situations as though I had no clinical knowledge at all. This I perceived as positive as it meant they were not making assumptions about my knowledge. It was not possible, or indeed desirable, to totally eliminate my influence, but I aimed to consciously monitor my effect on the research (Hammersley & Atkinson, 2019).

3.6 Ethical considerations and approval

This research was approved both by Lancaster University research ethics committee and the National Health Service Health Research Authority (Appendices 13 and 14). Prior to approving the research, the Health Research Authority requested assurance from the local Caldicott Guardian that the research did not constitute a breach of the common law duty of confidentiality. This assurance was received. Before the research was publicised, approval by the participating site was obtained. A local site requirement was that I had to be assigned a responsible manager, and a palliative medicine consultant agreed to take on this role. I received a formal letter of access from the hospital (Appendix 15).

I carried out the research guided by the four ethical principles of biomedical ethics: beneficence, non-maleficence, autonomy and justice (Beauchamp & Childress, 2013). Throughout the research process, I adhered to guidance provided by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Ethical integrity requires the research to produce new and worthwhile knowledge. Dissemination is an essential part of the research process. In addition to publishing the literature review in a peer-reviewed journal (Appendix 1), I gave an oral presentation of the empirical research findings and presented a poster of the literature review at the European Association of Palliative Care research conference in May 2024. I intend to seek further publication of my research in peer reviewed journals and to present at relevant conferences.

Ethical integrity also requires the benefits of research to be greater than its risks. Participants' autonomy was protected by gaining their informed consent and upholding their right to withdraw from the research. In addition, participants' anonymity and confidentiality were protected. I assured participants of confidentiality as far as possible, and all data were anonymised. It is possible participants could be identifiable through their participation in the research, hence, I gave scrupulous attention to anonymity and confidentiality throughout the research process. Confidentiality was upheld in accordance with the Nursing and Midwifery Council Code of Conduct (Nursing and Midwifery Council, 2018). Confidentiality and anonymity equally apply to the writing of reports and publications.

The subject matter of the research is sensitive and had the potential to trigger emotions. Therefore, I included a list of resources, detailing where participants could access support, in the participant information. I also developed a distress protocol outlining actions to be taken if a participant became distressed (Appendix 16).

Discussing sensitive issues and witnessing events can potentially affect the researcher. I had access to monthly clinical supervision and support resources through my employment with the National Health Service. My supervisors from Lancaster University were available to be contacted in case difficulties were encountered. I adhered to the Lancaster University lone researcher policy.

During the course of observation, patient care and conversations could be observed and there was potential for unprofessional or harmful practice to be witnessed. In addition, there was also potential for harmful practice to be revealed during interviews. I made participants aware that if I had serious concern about the wellbeing of a participant or anyone else, there may be circumstances where I would breach confidentiality, but this would be to the minimum necessary to ensure safety. I also made participants aware if a patient or anyone else was at risk of immediate harm, it could be necessary to intervene and then report the incident or behaviours to a senior member of staff. Whilst there were no situations where I had to overtly intervene or escalate to senior staff, there were situations where I was uncomfortable and felt care to be sub-optimal (4.5.1 and 4.5.3). There were also circumstances where I subtly intervened by making suggestions (4.5.3 and 4.5.6).

3.7 Data management

Data were managed in accordance with the Data Protection Act (Data Protection Act, 2018) and complied with Lancaster University policies. I immediately transferred the original interview recordings from my portable audio device to a laptop computer and then deleted the portable device recordings. The recordings were password protected when stored on the laptop. On the same day, I saved these recordings to Lancaster University OneDrive and also deleted any data stored locally on the laptop. I also saved recordings of interviews held on virtual platforms to Lancaster University OneDrive. I saved transcripts, field notes and consent forms on Lancaster University OneDrive and they were password protected. I securely destroyed hard copies of field notes and consent forms following copying and uploading them. Only I had access to data. I securely saved all identifying participant details separately from transcripts or recordings. They will be destroyed after the thesis is examined. All recordings will be deleted following examination of the thesis. After examination of the thesis, data, including transcripts, will be stored in Lancaster University's repository (via PURE) for ten years, after which they will be deleted. Only I, as the researcher, have access to the data set. Participants gave consent at the time of participation to anonymised data being shared in reports, conferences and training events.

3.8 Conclusion

In this chapter, I have explored the rationale for the research design and all my decisions throughout the research process. This research was based on an overarching philosophical perspective of constructionism. This assumes meanings are co-created between researcher and researched within specific contexts. I selected a focused ethnography methodology to address the research question and to guide this research, as this approach enabled me to explore the phenomenon in question within a very specific cultural context. Every stage of the research, from recruitment, data collection to data analysis, is coherent with constructionism and focused ethnography. I have described each stage in detail. I have also discussed ethical considerations, quality and data management. I have given particular emphasis to reflexivity, which was vital to the whole research process, not only to ensure transparency and to demonstrate quality, but also so I knowingly incorporated the effects of my own influence in making interpretations and conclusions. The findings and analysis are presented in the next chapter.

Chapter 4. Findings

4.1 Introduction

My research question was: *How does the culture of the acute hospital setting shape how nurses manage the transition to comfort-focused care for dying people?*

My aim was to explore the roles, perceptions and attitudes of nurses' working within acute hospital settings about the transition to comfort-focused care for people who are dying. In this chapter, the findings from my analysis of the ethnographic data are presented.

4.2 Quality

The criteria on which to judge the quality of qualitative research is the subject of much debate and controversy. Whereas validity and reliability are desired in positivist research and are a hallmark of quality, with constructionist approaches this is not necessarily relevant or achievable. There is general consensus that assessment of quality in qualitative research should be addressed differently (Bryman, 2016; Sandelowski, 1993), however, there is no agreed strategy to do this (Flick, 2008; Guba & Lincoln, 1994).

I adopted several measures and strategies to ensure and demonstrate quality. Firstly, every stage of the research, from the research question to methodology and methods, was coherent and consistent with constructionism. The reason for every decision I took and how all analytical interpretations were arrived at have been made clear. I have presented thick descriptions with detailed contextual information of the participants and the setting, as well as of the whole research process, to enhance understanding and to support my interpretations (Geertz, 2008). I carefully chose excerpts to accompany my findings to enable readers to understand how my analytical decisions were made (Shelton & Goodwin, 2022). I also related findings to existing literature and knowledge, so their relevance to other contexts can be assessed.

Triangulation was another measure I used. In the context of my research, triangulation involved my comparing data produced by interviews and observations to check for consistency or contradictions and to add further explanations and insights (Seale, 2017). In addition, reflexivity, which refers to the conscious awareness of my influence on the research, is addressed throughout this thesis (Morse et al., 2002; Sandelowski, 1993; Shelton & Goodwin, 2022). Reflexivity involved monitoring my own effect on the research and then being explicit regarding this throughout the research process. All these measures contributed to transparency. Finally, I used the Consolidated Criteria for Reporting Qualitative Research (COREQ), adapted for relevance to ethnographic research, to guide the explicit and comprehensive reporting of this research (Tong et al., 2007).

4.3 Setting

The nurses worked twelve-hour shifts, which started at 7.30 am and 7.30 pm. Shifts began with the nurse in charge of the outgoing shift providing a handover to the nurses starting the next shift. The doctors arrived on the ward at 8.30. A multidisciplinary team meeting was held three times a week. This was attended by the consultant, the nurse in charge, junior doctors, physician associates, physiotherapists, students and the discharge coordinator. The consultant's ward round started soon after the multidisciplinary team meeting.

On a typical shift, there was a nurse in charge (sister) on each ward, three to four staff nurses on the gastroenterology ward, and four to five staff nurses on the respiratory ward. In addition, there were healthcare assistants and often one or two student nurses. Each ward also had a matron who was a senior ward manager. A high proportion of the nurses on each ward were internationally educated nurses. The wards were nearly always full, and empty beds were quickly filled with new patients. See Table 4.1.

Table 4.1. Characteristics of wards

Characteristics	**Respiratory ward**	**Gastroenterology ward**
Total beds	28 (5 bays, 2 side rooms)	22 (4 bays, 4 side rooms)
Total establishment of registered nurses	29	20
Internationally educated nurses as a percentage of total registered nurses	76%	80%
Internationally educated nurses in UK < 1 year, as a percentage of total registered nurses	27.5%	45%

4.4 Observation and participants

I carried out 32 episodes of observation over twenty-three weeks. Each episode lasted between three and six hours, over a range of times of day including weekends, bank holidays and night shifts. There were 144 hours of observation in total.

I carried out 20 participant interviews of registered nurses in total. Most interviews were in person, four were virtual via Microsoft Teams. Interviews lasted between 45 minutes and an hour. Two interviews were shorter (30 minutes) due to clinical need on the wards, however, they contained rich data. The nurses all enthusiastically talked in depth about their opinions and feelings.

See Table 4.2 for participant details, including seniority of nurse, gender and length of time since qualification.

Table 4.2. Characteristics of interview participants

Individual participant characteristics (n=20)	Category	Total
Ward nurse worked on	Gastroenterology	12
	Respiratory	8
Seniority of nurse	Matron	2
	Clinical nurse specialist	1
	Ward sister	2
	Deputy sister	2
	Staff nurse	13
Years qualified	0-2	8
	3-5	4
	5+	8
Country qualified in	UK	8
	Ireland	1
	India	2
	Nepal	1
	Kenya	2
	Ghana	2
	Nigeria	4
Gender	Female	18
	Male	2

My findings from the data from both wards reflect each other, and so they are presented together. Where specific findings relate to an individual ward, I have highlighted this. Matrons, clinical nurse specialists, ward sisters and deputy sisters are all referred to as senior nurses in the findings to enhance anonymity. Each quote used is preceded by the seniority of the nurse and geographical region of their initial nurse education.

4.5 First impressions

I was immediately struck by the sensory stimulus of the ward environment: bright lights, people everywhere, numerous health care professionals including pharmacists, therapists and visiting specialist nurses, domestics sweeping floors. And the noise! Pagers bleeping, tea trolleys, confused patients calling out, the telephone, infusion pumps bleeping. One of the wards was used as a corridor to a neighbouring ward so patients in beds would just pass through the ward. It struck me that my own hospital is probably no different.

The nurses were courteous but not overly friendly to me, often avoiding eye contact. I interpreted this as concern I would ask them to do something. I felt uncomfortable and in the way. I explained my role as a researcher and what I was interested in. The overwhelming impression I had in those early days was how rushed the nurses were. Whilst always professional, sometimes their stress showed outwardly - fast paced walking, sighing and saying how busy they were. Over the course of the ethnography, they and I became more relaxed with each other. They understood why I was there and would helpfully suggest opportunities for observation.

4.6 Themes

Through analysis of the observational and interview data, I constructed six themes that explain how nurses manage the transition to comfort-focused care in the acute hospital setting for people who are dying. The themes are: Denial, Competing priorities, Discomfort, Moral dissonance, Nurse agency and Delay. I have selected participants’ quotes and extracts from field notes to illustrate these themes.

4.6.1 Denial

On the acute medical wards where I conducted fieldwork, there was a culture where dying was not openly talked about. From my first day I was struck by the indirect way of talking about it. In fact, dying was not even directly named or discussed. Here a staff nurse talks about her discomfort using the words death and dying:

> *Participant 15, p.5. Staff nurse, Africa: The words death and dying are a little bit more, you know, kind of to the point and a bit, yeah, daunting as well. Not words we use very often, you know. Sometimes the medical staff or the palliative care team may. But for me, day-to-day, I wouldn't no, no, unless it was imminent, no [emphatically]. ... I wouldn't use the word death, dying or anything.*

Staff used euphemisms to talk about dying. I observed doctors and nurses use various phrases such as *'low threshold for palliation'* and *'Just slipping, not long for this world'*, rather than actually saying the word 'dying'. These phrases were accompanied by knowing looks between staff and were understood. Nurses rarely used the word dying. Most of the nurses believed euphemisms were preferable to directly referencing dying, and their use softened the emotional impact. Here a nurse talks about this:

> *Participant 9, p.6. Staff nurse, Africa: I don't know. I think maybe they're uncomfortable using that word because it's quite sensitive. Yeah. So, I think they're just uncomfortable using it, as humans basically.*

For others, this was frustrating. Here an experienced nurse describes her frustration at dying not being explicitly named:

> *Participant 5, p.12. Senior nurse, UK: … so they went behind the curtain and this doctor just then proceeded to say she's very poorly. … and they said 'right, I'll leave you to it' and walked off. It's our code … when a doctor says poorly they mean dying, but it's not and it's having the courage to say the word.*

Nurses found talking to families about dying difficult and often tried to avoid it. Whilst English was not the first language of most of the nurses, this difficulty resulted from their discomfort rather than their grasp of the English language. Many of the nurses talked about not having 'the right words'.

Talking to families became easier with experience, although even senior nurses admitted to finding it challenging. Nurses recognised they found this difficult and were very keen for training on how to do it better:

> *Participant 8, p.4. Staff nurse, Africa: … they need to train us on how to speak to the relatives, … because you know you have to be empathetic; you should be able to say some words just for them to feel you care. … if you're not able to put your words right, you end up saying things you're not supposed to say.*

The reluctance of the nurses to explicitly name dying and talk about it openly reflects the wider UK society, where talking about death and dying is culturally unacceptable (Graham-Wisener et al., 2022). Whilst individual wards and specialties will have cultural differences, which will be reflected in the individual clinicians working there, the hospital reflected the values and culture of wider society (Van der Geest & Finkler, 2004). In the following quote, as well as revealing her strong discomfort with using the word dying, the nurse also explained how caring for dying people is not even what she believes the role of a nurse to be:

> *Participant 8, p.7. Staff nurse, Africa: The word dying isn't a very good thing. Dy....ing [said slowly with emphasis]. No. People don't tend to say it. No! It's better saying P-CEL, yes, than dying. You know, nursing is more [pause] trying to improve patient health. Yeah. So, when you hear dying it's like counter to what you're supposed to be doing.*

There was an acronym that was particularly embedded in the language of the setting and that was used and understood by all staff. The acronym was created from the first letters of the title of the care plan that was used for dying patients. Because this acronym is unique to this setting and could potentially identify it, I have substituted it with the acronym 'P-CEL', which stands for priorities for care at end-of-life. P-CEL was used as a noun, verb and adjective. Dying patients were called the P-CEL patient. When a decision was made to start the care plan, staff would say they were P-CELing someone, or they had been P-CELed:

> *Participant 7, p.1. Staff nurse, Asia: She deteriorated like, very, very quickly. When she came to our ward, she was for comfort care. I thought that she declined way too fast and then within two days they P-CELed her.*

I was surprised at the casual use of this acronym and how it had become shorthand for dying. Nevertheless, the staff all knew what P-CEL meant and were more comfortable using it than saying the word 'dying'.

Whilst patients frequently died on these acute medical wards, there was a strongly held belief amongst many of the nurses that care of the dying person was, at best, a secondary activity or should not be a role of the setting at all. Many nurses openly admitted this and that their preference was to care for patients who were going to live.

> *Participant 17, p.11. Staff nurse, Africa: Each of us likes seeing our patients get well. … I prefer taking care of patients that I know will be going home, than looking after patients who are dying.*

Some nurses, particularly internationally educated nurses, held strong beliefs that, irrespective of the consequences, end-of-life care was a last resort after everything possible had been tried:

> *Participant 17, p.8. Staff nurse, Africa: You know, one of the aims is to get patients healed as much as we can. Our aim is to get them healthy, so I would say the decision to put the patient on P-CEL is always delayed … what I'm trying to say is we make sure we expanded [sic] all our options and everything is being done.*

Despite this potentially resulting in very late recognition of dying and change in the focus of care, many of the nurses agreed with this approach:

> *Participant 18, p.7. Staff nurse, Africa: But it is GOOD [with emphasis], you want to be positive. You want to be optimistic. You want to like not give up on your patients.*

Senior nurses expressed insight that this approach was the default position in the setting, believing that it was not always right but was often driven by doctors:

> *Participant 1, p.4. Senior nurse, Europe: it's that doctor thing of I must save patients, I must keep going, we can do this, it's reversible and sometimes our senior team will challenge and just say, 'just cos we can, doesn't mean we should. And shall we not'.*

Nurses' responses to clinical concerns were determined by protocols and guidelines, which were mainly based on measurable factors, so what could not be measured may not be acknowledged at all. The National Early Warning Score (NEWS) tool, developed by the Royal College of Physicians to identify deterioration and the response to it, was the main tool used

(Royal College of Physicians, n.d). This score, along with other parameters such as blood test results, was the language of communication between doctors and nurses, dictating when nurses needed to communicate concerns or deterioration to doctors. However, this did not adequately allow for the communication of concerns about patients who could be dying and most of the nurses described the limitations of this – when scores and numerical values did not represent what they knew or could see:

> *Participant 10, p.1. Staff nurse, UK: I've had a few cases where we've had a patient and I've looked after them for maybe a week. Then there's been quite a sudden deterioration and at times the doctors are saying, 'but their NEWS is only a zero',*

Many nurses described intuition, often described as a gut feeling, sixth sense or instinct, as how they knew a person is dying. However, they also found the focus on measurable parameters meant expressing their intuition was problematic:

> *Participant 11, p.1. Senior nurse, Asia: Oh, so I think when someone is ending [sic], ... I always trust instinct and gut feelings, for example, ... when the doctors are dealing with the patients, they are focusing more on the physiological, like the bloods, observations, vital signs, blood pressure. They look at the numbers.*

This was particularly an issue with out-of-hours doctors and new junior doctors with whom nurses did not have established professional relationships and by whom nurses often felt not listened to. The nurses described having fewer problems communicating with consultants who they had often known for several years. This also reflects the differences in medical and nursing approaches; doctors place less importance on subjective symptoms and rely more on diagnostic technology, whereas nurses tend to have a more holistic approach and gain information and make decisions through their greater contact with patients and families

(Anspach, 1987; Vreugdenhil et al., 2023). The doctor-nurse relationship, the limited agency of nurses, and hierarchy all impact the transition to comfort-focused care and are explored in more detail in later themes.

Most nurses expressed strong views about the best location on the ward for a dying person to be cared for. This was almost always felt to be side rooms. When someone was dying, nurses made efforts to move the patient to a side room, but this was often a point of conflict with bed managers who managed bed allocation throughout the hospital. The nurses believed side rooms were important to be able to give the patient and their family privacy and dignity. However, although considered to be beneficial for the dying patients and families, the nurses also spoke about wanting to protect other patients from witnessing dying:

> *Participant 20, p.9. Staff nurse, UK: I think one of the challenges is, you might have patients who are on end-of-life care in a bay with five other patients and the P-CEL patient is probably actively dying. … it's not easy being in a ward, in a bay, with other patients; it's distressing for the family members and also for other patients.*

Despite their expressed belief that side rooms were better for dying patients, their families and other patients, nurses were very open and candid in explaining that once the dying patient was in a side room they sometimes forgot about them. Part of the explanation for this was the balancing of other patients' needs. However, this does not entirely explain this lack of attention. There was a contradiction apparent between what nurses said in interviews about their motivation to care for dying people and what I observed:

> *Field diary: It was 22.30. The ward was now quiet; the patients were settling for the night. There were very few call bells ringing. The ward lights were now dimmed. A dying patient was in a side room, but I noticed the bright light was left on in the side room. The*

> *spotlight was shining directly on the patient. He looked dishevelled. No nurse had been in the room yet during that shift.*

Later that night, I interviewed the nurse allocated to look after this patient during the shift. Her expressed high motivation and belief in the importance of end-of-life care contrasted with her practice that evening:

> *Participant 8, p.8. Staff nurse, Africa: People can be taught to care, to do end-of-life care in such a way that even the person dying and his relatives would see your input and, at the end of the day, appreciate you and be grateful that their relation was under our care before they died, because of the level of care you give.*

On one level, this patient had been overlooked and made invisible. This aligns with research which found placing patients in side rooms reduces visibility, making it more difficult to effectively monitor their condition (Maben, 2015). However, additional underlying factors were at play, including the nurse's own discomfort about end-of-life care and the competing needs of other patients, which are explored later. Dying patients are often moved, or sequestered, to side rooms to shield others from the discomfort associated with death (Lawton, 1988). However, beyond the practical reasoning, this practice can serve to avoid confronting the reality of dying.

Nurses caring for dying patients did so within a cultural climate of denial, where dying was not openly spoken about and where the care of dying patients conflicted with what nurses believed their role to be. Complicating this was the feeling among nurses that they lacked the language to talk about dying, as clinical discussions with doctors often focused on numbers, scores and test results, whilst more subjective observations of deterioration were not always taken seriously by some doctors. Moving dying patients to side rooms, where they were less visible, not only meant they could be forgotten, but also meant nurses could avoid confronting dying.

Adding to the challenge was the need to balance the needs of dying patients with those that were going to recover.

4.6.2 Competing priorities

Nurses consistently demonstrated empathy for dying patients and their families, recognising the emotional and physical toll of end-of-life care. Despite the significant pressures they were under, including managing the competing needs of acutely ill patients requiring an immediate response, nurses understood the importance of providing compassionate, individualised care to dying patients. For many nurses, delivering high-quality end-of-life care was not just a professional responsibility but a deeply held value. They often spoke about supporting families and ensuring that patients' dignity and comfort were maintained (see 4.5.3).

> *Participant 2, p.3. Staff nurse, UK: We must do our best for patients. We only get one chance. We must do our best to make sure they are comfortable. We must support the family as well – as well as the patient. I try and put myself in their shoes and comfort them. We give them foldable beds and tea, coffee, snacks and they can rest in the relatives' room.*

While many nurses admitted to feeling uncomfortable with aspects of end-of-life care, particularly in dealing with their own emotional responses to death, they consistently showed kindness, gentleness, and respect in their actions (see 4.5.4). Even when faced with the demanding reality of balancing critical care for acutely ill patients, I often witnessed nurses carefully listening to families, offering comfort and attending to patients with a calm and reassuring presence. Their actions reflected sincere compassion, even when they lacked confidence in what to say. This approach highlighted that, despite the emotional and physical challenges they faced, nurses remained committed to providing the best possible care, grounded in empathy and respect for both the patient and their family.

Nurses, both individually and as part of the broader healthcare system, faced the difficult reality of having to balance the needs of acutely ill patients with those of dying patients. In a system with limited resources and constant pressure, nurses found this particularly challenging. They were candid in expressing the emotional burden of feeling compelled to deprioritise dying patients, even though this was not a decision made lightly. I was struck by their honesty in sharing this. They explained that, due to the immediate needs of acutely deteriorating patients, the needs of dying patients often had to take a backseat:

> *Participant 6, p.2. Staff nurse, Africa: So, most of the time you have patients NEWSing [sic] that are for active treatment. And then you have a patient on P-CEL. They just have to wait. First you have to take care of the active [patient]) and ignore the P-CEL.*

However, there were other factors impacting their ability to care for dying patients. Nurses described how the types of diagnoses on their particular wards, as well as the demands of confused patients and patients with mental health issues, affected their ability to provide end-of-life care. Here a nurse describes this:

> *Participant 12, p.7. Senior nurse, UK: ... so if you've got someone that's on a day three detox, which is normally the day where they start to get the agitation ... sometimes they get aggressive or verbally abusive. I think, yeah, that definitely can be quite difficult.*

This nurse also described the unpredictable nature of some conditions that added additional challenges:

> *They can be fine one minute and within the next, the second part of the shift, they could be deteriorating. ... if you've got all of that going on in your bay, as a nurse it's.... [thinking], so I've got someone who's literally screaming out in pain who's dying who doesn't have the right pain relief at the moment, or I've got someone who is also NEWSing 14 [sic] who's still for full escalation.*

From the start of their shifts, nurses were immersed in time-critical tasks, documentation, and administrative responsibilities, all of which demanded immediate attention. One nurse shared how, despite their best efforts, the pressure of these duties led to the needs of dying patients being deprioritised:

> *Participant 17, p.9. Staff nurse, Africa: If I'm having someone that is not P-CEL and he's having some critical presentations differences, the sats [sic] drop, I have to attend to that patient first. ... that is prioritising the patient according to the immediacy and urgency at which their situation has to be attended to, so you have that patient dying already on P-CEL and I have a patient that is gasping for breath, I have to attend to that patient first ... because I know the other patient is approaching end-of-life already.*

Several nurses expressed sadness and even guilt at this deprioritisation of dying patients:

> *Participant 20, p.9. Staff nurse, UK: ... so you might not have time to try and go and do things for the P-CEL patient because you know you're not actively treating them which feels sad and it's bad, but sometimes it comes to prioritising basically, but it's not nice, you know, just because they are end-of-life ...*

The pace and unrelenting workload of the wards meant nurses needed to adapt and respond to quickly changing situations:

> *Participant 8, p.4. Staff nurse, Africa: So, the challenge I'd say is the most immediate challenge, but I think, [pause] it's so busy sometimes you may forget to even go to the [dying] patient.*

And the demands of daily care routines continued:

> *Participant 7, p.6. Staff nurse, Asia: … we have to umm, give medications, take bloods, do all that stuff, a lot of work on the day shift. So sometimes we are not able to do that hourly, two-hourly checks of dying patients. So that's difficult. We have patients who are NEWSing [sic]. Once the patient NEWSes 5 [sic] we need to take observations and take bloods. Depending upon those bloods, they have fluids, go for tests and we have to take calls from relatives, pharmacy. So, it's not possible to do the checks on dying patients*.

Dying patients typically do not require the same routine interventions, which often meant their needs were not attended to with the same frequency as those of other patients. Below I describe a morning handover on the respiratory ward:

> *Field notes: The nurses all assembled for the morning handover. The night nurse in charge went through lists of tasks or interventions such as non-invasive ventilation, chest drains, nasogastric tubes, patients who were NEWSing [sic] highly, at high risk of pressure sores or were not for cardiopulmonary resuscitation. The patients weren't referred to by name, only by diagnosis, intervention, bay and bed number. That was it!*

I was taken aback the handover was so overtly task-oriented, conflicting with the current drive for person-centred care (Abou-Saleh, 2023). This illustrates the emphasis on task completion and the task focused culture that predominated. There was a tension between the pressure to complete tasks and the nurses' own values and desire to provide person-centred care. One of the senior nurses regretfully spoke about this:

> *Participant 16, p.12. Senior nurse, UK: … the focus has drifted from the leadership where you want people to be hands on and visible, to a lot of tick boxes.*

This nurse went on to describe a complaint she had received from the family of a dying patient that no nurse had entered the side room of their relative for six hours. However, when she checked the P-CEL care plan, the two-hour patient checks had all been ticked as completed. When asked, the nurse who should have been caring for the patient that shift admitted she had not seen the patient. This illustrates how the drive for task completion took precedence over actually delivering the care.

The nurses walked at a fast pace, eyes down, avoiding eye contact. They talked quickly. They were courteous, with only occasional irritation apparent. There was a routine of tasks that needed to be completed, starting with medicine administration, observations and 'rounding charts', which listed patient care tasks. Nurses' focus was on getting these tasks completed or 'ticked off', and they were uncomfortable and distracted if they had to deviate from this.

The nurses spoke often about being busy and of the impact this had on their ability to care for dying patients. The word 'busy' featured frequently during both interviews and in comments made during observation. The needs of dying patients took second place, or were even neglected, as a consequence of the nurses being busy with other patients:

> *Participant 13, p.4. Staff nurse, Africa: … sometimes you get carried away with other patients and other tasks and activities you have to do, and you may forget to check in with the dying patients because most of the time we try to put them in a private room …*

The nurses were rarely able to join the doctors on ward rounds as they were too busy. This limited the opportunity for nurses to convey their opinions and observations and to contribute to discussions and decision-making, which limited their agency. However, a senior nurse questioned the ‘busyness’ narrative and expressed her belief the solution was better prioritisation:

> *Participant 16, p.13. Senior nurse, Asia: And what is the busyness about or, ‘Oh I need to do this by this time. It is busy’. That's why they are on an acute ward. It is always going to be busy. We need to get our prioritisation right and I say to my team, ‘there is no rule that says people must be washed by two’. If I [patient] come in I want you to get me better … I'm not gonna die because I've not had a wash today. But I would die because I've not eaten, I've not drunk, I'm not taken my medicines, or I've fallen and fractured.*

This same senior nurse was responsible for changing the respiratory ward handover to a list of tasks, revealing conflicting priorities between person-centred and task-oriented care. It was clear nurses found prioritisation difficult and a burden, and the pace and intensity of work impacted their ability to provide the quality of end-of-life care they wished. Here a recently qualified nurse explained how she feels:

> *Participant 10, p.4. Staff nurse, UK: … I feel like I've not cared for them how they should be. Nobody wants to spend those last few days on their own. And I feel like because of the staffing issues, because of the acuity of the ward, the busyness of the ward, we can't spend much time with these patients… yeah, I find that hard.*

Despite their strong commitment to patient care, nurses found themselves caught between their values and the pressures of the healthcare system. Systemic challenges, such as the lack of available home care services, meant that patients could not be discharged home - a situation over which nurses had little control. There was also pressure on side room availability, as these rooms were prioritised for patients with infections rather than for dying patients, sometimes contrary to nurses’ views on this. Nurses expressed negative opinions about bed managers (who were responsible for the allocation of beds in the hospital) and senior managers, and felt their support and understanding were lacking:

> *Participant 16, p.12. Senior nurse, UK: People [managers] need to get out of the corridors, hang their coats up there. And when the ward is struggling you [managers] can even come to give out meals. You don't have to be advanced to answer a call bell or take a message. How would you know that your staff are not confident enough to look after end-of-life patients when you're not working alongside them. How do you know? You're not going to know.*

Dying patients were sometimes given less attention as nurses were compelled to prioritise the urgent needs of acutely deteriorating patients and others requiring more immediate care. These decisions, though difficult, were made in the context of managing overwhelming demands and limited resources, highlighting the challenging nature of their role. Contributing to this was a culture where a task-oriented approach dominated over a person-centred approach, conflicting with nurses' expressed values. However, the underlying discomfort many nurses felt around death and dying sometimes meant that the needs of dying patients were unintentionally placed second, despite the nurses' strong commitment to providing compassionate care. This is explored further in the next theme, discomfort.

4.6.3 Discomfort

There was a pervasive culture of discomfort around death and dying. This meant nurses at times physically avoided dying patients. I observed this whilst observing an internationally educated staff nurse who, together with a student nurse, was allocated to look after a dying patient in a side room.

> *Field notes: It was 11.30 in the morning. The student was becoming increasingly frustrated that the staff nurse had not yet entered the room [the patient needed two people to carry out personal care]. Eventually, when the staff nurse was ready to go into the room, she looked visibly uncomfortable and stayed for the shortest time possible. She took me aside and explained her conflicting thoughts, saying, 'I want to care for dying patients because I want to become more confident, but then I don't want to'. She went on to explain that although she was uncomfortable, she realised she needed the experience to become more confident. The patient's family were waiting outside the room, looking understandably distressed. She avoided eye contact with them. There was no attempt by the nurse to engage with them. It was left to the student nurse to comfort the family.*

Previously when interviewed, this nurse had expressed high motivation to care for dying patients and a belief in the importance of attentive end-of-life care. Her behaviour contradicted this and was as a result of her inherent discomfort and lack of confidence, rather than not caring.

Some discomfort towards end-of-life care came from nurses' concern about their actions potentially precipitating dying and being culpable for patients' deaths. The following quote illustrates this and describes the discomfort some nurses feel around administering opioids to dying patients:

> *Participant 17, p.6. Staff nurse, Africa: Death should be natural, not we nurses being the cause of the death. So, it's something we should worry about ... we have to be very careful because there is just a thin line between it as well. ... Because, you know, definitely we don't want to overdose the patient, because it might lead to sudden death, which we don't want ...*

I also observed these concerns during observational episodes:

> *Field notes: There was a patient in the final stages of dying in the bay. The nurse and healthcare assistant were very attentively caring for the patient. The patient was restless and they were discussing whether to give medication to help settle the patient. The nurse appeared worried and reticent. I asked about her thoughts on this – she explained she was uncomfortable about giving 'end-of-life' medications as they 'suppress' the patient and she had not had experience of using these medications in the country she trained in. Despite her apprehension she did administer medication. The patient died soon after. I wondered if this would reinforce her beliefs.*

'End-of-life medications' refers to medications that are prescribed pre-emptively to manage common symptoms that may occur in dying patients. These fears and concerns suggest a lack of confidence and knowledge around end-of-life medication, such as opioids. These examples also suggest a lack of knowledge or ability to apply principles of medical ethics, that is a lack of ethical competency (Andersson et al., 2022). Ethical competency refers to where healthcare professionals are able to identify and manage ethical challenges. A lack of ethical competency can contribute to moral distress. I observed another example of this when a nurse who was qualified for less than a year was caring for a dying patient in a bay. The doctors had made changes to the patient's plan, leaving the nurse to explain these decisions to the family - decisions the nurse had not been involved in. The excerpt below illustrates the nurse's fear of being held responsible for the patient's death:

> *Field notes: The night nurse handed over to the day nurse that the doctors had asked that they switch from 15 litres oxygen via a rebreathe mask to four litres via nasal cannulae on a dying patient. The day nurse said to her colleagues she was not happy to*

> *do this because she was worried the family would have ‘the perception we are killing him’. The family were on their way into the hospital.*

Other nurses spoke about feeling culpable for the death of the patient. This quote reveals the burden nurses feel:

> *Participant 18, p.3. Staff nurse, Africa: … you have to just gather yourself together, try and think it through like you're not responsible for the death of this patient. You're not responsible for the patient dying. The patient is dying. … we are trying our best.*

On the respiratory ward, removal of non-invasive ventilation in dying patients was not uncommon. This adds a different dimension to end-of-life care as there is a direct relationship between the withdrawing of non-invasive ventilation and the very imminent death of the patient. However, continued non-invasive ventilation can delay inevitable death and prolong suffering. Adding to the challenge, unlike many other dying patients, these patients may be conversant and cognitively aware. I observed a patient who had been dependent on non-invasive ventilation for two and a half weeks but whose comorbidities and condition meant it was impossible for him to survive without it. He was finding the non-invasive ventilation difficult to tolerate. The doctors were reviewing the patient on the morning ward round:

> *Field notes: The nurse had not joined the ward round. She was in the same bay and had read the plan to remove the non-invasive ventilation in the electronic notes. She was visibly uncomfortable about this, saying to the healthcare assistant, ‘What are they doing?’, because the patient was currently settled and she believed he would be in distress without the non-invasive ventilation. The registrar leading the ward round proceeded to remove the non-invasive ventilation and replace it with a normal oxygen mask. The patient became immediately distressed. It was obvious to me the registrar*

> *was not confident and was unsure how to manage this. After a couple of tries, they put the non-invasive ventilation mask back on and abandoned the withdrawal. The nurse was shaken and looked upset at what she thought was poor management of the withdrawal. I asked her if she was ok. She replied, 'sort of'. I was concerned that the patient remained unsettled and appeared agitated. Whilst I was aware I did not have access to all the patient information and was conscious of my role as researcher and not palliative care nurse, I asked the nurse whether the 'end-of-life meds' were prescribed, in an attempt to support the nurse in helping the patient in an exceptional situation. 'Oh, which one do you think?' she said. I suggested medications and advised she spoke to the ward sister for guidance. 'Good call' she said.*

The nurse was not involved in the discussions around withdrawal of the non-invasive ventilation and she did not have the knowledge, experience, or authority to manage it herself. Although practice may vary, in my experience successful withdrawal usually involves administering opioid medication and benzodiazepines to ensure the patient is comfortable prior to removal, with repeated administration if the patient shows any distress. This was a Friday before a long bank holiday weekend. No further attempts to withdraw the non-invasive ventilation were made over the weekend. The following Tuesday, when the consultant was back on duty, following discussion at the morning multi-disciplinary meeting, the decision was made to involve the palliative care team and ask them for support in managing the withdrawal. This example highlights the nurse's lack of knowledge and agency to influence care despite her belief what was happening was not right. This caused her distress and highlighted the disempowerment of nurses. This will be explored further in the theme 'Nurse agency'.

Sources of support

Nurses spoke about receiving support from senior nurses in caring for dying people, finding this important and valuable. Senior nurses took this role very seriously. Generally, senior nurses were very visible on the wards. This was apparent following the situation described above (p.102), when I described how a nurse did not feel confident to reduce the oxygen of a dying patient as she was concerned about being held responsible for his death:

> *Field notes: The nurse went behind the curtains to see the dying patient and to speak to his family. Afterwards, the nurse again told me she was not going to reduce the oxygen in case she was blamed for his death. A senior nurse then came to offer support and give guidance. The senior nurse said she would contact chaplaincy, advised lots of mouth care and that she would try to get a side room. She then explained how to wean the oxygen. The nurse was reassured and changed the mask to nasal cannulae.*

The hospital palliative care team had a prominent role in supporting end-of-life care on the wards. They were held in very high esteem by the nurses and doctors. Nurses looked particularly to the palliative care nurses when they needed support in influencing the direction of care.

> *Participant 12, p.1. Senior nurse, UK: So, I actually went and contacted palliative care myself and I asked them, 'can you please review this patient?' .... and they actually agreed with me. Yes. And end-of-life care was commenced you could just tell the patient seemed a lot more comfortable and the family were all in agreement with it as well.*

In this example, the nurse knew the patient was dying and receiving treatment she believed to be futile. However, as this was not being recognised by the medical team, she looked to the palliative care nurses for validation and for support to influence the direction of care to a comfort-focused approach. At times the decision-making was delayed until the palliative care nurses had reviewed the patient, suggesting a dependence on the palliative care team.

> *Participant 20, p.4. Staff nurse, UK: … so sometimes we get told you know this patient is for palliative [sic] and we are still sometimes waiting for the palliative team to come and review and make that decision. So, it's not always, uh, on time if that makes sense. Not on that day. And you might have a patient deteriorating and you want that decision to be made as soon as possible.*

This was also apparent during observation:

> *Field notes: During the handover, the staff nurse said she thought a dying patient was agitated. The sister told her to ask the palliative care team to come and see the patient and to advise. I thought the nurses seemed very reliant on the palliative care team. The end-of-life medications were prescribed to be given as needed but the nurse told me she was not sure what medication to give for the patient's symptoms.*

Death happened frequently on this ward (respiratory), so I was surprised the sister did not administer the medication. The reliance on the palliative team could lead to delays in implementing end-of-life care. However, the nurses often sought the palliative team's validation due to their own lack of confidence and limited agency. Nurse agency and delay in the change of approach of care of dying patients are further explored later in my findings.

Cultural differences

Discomfort towards death and dying was embedded throughout the setting. However, this was more marked amongst the internationally educated nurses. These nurses explained the requirements and preparation they undertook to practice as registered nurses in the UK focused mainly on practical skills and technical knowledge but did not prepare them for undertaking end-of-life care. They spoke about the differences in approach to end-of-life care in the UK compared to the countries where they undertook their initial nurse education. For many of the nurses, end-of-life care was a completely new concept. The main differences they described were ‘never giving up’ and that people mostly died at home.

> *Participant 13, p.6. Staff nurse, Africa: Where I come from, they just never give up on anybody. Not until the person takes his last breath.*

This nurse explains further the different beliefs and attitudes towards dying:

> *In my country it's totally different. ... we don't do the whole helping the patient to die peacefully, put the patients on syringe driver, prioritise comfort. No. I think they look at it like mercy killing because you're helping this person die. I don't know how to explain it, but I was never involved in end-of-life care in my country because traditionally in my country people die at home.*

This quote illustrates the inexperience and discomfort towards end-of-life care of the internationally educated nurses. Talking to families about dying had not previously been part of their role. It also illustrated other causes of discomfort, such as culpability and ethical issues and the belief treatment should continue at all costs.

A senior nurse, trained in the UK but originally from Africa, described how some of her internationally educated nurse colleagues struggled with the concept of end-of-life care:

> *Participant 16, p.6. Senior nurse, UK: But what I found across the trust, with internationally educated nurses, is culturally people are not supposed to die. Which is where some of my struggles have been. I try to get my staff to understand that you are a nurse; we aim to get everybody better, but some people will not get better.... which is*

> *where the trouble in an acute setting is for the nurses from my background, the {removed} background, because we go to hospital to get better and come home. Yeah. They don't go to hospital to die in hospital.*

A nurse described their challenge adapting to the different approach and how it affected them:

> *Participant 13, p.6. Staff nurse, Africa: It was difficult because I felt like, I felt bad. I felt, 'You've not tried all options, keep exploring all options', because mostly in my country people die being treated actively. Yeah, people just shut down and die being treated actively. When I came here and they said, 'Oh, they have stopped treatment. Oh we're no longer treating this person' and all that. It sounds strange. It sounded strange to me ...*

Experience and knowledge.

Experience, knowledge and confidence are interlinked in influencing nurses' agency to undertake end-of-life care. Many nurses spoke about becoming more comfortable looking after dying patients the more experienced they became. Nurses expressed that, in addition to more experience, they wanted more training in end-of-life care, including on how to speak to relatives. Senior nurses believed more training was needed and that training in end-of-life care should be considered equally important to training in care of acutely deteriorating patients:

> *Participant 1, p.7. Senior nurse, Europe: They're starting to talk about making things like deteriorating patients study days mandatory, and that's absolutely the right thing to do because a deteriorating patient is massive. But if you are not acutely treating a deteriorating patient then most likely you're looking at end-of-life care, and those are the two choices that you have for somebody who's that level of unwell. You fix them or you decide to make them comfortable. What can you do? So one shouldn't be more*

> *important than the other because it's one of two options for people at that point in their life.*

Dying within these acute wards occurred within a culture of denial and a climate of discomfort. Lack of confidence, experience and knowledge contributed to nurses' discomfort. There was a large gap between the confidence and knowledge of more experienced and more senior nurses and that of those who are newly qualified or recently arrived in the UK. Talking to families of dying patients caused nurses anxiety, so they tried to avoid it or left it to doctors and senior nurses. Nurses’ discomfort towards dying, along with balancing the needs of different patients and busyness, contributed to the needs of dying patients taking second place.

4.6.4 Moral dissonance

Nurses experienced an emotional burden caring for dying patients, which was contributed to by the cultural climate of the setting. Despite a culture of denial and the deprioritisation of dying patients, nurses of all levels of seniority and experience expressed a belief in the importance of high-quality care for dying patients and their families. End-of-life care was spoken about with almost reverence at times. This senior nurse spoke about the importance and significance of end-of-life care:

> *Participant 3, p.11. Senior nurse, UK: I'm really passionate about end-of-life. It’s the last moment on earth for somebody, whatever you believe, that's their last thing. This is the last thing you will ever do for somebody. It's a privilege. Understand that, accept it and acknowledge – make death as good, comfortable, whatever it is. Try and fulfil that patient’s wishes. Do it for the people that are left behind. Do it for the person in front of you and do it, if you wanna be really that way inclined, as it'll make you sleep easier at night. You know you've done everything. Death is the only certainty; we are in a very, very privileged position, and we should never forget that.*

Nurses’ belief in the importance of end-of-life care and their need to acknowledge its significance reveals a dissonance with the culture of denial and deprioritisation of dying patients.

Once a patient was recognised as dying it was important to the nurses to acknowledge this amidst the noise, the rushing and normal continuing routine of the rest of the ward:

> *Field notes: The nurse and the healthcare assistant were caring for a patient dying peacefully in the six-bedded bay with a quiet respectful efficiency. They seemed*

> *subdued and sad. Nobody openly spoke about it – but the other patients, looking sad, indicated they 'knew', making eye contact with me and nodding towards the dying patient who was screened from view. There was a butterfly symbol placed on the curtains, and a butterfly was also placed outside the bay. I was told this was to inform and remind everyone that a person was dying and to show extra respect and to be mindful of noise levels. There was also a large plastic sweet jar containing artificial butterflies and flowers placed on the nurses' station as a sign to people entering the ward a patient was dying.*

Nurses explained to me this was what they always did when someone was dying. In an environment they believed was less than ideal to care for dying people, the butterfly symbol was a way of showing respect. It was also a way of communicating to all staff that someone on the ward was dying without having to say the words that were so difficult for them to say. Using the symbol seemed to be an attempt by nurses to mark the significance of this life event in the busy ward environment. Symbols are commonly used in this way in end-of-life care. Mayr et al. (2022) suggest organised rituals in end-of-life care facilitate a momentary pause for reflection in the hospital routine. They term these 'reflexivity rituals'. Here, an internationally educated nurse struggled to explain her belief that dying should be recognised and not simply become part of everyday routine.

> *Participant 6, p.7. Staff nurse, Africa: I think if you get so used to something and you're so familiar with it, it's no longer important. The kind of familiarity I'm talking about is the one that makes you just do it, instead of doing it empathetically. ...*

This was the same nurse who was observed avoiding a dying patient, and despite her discomfort towards end-of-life care, expressed that she needed and wanted more experience to feel more comfortable caring for dying patients (p.101).

Nurses experienced distress caring for dying patients. The same nurse explained her feelings:

> *No, I find palliative [sic] emotional. It's hard for me to see my patient dying. Yes. It is hard for me [whispering] … there's nothing else to do. So, we just do what we can to make it more peaceful.*

Although this nurse wanted to care, she was dealing with her own discomfort with death and dying. In addition, nurses found it emotionally challenging interacting with and supporting families of dying patients. Nurses strongly empathised with dying patients and their families, and this contributed to nurses' distress:

> *Participant 9, p.10. Staff nurse, Africa: It's challenging. Yeah. Yeah, it's challenging because we are humans. Do you understand? Apart from the fact that you are a healthcare professional, you've got empathy towards people. And this is a loved one, a person.*

During the course of the ethnography, I sometimes observed nurses caring for some patients over a period of a few weeks. Nurses described finding it particularly emotionally challenging looking after dying patients when they had known the patient and family for some time. A nurse explained this to me during a period of observation:

> *Participant 3, p.10. Senior nurse, UK: When we're caring for these people all the time, sometimes you can't look at it that objectively and you're like, 'Help this person. I really like them'. And the case is not everybody can be helped …*

The nurses built strong rapports with some patients, sometimes over numerous admissions. On the gastroenterology ward there would frequently be younger patients who were dying, and this added to the emotional burden for the nurses.

> *Participant 3, p.11. Senior nurse, UK: It's about nature isn't it? We don't reconcile that people should die of anything but old age, but they do, and you know we've had people in their 20s. It's horrid, but I think people get stuck in the natural cycles of it shouldn't be this way.*

Contributing to the emotional burden is, as described earlier (p.91), end-of-life care conflicted with what some nurses, particularly the internationally educated nurses, believed their role to be:

> *Participant 8, p.3. Staff nurse, Africa: Nursing is trying to help a person become better, trying to save their life. So, if you nurse the patient whose life you can't save, it's distressing for me.*

However, there was a contradiction apparent between the belief end-of-life care should not be a nurse's role and the obvious frustration and distress, mainly from UK educated nurses, when patients continued to be actively treated when they believed them to be dying and the treatment to be futile:

> *Participant 10, p1. Staff nurse, UK: Sometimes it can be quite difficult. Actually, I've witnessed sometimes a lot of the time they [doctors] will say, 'Let's trial 24, 48 hours of antibiotics, fluids, let's throw everything at them', which sometimes I agree with, not always. I had a patient not that long ago actually, where the doctors wanted to continue for another 48 hours. And the patient had started displaying signs of a change in breathing. They were Cheyne-Stoking! [aghast].*

The continuation of active treatment often meant there was a delay in implementing comfort-focused care until very close to the time of death. This will be explored further in the theme, delay. This staff nurse explained how this impacts patient care and adds to their burden:

> *Participant 12, p.2. Senior nurse, UK: I feel like those three to four hours could have been a lot better for that patient and for the family as well, because it's annoying enough every 12 hours someone putting a blood pressure cuff on you or sticking a mask on you, let alone every 15 minutes. Because they were NEWSing [sic], every 15 minutes I was having to go in there and disturb the patient and it's, yeah that, that frustrated me.*

As discussed earlier in these findings, nurses at times felt compelled to prioritise other patients over dying patients due to 'busyness' (4.5.2). Nevertheless, nurses found it distressing when they could not provide the level of care they believed they should give:

> *Participant 10, p.3. Staff nurse, UK: They don't get the care that you want to deliver.... someone who is at that stage of life, I feel, should have someone there whenever they need something. ... You don't get that here. I find that quite difficult. ... I feel like I've not cared for them how they should be. Nobody wants to spend those last few days on their own. And I feel like because of the staffing issues, because of the acuity of the ward, the busyness of the ward, we can't spend much time with these patients.*

This reveals an emotional burden including feelings of guilt. The gap between the care nurses wanted to and felt they should give and what they actually could provide led to distress. This is consistent with moral distress, that is where institutional constraints prevent the individual from acting in the way they believe is right, in conflict with their moral values (Jameton, 2013). However, whilst the nurses felt supported by senior nurses and each other, the busyness and unrelenting pace and routine meant they had little time to process or reflect on events. Here a staff nurse talks about what happened after a patient she was caring for died:

> *Participant 9, p.11. Staff nurse, Africa: So, I was just emotional. And then she [ward sister] just made me more comfortable and just allowed me to have my moment. And then when I was done, I just went back to work. That was it.*

The distress nurses felt in caring for dying patients was exacerbated by having to provide it within a culture that denies death and dying in which the care of dying patients is deprioritised. Despite this, nurses believed in the importance of end-of-life care, but the cultural landscape they were required to provide this in conflicted with their values. Nurses experienced distress when patient care was inconsistent with their values and beliefs. I observed this particularly in UK educated nurses when active management continued when they believed a change to a comfort-focused approach was needed. However, in contrast, many internationally educated nurses found the concept of palliative care and stopping active treatment conflicted with their values. Nurses empathised with dying patients and their families, adding to their emotional burden. When patients were declared to be dying by a doctor and a decision was made to change to a comfort-focused approach, uncertainty resolved and nurses were relieved.

4.6.5 Nurse agency

Nurses noticeably lacked a voice to influence care. They did not feel their opinions were always listened to or trusted, particularly by junior doctors or doctors covering weekends and nights, despite the nurses spending much more time with patients. A contributing factor was regularly changing doctors with whom they did not have established professional relationships:

> *Participant 4, p.4. Staff nurse, UK: ... the problem is we don't have the same doctors all the time. They rotate quite a lot. ... if we have the same doctors for a while they know us, so I think it's about believing us as well. I've realised with some new doctors that it's different. I'm not saying all the doctors are the same, but sometimes they don't believe us, our clinical judgement.*

However, there was more trust from doctors they knew well, particularly consultants.

> *Participant 10, p.2. Staff nurse, UK: I think that they're quite good at listening to us. Yeah, sometimes I feel we've had to escalate above the junior and go to the consultant because maybe they don't want to make that decision. I think it helps because they know us. ... they realise if we're escalating to them then actually [pause], there's an issue.*

Even when nurses disagreed with the treatment plans, most nurses would not generally question or challenge doctors. Senior nurses were more confident to raise concerns with doctors.

> *Participant 12, p.1. Senior nurse, UK: I went and spoke with the doctors and I said, 'look what are we doing here, what is actually going on because this patient is clearly dying,*

> *and I think all this treatment that we're doing is making him worse off and the family are very distressed as well'. The doctors didn't really seem keen to be listening to me.*

The excerpt below emphasises the lack of agency of nurses. Here I describe a situation where a nurse's views and opinions were disregarded:

> *Field notes: A patient who had been on the ward for several weeks, was discussed in the multi-disciplinary team meeting. Earlier that day, a senior nurse described him to me as 'a ticking time bomb' and said, 'one day he'll just go'. She discussed with the doctors how he had deteriorated and said, 'My instincts tell me he isn't going to do well'. The consultant was dismissive and said the patient was confused because he had not had his medication for encephalopathy [because he could not tolerate a naso-gastric tube needed to administer it] and 'we haven't reached maximum treatment yet'. This sounded reasonable, but afterwards the nurse took me aside and repeated that she thought the patient could be dying. The trajectory of the patient's condition was unpredictable; therefore, prognostication was challenging [decompensated alcoholic liver disease]. The consultant did not listen to her concerns or consider dying a possibility. Other nurses that morning described the patient to me as 'being on the edge' and said they thought he could be dying.*
>
> *Four days later the patient had not improved, and he continued to deteriorate. He had endured several attempts by nurses to insert a naso-gastric tube, which he pulled out each time. The nurses found this distressing to do. In the multi-disciplinary team meeting the same senior nurse said, 'He needs to be P-CELed, we need to P-CEL him'. She believed him to be dying. She also tried to be further persuasive by telling the doctors that she thought he was already at 'maximum treatment' but had not*

> *responded, and the patient's sister thought it was unfair to put the naso-gastric tubes down. He was agitated, increasingly drowsy, not eating and drinking; to me he appeared to be dying but the dying word was never mentioned.*
>
> *Despite the senior nurse's views, this patient continued to be actively managed. The senior nurse was very experienced and had worked on the ward for many years. She was also markedly braver and more vocal in expressing her views than the junior nurses and most of the other senior nurses. She had a relaxed and familiar relationship with the consultants, despite this, she still did not manage to influence the course of treatment and the speed of change to a comfort-focused approach.*

The next day, following the consultant's ward round, the patient was commenced on the P-CEL care plan. The patient had deteriorated to a degree that was hard to ignore. Commencing the P-CEL care plan signified recognition he was likely to be in the last days of life, and the main priority of care was comfort. This prompted a series of actions: referral to the palliative care team, prescription of end-of-life medications to manage symptoms and referral to a hospice for end-of-life care.

The nurses recognised the patient was dying days before the change to a comfort-focused approach. However, the patient had to be recognised and declared by the doctors as dying for this to happen. The senior nurse's views and opinions were not listened to. She was visibly demoralised and discouraged by her views and opinions being so patently discounted. Eventually, there was an abrupt change of approach, very near to the time of death.

Nurses were unhappy when they disagreed with what was happening, but generally, they did not seek to change the direction of care. When discussing medical plans in handover meetings, I noticed nurses frequently used 'they' to refer to the doctors - 'they haven't done this' or 'they should do that'. Nurses complained and sighed but did not suggest taking any action. This suggested powerlessness and a lack of agency to influence. The internationally educated nurses notably did not question or challenge doctors. An experienced nurse, who had come to assist from another ward, encouraged the nurses during handover to speak to the doctors about their concerns about a patient. She said to me afterwards, '*nurses are not confident to speak to doctors nowadays'*.

A senior nurse described the consequence of this:

> *Participant 1, p.7. Senior nurse, Europe: ... what's concerning now is that we have a really junior workforce who don't recognise when that's the appropriate thing to do [challenge doctors] and maybe are not confident enough to do it [speak up]. So, because of that, we're going to see more cases of inappropriate care for longer periods when we could just be making those days, those final days for people, comfortable.*

Nurses recognised the consequences of not speaking up could be the continuation of futile treatments and the prolonging of the suffering of dying patients.

> *Participant 3, p.8. Senior nurse, UK: We need to be braver. We need to discuss it as nurses, why they haven't spoken up and challenged the decision.*

Nurses deferred to doctors even when they were aware they had more knowledge and experience than a newly qualified doctor, particularly around recognising dying. Interestingly, I also saw nurses defer to physician associates who had less experience than many of the nurses. Physician associates train within a medical model. They acted like doctors and nurses appeared to ascribe a similar status to them.

The following passage highlights how nurses have limited agency to act in ways they believe are in the best interest of their patients:

> *Field notes: The night nurse was tired and appeared stressed when she came into handover. A patient had deteriorated overnight. Their NEWS score was 17. By the morning, she was unresponsive and dying. In the handover the night nurse told how she had called the on-call doctor. She was upset the on-call doctor did not start the P-CEL care plan. She said, 'to be fair our team should have done it' [meaning the day medical team]. The patient was in fast atrial fibrillation. The nurses were asked to insert an intravenous cannula so medication could be given to treat the atrial fibrillation, but they were unsuccessful in their attempts. The medication was instead given orally. The nurses were angry that she was actively treated. They said she had been deteriorating over days and, in their opinion, she was dying. They saw the treatment as prolonging her suffering. A senior nurse said 'they [doctors] need to trust nurses more and listen to colleagues'. Another nurse said, 'There's an issue in this Trust, doctors think nurses know shit'.*
>
> *Later that morning in the multidisciplinary team meeting, another senior nurse (participant 3) was particularly vocal and angry about the overnight events. The consultant defended the actions the on-call doctor took as the 'patient was symptomatic' and consented to the treatment. The consultant was defensive and spoke with authority. I was surprised at how quickly the nurse backed down and deferred. She said to the consultant, 'Ok I understand', but for me there were still questions unanswered.*

Later that day, I interviewed this nurse. She explained how she had known the patient for around six months, and she had recognised over a week before that she had deteriorated. She said:

Participant 3, p.2. Senior nurse, UK: *'I could see a vast difference and even in like a pallor, everything was different'.*

She and the medical team had previously had conversations with the family and the patient, who were aware there were no curative treatments. The patient had had Cheyne Stokes breathing that night and the nurses thought it clear she was imminently dying.

As soon as this nurse arrived on the ward that morning, she went to see the patient. She stayed with the patient and was with her during the handover when she died. She said to me:

> *p.7: 'If you've decided someone's going to die why do her obs [sic]? Why are we canulating in the last hours of their life? What are you doing? To me – and I may be very wrong, why? I don't understand that'.*

She questioned whether the patient really could give informed consent for treatment, as I did. She said:

> p.7: '*Yeah, did she really? So how have they explained what they're going to do to her? So, have they said this will make everything better? Like what words did they choose? Have they sold her a cure by just using the wrong words? So has she agreed because she thinks this will buy her a few more days. That was what I was so frustrated about, and I just feel that, all right, maybe it's my own, my own ideals of what I see as a good death. Maybe I'm in the wrong … I think we all build these pictures in our heads, and we all have our own ideals of what we would or wouldn't like, but for me it's about peace. It's about being pain free. It's about I mean - hospitals. You know, some people do choose to die here, and it is more common, but make it as comfortable an environment as you can. It's*

> *not about being stuck with needles and cannulas and giving boluses of drugs. That's what I was annoyed about and [pause], It's hard, it's hard.'*

This nurse reasonably questioned why they were still taking observations on someone who was dying. I would ask, why continue these observations when they could only either be ignored or acted upon inappropriately? I also question whether treating the atrial fibrillation was the best way to manage symptoms, rather than a comfort-focused approach that included administration of medications such as opioids and benzodiazepines. The patient's medical records and clinical information were not available to me, but I recognised I sympathised with the nurse's opinions and shared her discomfort about the overnight events.

The above episode highlights several issues. Firstly, the night nurses were disempowered to act in the way they felt was right. Interestingly, the senior nurse suggested to me that the nurses' inability to cannulate the patient could be a covert method of the nurses avoiding acting in a way that they believed was wrong. This reflects findings from an ethnography on an acute elderly care ward which described nurses using alternative strategies such as 'go slow' or passive-aggressive strategies when they disagreed with treatment decisions (Costello, 2001). The junior doctor involved did not have sufficient guidance or information from the patient's usual medical team, hence was not confident to make the decision to start the P-CEL care plan. The senior nurse was very experienced and knowledgeable and unusually outspoken, but even she quickly retreated and readily conceded to the doctors when they defended the overnight decisions. I was struck by how disheartened she was and how much the events conflicted with her values.

Nurses had insight into and were sympathetic to the challenges faced by doctors, particularly when expected to make decisions where the regular team had not adequately communicated plans or limits of interventions. A nurse gave her opinions on this:

> *Participant 11, p.10. Senior nurse, Nepal: The on-call doctor will put the patient on P-CEL if there is a plan from the consultant from the daytime saying, 'OK. If the patient deteriorates tonight dot dot dot [sic] the plan is to put the patient on P-CEL. ... or the doctor says, 'if the patient becomes unwell tonight and starts to desaturate the patient can be P-CELed'. But if there is not any plan from the regular doctors it's a very big decision for the on call FY1 [newly qualified doctor] to put the patient on P-CEL.*

On several occasions I observed situations when the regular consultants had documented clear plans and ceilings of treatment, with advice to start the P-CEL plan should the patient deteriorate. Even in such cases out-of-hours doctors were not always confident to start the P-CEL care plan. Only a doctor could make the decision to start the P-CEL care plan. A question for me is why the nurses could not implement the P-CEL care plan, especially when the patient's medical team had clearly outlined that this was appropriate. Not empowering nurses to do this seemed like an important limitation of a care plan that was meant to enhance end-of-life care:

> *Participant 12, p.2. Senior nurse, UK: It was clearly documented on the plan that if patient loses access [intravenous] then they will be for end-of-life [sic] and the patient's cannula was clearly tissued [sic]. And I was like, yeah. I need to let the doctors know that this is the plan from the day team, I was on a night shift, but I think I was waiting about three or four hours for a doctor to finally come up and make that decision.*

In addition, whilst senior nurses expected the nurses to participate in ward rounds, nurses felt they were too busy and rarely did. This limited nurses' opportunities to express their opinions and contributed to their disempowerment. Nurses kept themselves informed by reading the patients' electronic patient records afterwards, but this could be several hours after the ward round.

As discussed in the theme 'denial', the language of communication in the setting was numbers, scores and other measurable parameters. At times, nurses found this inadequate and tended to rely more on intuition and visual signs and symptoms. This led to communication problems between nursing and medical teams. Doctors prioritised patients for review based on these scores. This limited nurses' ability to influence. Here a nurse describes the impact of this when she asked a doctor to review a patient she was concerned about:

> *Participant 7, p.5. Staff nurse, Asia: … I did escalate to doctors, but they asked what the NEWS score was. Her NEWS score was zero and her GCS [Glasgow coma scale] was 15 so in that case I found it challenging. I didn't know what to tell the doctors because we cannot ask them to rush come down because [pause] her GCS is 15, NEWS is zero, but she IS slowly declining. When I call the doctors they want to know the NEWS score …*

Nurses' limited ability to influence care was a symptom of a hierarchy. The consultants introduced themselves and were called by their titles, but they called the nurses, even the senior nurses, by their first names. This is so commonplace in clinical settings that it almost seems unnecessary to mention, yet it serves as an indicator of how embedded hierarchy is in the cultural fabric of the environment.

Nurses talked about not being allowed to act on their own initiative:

> *Participant 19, p.8. Senior nurse, Asia: We cannot do anything. We are not the doctors, so if they don't take the decision, ... we just carry on with what they are saying.*

> *Participant 9, p. 8. Staff nurse, Africa: ... we might actually see this patient needs to be on P-CEL as she is actually passing [sic]. The obs [sic] are all over the place. So yeah, based on our own conclusion, it might just be like, if she's on P-CEL we will make her more comfortable. But if she's not then you still give the active treatment ...*

Nurses continued to carry out treatments they believed were futile, despite recognising a patient was dying. A senior nurse explained this was partly because they were worried that, unless they were explicitly told not to, they would ‘get into trouble’. Instead, they continued until they were told otherwise.

> *Participant 12, p.2. UK: ... we’ve had patients that doctors have made the decision to put on end-of-life [sic] and then they’ve died within the hour ... Sometimes that just makes me think how long they have just sat there when we could have been doing pain control, pain management, or you know, the family could have seen him a bit more comfortable. ... if I see a patient is clearly dying, that they’ve probably got hours or even days, if they’re NEWSing [sic] a 12 I still have to escalate that because they’ve not told me to stop.*

These above quotes also highlight another issue: the apparent dichotomy between active and palliative management. Comfort measures and active management were viewed as mutually exclusive.

Whilst some, but not all, experienced nurses were confident to question doctors, most nurses were not. Many nurses had strict perceptions about what they were allowed, or not allowed to do, including with regards to talking to families about dying:

> *Participant 13, p.3. Staff nurse, Africa: I try not to disclose the information, especially to families or relatives, because it's not my place to have that conversation with them. I have never told a relative that this patient is dying unless the doctor has already said this patient should be put on P-CEL and the nurse-in-charge is aware.*

Some of these perceptions were not based on any official protocols or guidelines but were implicit and embedded in the setting's unwritten rules and were observed. They were symptoms of a culture that maintained the traditional power dynamic between doctors and nurses (Costello, 2001). However, adhering to these 'rules' masked nurses' lack of confidence and discomfort about death and dying.

The reduced agency of nurses may hinder them from acting in the best interests of their patients. Ultimately this could lead to the prolongation of futile treatments and delay change to a comfort-focused approach for dying patients. A patient had to be 'officially' recognised as dying by a doctor, which then prompted a series of actions. This is discussed further in the final theme, delay.

4.6.6 Delay

The culture of denial and discomfort, along with the limitations on nurses' agency, all contributed to a delay in the change to comfort-focused care. For a transition to comfort-focused care to occur, the possibility of dying needs to be acknowledged. Recognising dying is known to be complex and often only happens very close to the time of death. This is problematic as it can mean futile treatments are continued that may increase or prolong suffering.

Recognising dying on these acute medical wards was characterised by uncertainty. Integral to recognising dying is recognising the futility of continuing active treatment and that the trajectory towards death is irreversible. Recognising dying on the gastroenterology ward brought challenges due to an often younger age group of patients, for example, patients with alcoholic liver disease. Whereas decline may be obvious where there is frailty, in the younger age group their deterioration may be less obvious. Nurses spoke about how lack of frailty and relative youth could mask the extent of a patient's ill health, in conflict with the picture their biochemistry results gave. This could result in the recognition of dying being delayed and the change to comfort-focused care occurring very near to the time of death.

Nurses also talked about the prognoses of some diagnoses being more unpredictable, making recognising dying more challenging. On both wards, patients would frequently be admitted very unwell, were treated, and then sometimes beyond expectations, would recover and be discharged only to be admitted a few weeks later with the same issue. This led to a challenge in determining when active treatment should be stopped and a change made to a comfort-focused approach:

> *Participant 16, p.5. Senior nurse, UK: You don't know when to stop because you know that some of them could rally back.*

This cycle would continue until one day the patient stopped responding to the treatment.

Nurses recognised dying through a combination of intuition and various sources of information, including knowledge of the patient's history, blood test results and observations, as well as declining function.

> *Participant 5, p.3. Senior nurse, UK: You get a sense of people when you've nursed people for a long period of time, and you can come in and sort of look at something and*

> *think, ‘Oh you're not right’. I mean, obviously sometimes the observations will tell you if the blood pressure is in their boots and their heart rate’s all over the shop or they're a little bit more muddled than they usually are. Or their mobility just suddenly crashes, and they were previously up and mobile, and now they're not.*

This often involved a gradual realisation based on the patient not getting better despite interventions.

> *Participant 13, p.2. Staff nurse, Africa: … the patient may not be responding to interventions. So you just know that the medics are running out of options, and it is possible the patient may be dying.*

However, inexperienced nurses relied more on measurable parameters such as observations, NEWS scores, urine output and oxygen saturation, suggesting that intuition and the ability to integrate different sources of information comes with experience.

Knowing patients over time impacted how nurses recognised dying. Nurses were aware they knew patients better than the doctors, and the doctors knowing patients less well could be a barrier to recognising dying. Nurses’ greater familiarity with patients enabled them to recognise more subtle signs and changes in behaviour.

> *Participant 12, p.4. Senior nurse, UK: … you get to know them; you know what they’ve come in with every time. You sort of know when they started to get unwell, you know when they're starting to get better, and then once you then start to recognise what you’re doing isn’t really working … when they start coming in more frequently, you know that there is something going on.*

When a patient failed to respond to treatment, there began a period of information gathering until the point of realisation a patient was irreversibly dying. This period eventually culminated in a doctor declaring a patient was dying, meaning a change in approach to comfort-focused care could occur. This process was influenced by several factors already explored, such as the culture of denial of death, discomfort with dying and the limited agency of nurses, whose opinions were not heeded. Organisational issues also impacted the process, such as a senior doctor not being available to confirm dying. During this period several actions took place: discussions with families, decisions about the limits of treatments, such as not to escalate care to the intensive care unit and the completion of a ReSPECT form. The ReSPECT form is used in many hospitals and other settings in the UK. It is a summary plan for escalation in emergencies (Resuscitation Council UK, nd) and is where 'do not attempt cardio-pulmonary resuscitation' discussions are documented. During this period, 'end-of-life medications' were often pre-emptively prescribed for managing common symptoms such as pain, agitation, nausea and secretions. These actions were implemented by doctors, but sometimes nurses, particularly senior nurses, would prompt or suggest them. Sometimes the palliative care team would be asked to review a patient to assist with decision-making around the goals of care or symptom management. Nurses would often initiate this referral, especially when they felt they needed support in influencing a change to a comfort-focused approach or did not feel listened to by the medical team. All this activity occurred whilst active treatment, investigations and observations continued. Regardless of an awareness that continued treatment was futile and a patient may die soon, the final change to a comfort-focused approach was often delayed to very close to the time of death. This was sometimes as little as a few hours, or did not happen at all:

> *Field notes (gastroenterology ward): During the morning handover, a patient with advanced cancer was discussed. He was said to be in 'the last weeks'. The night nurse*

spoke of him being unsettled and agitated all night with no apparent cause. I wondered whether he could be terminally agitated. After handover, I decided to focus my observations on the nurse allocated to care for this patient. The patient looked uncomfortable and his eyes were closed. He was trying to get out of bed. The nurse carried out some observations on the patient. There was little interaction between the nurse and the patient, and the nurse focused on tasks such as attending to the intravenous lines. I asked him, an internationally educated nurse who had only been a nurse in the UK for 6 months, what he thought was happening with this patient. He seemed unsure and hesitant. He told me that the patient was having intravenous antibiotics and intravenous fluids and had a syringe pump for pain management. He didn't mention that the patient could be dying or express any concern about the patient's condition. To me, the patient looked like he could be terminally agitated [restlessness commonly seen close to the time of death]. I was concerned that his agitation was not being noticed and was certainly not being addressed. I was aware that my role was that of researcher and not a nurse, but I was also aware that, as an experienced palliative care nurse, I was more likely to recognise signs and symptoms of agitation and to know how to respond. I felt the morally correct course of action was to intervene. I asked the nurse whether the palliative care team knew about this patient. He told me they did, so I suggested he called them to ask them to review the patient. At this point I left the bay and went to the multi-disciplinary team meeting. This patient's current condition was discussed - the consultant said to cancel the CT scan planned for that day and 'get him to the hospice'. Dying was not mentioned but was inferred. Moments later, the crash bell went. The doctors and nurses immediately rushed out of the meeting. The patient had had a large bleed and died.

I spoke to the staff nurse later and asked him if he was surprised that the patient had died that morning; he said he was, but didn't elaborate further. He looked out of his depth and uncomfortable. The nurse in charge said she knew the patient was very unwell but also did not expect him to die that morning. She went on to explain how frequently patients had sudden bleeds on a 'gastro' ward. In this case, the actual imminency of dying may have been difficult to predict. However, as the patient was being referred to the hospice for end-of-life care, the doctors had clearly recognised the futility of active treatment. The nurse in charge explained her views about delayed change to a comfort-focused approach, when, despite decisions about limits of treatment and recognising inevitable dying, there was no change in approach:

> *Participant 5, p.9. Senior nurse, UK: I think that you get to that point where people want to carry on actively [sic], for example, someone's on the highest strength antibiotic that we can possibly throw at them, non-invasive ventilation, and we're going to try that for 48 hours. And then we're going to stop. We're not gonna add anything. We're not gonna escalate their antibiotics. We're not gonna escalate them to ITU, we don't need outreach to come and see them. Not going to do any more investigations. We're not gonna do an ABG [blood gases] if their oxygen drops. So at that point, I would argue you put your P-CEL paperwork in ...*

In order to effect a change to comfort-focused care, a doctor had to declare someone as dying. This prompted several actions: referral to the palliative care team if they were not already involved, and, most importantly, the P-CEL care plan was started, commonly described as the patient being 'P-CELed'. This occurred when a patient was thought to be in the last days or hours of life and signified the change to comfort-focused care. The P-CEL care plan prompted other actions such as attempts to move the patient to a side room, referral to the chaplaincy for pastoral or spiritual support, provision of comfort measures for families such as a quiet relatives' room, and relaxed visiting hours. Starting a patient on the P-CEL care plan, or 'P-CELing' someone, was a watershed moment, representing a distinct step. Glaser and Strauss (1968) called this a 'critical juncture'. P-CEL consisted of guidance for end-of-life care involving two-hourly patient checks with patient comfort as the priority and main focus. This change in approach was often abrupt - treatment with the intention of prolonging life continued, and then was stopped. This would often occur very close to the time of death. The P-CEL care plan signified a change in the status of the patient. Despite the nurses' apprehension and discomfort around dying and the emotional burden they experienced with end-of-life care, nurses became visibly relieved once P-CEL was implemented. Nurses spoke positively about P-CEL, even those that found the concept of end-of-life care challenging.

> *Participant 20, p.9. Staff nurse, UK: So if I know that this patient is not getting any better and he's dying, yes I feel sort of, you know, what is the word, sort of relief. So we're not poking that patient. We're not, you know, causing them discomfort and pain and things. So yeah, I feel as soon as I know that patient is on P-CEL, so for the patient I feel better, because we're prioritising comfort now. So we're not actually bothering them with needles and those sorts of things.*

Nurses, particularly the less experienced ones, found P-CEL helpful as a prompt:

> *Participant 9, p.7. Staff nurse, Africa: OK, so there is like a P-CEL plan. So we follow that every two hours. So you fill it up - is the patient comfortable, has the patient had mouth care, has the patient had hygiene? ... Do they need anything basically. ... so it's like a prompt.*

However, several nurses described it as a 'tick list'. A nurse described the limitations of this:

> *Participant 3, p.8. Senior nurse, UK: It's just a tick list at the end of the day, so you stop using your eyes, your ears, your brain and you're just like 'oh they're not in pain, well they're OK, I can tick that one off' ... but are there things you're not noticing because you're focusing on a checklist?*

The P-CEL care plan suited the protocol and routine driven nature of the nurses' work, partly explaining their comfort with it. Once the patient was on the P-CEL care plan, the doctors then stepped back, and nurses took the leading role.

4.7 Conclusion

The transition to comfort-focused care for dying patients in the culture of these acute wards was complex and was influenced by many interlinking factors, which impacted how nurses managed this process. In this chapter, I have presented six themes to explain how nurses in the acute hospital setting manage transitions to comfort-focused care for dying people. Firstly, there was a culture that denied dying, where speaking about dying was fraught with difficulty and some nurses did not view end-of-life care as a nurses' role. The needs of dying patients were sometimes placed second due to the competing demands on nurses' time and attention and the more time critical nature of acutely ill patients' needs. This was not a result of intentional neglect but rather a difficult consequence of both individual nurses' responsibilities and broader system constraints. However, nurses' discomfort with end-of-life care sometimes led them to avoid engaging with dying patients. While this also was not an intentional act of neglect, it was a response to the emotional challenges they faced. Nurses experienced moral dissonance, particularly when required to continue treatments that conflicted with their values and opinions on the balance of benefits and harms of those treatments. For some nurses, particularly internationally educated nurses, the concept of palliative care itself was challenging as it conflicted with their belief that active treatment should continue until the moment of death. Nurses' ability to influence a patient's transition to comfort-focused care was diminished as their views, opinions and knowledge were not heeded. This failure to have an effective voice meant nurses were not empowered to influence the priorities and direction of care. The culture of denial and discomfort towards dying and the limited agency of nurses contributed to the delay in the acknowledgement of when treatments were futile, deterioration irreversible and a person was dying. Dying was 'officially' confirmed by doctors, at which point the status of the patient was changed to a dying patient or the 'P-CEL' patient. The care of the patient was then changed to a comfort-focused approach. This was a distinct shift and often close to the time of death. It was a case of active management – or not. However, despite the emotional challenges nurses experienced caring for dying patients, they were relieved and more comfortable as the priorities of care were then clear and agreed and P-CEL gave the nurses clear directions to follow.

Chapter 5. Discussion

5.1 Introduction

The purpose of my research was to explore how nurses working in acute hospital settings manage the transition to comfort-focused care for people who are dying. I collected ethnographic data through observation and interviews, over a period of twenty-three weeks. Using Roper and Shapira's approach to analysing ethnographic data, I developed six explanatory themes (Roper & Shapira, 1999). These themes are presented in Chapter 4. I named them Denial, Discomfort, Competing priorities, Moral dissonance and Nurse agency, and they culminated in the final theme, Delay. These themes illuminate the complex intersection of influences on and features of how nurses manage transitions to comfort-focused care in the culture of acute settings. In this chapter, I discuss how these themes relate to existing literature and highlight what my research contributes to knowledge.

I start by summarising my main findings. I then discuss the cultural context of the research setting. Issues arising from the findings are explored, including challenges experienced by internationally educated nurses, a task-oriented approach to care, emotional and moral distress, futility, and finally, ritual and transition. I discuss the strengths and weaknesses of my research, its contributions to knowledge, and my recommendations for policy, practice and future research. Finally, my overarching conclusion reflects back to the original research question and summarises the implications of my findings.

5.2 Summary of findings

My research revealed a culture of denial towards death and dying. Dying was not directly talked about, and euphemisms and acronyms were used instead. Many nurses believed that end-of-life care was at best a secondary activity, or even should not be a role of the setting at all.

Nurses felt compelled to prioritise care of acutely deteriorating people where there was hope of recovery over care of dying people meaning the needs of dying people were attended to later. Nurses prioritised routine tasks over person-centred care, even when this conflicted with nurses' own values. There was discomfort towards dying, leading to nurses, at times, avoiding dying people. Inexperience, lack of knowledge and confidence contributed to this discomfort. There was a large gap between the knowledge, confidence and experience of senior nurses and the newly qualified nurses and internationally educated nurses who had recently arrived in the UK. Senior nurses played an important role in supporting less experienced and junior nurses. The nurses looked to palliative care nurses for support and for validation of their opinions. Caring for dying people within a culture that denies dying and where dying people are deprioritised had an emotional impact on nurses, especially when it resulted in nurses giving care that conflicted with their views and values. The empathy nurses felt towards dying people and their families added to the nurses' distress.

There was a hierarchy that disempowered nurses and lessened their agency to influence the transition to comfort-focused care. The culture of denial and discomfort towards dying and the limited agency of nurses all contributed to late recognition of dying and a delay in the change to comfort-focused care. This change was a watershed and often happened abruptly. Once the patient was declared as dying by a doctor and the decision was made to change to a comfort-focused approach, nurses felt relieved and more comfortable.

5.3 Cultural context of dying in the acute setting

In these acute wards, the transition to comfort-focused care occurred in a culture where end-of-life care sat uncomfortably alongside the priorities of treating, stabilising and discharging patients within as short a timescale as possible. The culture of the acute medical wards where I carried out this research was one in which dying was not directly spoken about (4.5.1). This denial was evident from the indirect ways adopted to refer to dying but also, although with good intentions, by the removal of dying patients from view to help protect the feelings of other people. Dying patients were contained and separated in side rooms whenever possible. Over fifty years ago, Glaser and Strauss (1968) observed in their study of dying in hospital that dying people were separated so nurses could control their work and manage their own emotional response and to protect others from the unpleasant or distressing aspects of dying. A later study similarly suggested that in hospices, people who are unpleasantly dying or have ‘unbounded bodies’ are segregated to outwardly maintain a sanitised version of death and dying (Lawton, 1998). My research reveals that little, if anything, has changed.

Many nurses believed the fundamental role of the acute wards was to save lives, not to provide end-of life care (4.5.1). However, caring for dying patients is clearly a role of the acute hospital setting; in the UK in 2022, 43% of deaths occurred in hospital (Office for Health Improvement and Disparities, 2024). Despite the trend for people to die at home, dying in hospital is inevitable for many people. People are admitted to hospital due to acute events or deterioration of chronic illness, and, despite efforts to stabilise and cure, at times they do not recover. People are also frequently admitted to hospital when death is relatively imminent due to a health, social care or family crisis.

For nurses the transition to comfort-focused care was fraught with uncertainty, anxiety and, sometimes, frustration. This was a social transition phase or state of liminality (Van Gennep, 1960) (originally published in 1909). However, during this transition, the patient would receive treatments and interventions until either they recovered or the futility of continuing treatment could no longer be denied, and the person became categorised by a doctor as a dying patient. The interval between doctors recognising a patient’s irreversible deterioration and the futility of active treatment and their death could be as short as a few hours - or be non-existent.

The culture of the acute hospital represents and reflects the wider culture in which it is situated (Van der Geest & Finkler, 2004). Death within UK culture is much less manifest than a hundred years ago. Improvements to survival rates have meant people have less direct exposure to death. Familiarity with dying has been replaced by increased medicalisation of dying and discomfort towards it (Wilson et al., 2024). Whereas in the 19th century hospitals were places the poor went to die, the 20th century saw hospitals become medicalised and places of treatment and recovery (Glaser & Strauss, 1968; Kisacky, 2019). Modern medicine has meant that the timing of dying in acute settings can, to some extent, be controlled; the timing of death may, at times, be negotiated between doctors, nurses, patients and their families (Helman, 2007). Over the last few decades, there has been an increasing drive towards evidence-based care that is protocol driven, measurable and auditable and under which patient deterioration is responded to by escalation and treatment. End-of-life care, the primary aim of which is comfort, does not sit naturally with this model.

5.4 Internationally educated nurses

The majority of the nurses I studied were internationally educated nurses from African countries. Most had been in the UK less than two years. The cultural differences between beliefs and attitudes towards end-of-life care prevalent in the UK and of the country in which they trained, brought challenges for internationally educated nurses (Balante et al., 2021; Zanjani et al., 2018). Some challenges, such as discomfort talking to families about dying and lack of relevant experience and confidence, were the same as faced by UK educated nurses but were amplified for these nurses due to cultural attitudes and beliefs about end-of-life care and around nurses' place within the hierarchy. End-of-life care was an alien concept for many. Many saw it as giving up on the patient, a last resort (4.5.1). These nurses spoke of being well prepared for the technical aspects of nursing but felt underprepared for the culturally different approach to end-of-life care. Many of the nurses explained that in their home countries people did not generally die in hospital, or if they did, they were actively treated until they died. These nurses were experiencing their own social transition from being a newly arrived, internationally educated nurse to becoming comfortable and adjusting to their role in a new setting. Choi et al. (2019) suggest that internationally educated nurses are in a liminal space as they go through the acculturation process. As well as needing to adjust to different beliefs, values and organisational culture, they often experience challenges in adjusting to differences in power differentials between members of the clinical team. Adjusting to differences in hierarchical relations can be particularly challenging to these nurses due to deeply held beliefs about professional hierarchies (Choi et al., 2019). This helps to explain the reluctance and difficulties I observed in internationally educated nurses around challenging doctors.

Being exposed to cultural conflicts can lead to anxiety, helplessness and distress, and prolong the liminal stage (Choi et al., 2019; Zanjani et al., 2018). As Balante et al. (2021) suggest, understanding the experiences of internationally educated nurses is essential to support and enable them to provide culturally competent care. However, the findings of my research suggest it is equally important to build their confidence, skill and knowledge to support them to adapt to the cultural context of end-of-life care in the UK and to emotionally prepare them to undertake this work.

Although the internationally educated nurses had some beliefs, attitudes and challenges in common, they came from diverse cultural backgrounds and geographical regions. They were therefore likely to have differing and diverse beliefs, attitudes and practices around end-of-life care; further research would need to elicit the nuances of these. There is limited specific research about the experiences of internationally educated nurses in end-of-life care. Given the extent to which internationally educated nurses are employed within the UK health service, further investigation is urgently needed on how a culturally diverse nursing workforce influences both ward culture and end-of-life care, and how different world views can be accommodated. Supporting the nurses with acculturation requires mutual accommodation (Choi et al., 2019; Willis & Xiao, 2014). This requires humility from the host organisation and a shift in attitude from a belief in the innate superiority of westernised nursing (Choi et al., 2019).

Amid a growing international nursing workforce, nurses are required to care for an increasingly culturally diverse population. To provide safe, equitable and effective care requires all nurses to be culturally competent (Ličen et al., 2019). Cultural competence is essential as dying is culturally and socially situated, is associated with high levels of distress and requires culturally sensitive care to meet the holistic needs of dying people (Lambert et al., 2023).

5.5 Task-oriented care

Particularly apparent in the theme 'Competing Priorities' was the embedded culture and normalisation of fast-paced 'busyness,' with little time for nurses to reflect and process events. Busyness was a dominant narrative. The normalised context of busyness was used to justify the prioritisation of acute tasks. This reflects previous research that found that the narrative of busyness controls and dictates nursing work (Chan et al., 2018; Nagington et al., 2013) and also determines expectations of patients, families and the organisation (Nagington et al., 2013). There was an innate assumption as to the greater importance of curative care over end-of-life care. Other recent studies similarly found that nurses favoured a task-oriented approach under which they prioritised biomedical tasks prescribed by doctors, whereas 'palliative tasks' were deprioritised (Chan et al., 2018; Sharp et al., 2018). As a consequence of this busyness, nursing tasks were often incomplete. However, Govasli and Solvoll (2020) found the more relational aspects of care and addressing patients' emotional needs were most neglected. This was reflected in my findings by the deprioritisation, and, in effect, second-class status of dying patients. Although the prioritisation of task completion and technical tasks was common to most nurses, this was amplified by the preference of internationally educated nurses for this approach and reflected their discomfort and lack of confidence in caring for dying people. (4.5.3).

At times it was more important for the nurses to be seen to have completed the tasks and ticked the boxes in the P-CEL care plan than to have actually provided the care to the dying patient. A stark example of this was the situation relayed by a senior nurse where two hourly checks of a dying patient were ticked as having been completed, despite their family reporting that no nurse had entered the room for six hours (4.5.2). The P-CEL care plan provided a structure for the application of a task-oriented approach to end-of-life care, in keeping with the rest of the nurses' work. Many nurses referred to the P-CEL care plan as a tick list. This is reminiscent of the Liverpool Care Pathway, commonly shortened to LCP. The Liverpool Care Pathway was a widely used UK care plan to guide care of dying people, which was withdrawn following concerns about poor and inappropriate implementation (Neuberger et al., 2013). The official investigation found that the Liverpool Care Pathway was sometimes used as a tick box exercise, often in the absence of actual care (Neuberger et al., 2013). It was followed as a protocol rather than used as guidance, at times being routinely and inappropriately applied, with a lack of consideration of the individual needs of dying people. People were even referred to as being 'LCP-ed', used as a verb, seemingly reducing it to a single action (Neuberger, 2016). The similarities I observed in the use of the term P-CEL, for example, P-CELed, P-CELing, the P-CEL patient, were striking and indicated lessons had not been learnt at an organisational level.

This prioritisation of technical tasks and task completion occurs despite the ostensible drive and rhetoric about person-centred care in the UK over the last two decades (Abou-Saleh, 2023). Recent studies found that nurses prioritise task completion and physical care over individualised holistic care (van Belle et al., 2020). Costello (2001), in an ethnographic study of an acute elderly care ward, similarly found inconsistencies between nurses' stated beliefs in the importance of psychological care of dying people and their actions; despite nurses expressed beliefs, physical care was prioritised over psychological care. This inconsistency was demonstrated in my research by the nursing handover on the respiratory ward, which simply consisted of a list of tasks and bed numbers (4.5.2). This reflects previous research, which found efficiency and task completion to be highly valued by nurses and gained the approval of colleagues. However, this creates a tension for nurses as the failure to provide person-centred care conflicted with their professional values (Sharp et al., 2018).

The drive for efficiency and task completion was a contributing factor in the deprioritisation of dying patients. Dying patients, especially in side rooms, were avoided and attended to last (4.5.1), after medicines had been administered and observations taken on the other patients. This points to a tension between curative acute care and end-of-life care (Chan et al., 2018). The prioritising of curative care over end-of-life care reflects the cultural beliefs and attitudes that hospitals are there to save lives and are not for the dying. It also reflects the wider societal cultural discomfort towards dying. Unfamiliarity with dying and the medicalisation of dying, contributes to a social expectation of hospital admission, even when there is unrealistic hope of recovery.

The deprioritising of dying patients and the task-oriented approach were a response to numerous factors, including staffing levels, busyness and volume of work, rather than a conscious intention of individual nurses to neglect the needs of dying patients. Indeed, findings from high profile UK health scandals suggest that nurses' approach to care practices is a response to organisational culture and circumstances rather than individual culpability (Francis, 2010; Kennedy, 2002, 2010). There are parallels with Goffman's 'Total Institution' theory (Goffman, 1961). Jenkins et al. (2022) suggest that modern day hospital culture has elements of these 'Total Institutions'. Just as patients are 'mortified', or subjugated when they are admitted to hospital and expected to conform, comply and renounce their identity, nurses are also subjugated (Jenkins et al., 2022). Factors such as electronic record systems, key performance indicators, audits and inspections mean nurses' work is under constant surveillance, and their own agency and autonomy are reduced to serve the organisational drive to maximise efficiency. This militates against person-centred care and nurses' autonomy and agency and can result in nurses being compelled to administer treatments they disagree with, poor care and moral distress.

5.6 Emotional burden and moral distress

Nurses expressed regret about the deprioritisation of dying patients, but they felt they had no choice. This signifies the innate, unspoken assumption that dying patients should take second place to those that were going to recover. However, this deprioritisation contributed to the emotional burden nurses experienced with end-of-life care. Nurses expressed guilt and distress as this conflicted with their personal and professional values (4.5.4). Nurses may also distance themselves from dying patients and favour task-oriented care as a protective mechanism to avoid exposure to patient suffering (Fernández-Basanta et al., 2023). Also contributing to nurses' emotional burden was their lack of time to pause and reflect due to the unrelenting pace and pressures of their role. Storaker et al. (2017) termed this 'painful busyness'. They describe this as an unpleasant experience for nurses that is determined by the volume of work and pace and the inability to provide care that nurses believe patients need, resulting in feelings of guilt and powerlessness.

Emotional burden and distress caused by the inability to act in what is thought to be the ethically correct way due to institutional constraints is termed moral distress (Jameton, 2013). In my research, I found the distress that nurses felt was often consistent with this. Moral distress is important as it is known to affect nurses' physical and psychological wellbeing and can lead to 'burnout' (Lamiani et al., 2017; Xue et al., 2024). Nurses described and were also observed in situations where their actions conflicted with what they believed was right. This included when active treatment continued despite their belief it was futile and was adding to the patient's burden (4.5.4).

Nurses also experienced moral distress when their views and observations were not listened to or believed, and they felt powerless to influence patient care (4.5.4, 4.5.5). In a recent study, this type of moral distress was described as ‘epistemic injustice’, which refers to when nurses are not considered ‘credible sources of information’ (Morley et al., 2023). This contrasted with the attitudes of nurses and doctors towards palliative care nurses, who were relied upon to guide decision-making and were highly respected (4.5.3). Radford (2012) argues that where specialist nurses have achieved more power and influence, this in turn can reduce the power and influence of non-specialist nurses and junior doctors. Certainly, a change to comfort-focused care was at times delayed until the palliative care nurses had reviewed the patient (4.5.3). Nurses and doctors also relied upon these specialist nurses to instigate symptom management, and nurses trusted and relied upon them for backup and support when they felt their voices were not being heard (4.5.3). However, since Radford’s research, nurses working in specialist and advanced practice roles have increased and their roles have evolved; hence, the impact of this on the agency, confidence and influence of ward nurses would benefit from further research.

Nurses are more closely and constantly involved with patients than doctors and therefore arguably feel patient distress and suffering more intensely. Consequently, futile treatments that add to the burden of patients are more likely to have an emotional impact on nurses. In keeping with other studies, looking after younger patients and patients they knew well increased nurses’ emotional distress (4.5.4) (De Brasi et al., 2021). Talking to relatives of dying patients was a key source of anxiety, and nurses wanted support in this area (4.5.1). The nurses expressed a desire for more experience and training in end-of-life care (4.5.3). Selman et al. (2015) found that end-of-life care education increased confidence, particularly in communicating with patients, families and colleagues. However, the effectiveness of training courses in supporting nurses to deal with the emotional burden of end-of-life care is variable (De Brasi et al., 2021). Although education and training may address some of the causes of emotional burden in end-of-life care, such as lack of knowledge, this assumes that the problem lies with individuals rather than the culture of the organisation. Education alone would not address many of the issues that constrain nurses, such as their limited agency, the drive for task completion, and being required to carry out care in conflict with their beliefs and values. Addressing these would necessitate a change in culture that would require organisational, structural and leadership change.

5.7 Futility and uncertainty

The ward discharge coordinator had a prominent role in the ward team and attended the daily multi-disciplinary meetings. The need to free beds for waiting patients was a constant imperative driving the discharge process. The dominant goal was to cure, stabilise and then to discharge patients. Patients who were not improving in the expected timescale disrupted this process, and patients could become ‘stuck’ (Kaufman, 2005). This prompted interventions and treatments until patients stabilised and improved, or a doctor declared these to be futile and the patient to be dying.

Futility refers to when it is perceived that there is no benefit to a course of action in terms of cure, alleviation of symptoms or prolongation of life, or that any benefit of such action is outweighed by the potential harm. Futile treatments and investigations can harm patients, cause moral distress to staff and waste resources (White et al., 2016). Although there is broad agreement as to the meaning of futility, there is wide variability in how it is applied (White et al., 2016). Judgement of futility depends on the situation and perspective of the individual clinician. I often observed differences of opinion between the doctors and nurses on whether interventions were futile, with doctors often wanting to continue treatment when nurses believed the focus should change to comfort (4.5.5). A recent study also found that disagreement, particularly between doctors and nurses, often impeded recognition of dying, with consensus only reached very close to the time of death (Green et al., 2023).

Recognising futility is closely related to recognising dying. Recognising dying is complex, with several influencing factors. Not only are there no definitive signs and symptoms specifically indicating the last days or hours of life, there are multiple contextual factors impacting on recognising dying (Chapter 2). Research has shown that a barrier to recognising dying for doctors is the fear of being held culpable for the patient's death (Reid et al., 2015). Mohammed and Peter (2009) suggest that certain interventions, such as cardiopulmonary resuscitation, can be a response to this fear. Doctors cannot then be held responsible for the death of the patient through withholding or withdrawing interventions. Consequences of futile invasive interventions can include increased suffering and delay in transitions to comfort-focused care; however, the question remains as to whether less invasive interventions, such as measurement of vital signs or slow continuation of fluids, have a value for clinicians in easing the transition without harm to patients. Mohammed and Peter (2009) suggest that although futile treatments cause nurses moral distress, they may also benefit from these softening the impact of confronting death and removing their feeling of responsibility for the death. Indeed, during my research, some nurses expressed concern about precipitating death (4.5.3) and a belief, particularly amongst the internationally educated nurses, that all treatment options should be exhausted before changing to end-of-life care, whatever the consequences (4.5.1, 4.5.3). The continuation of futile treatments may also have a ritualistic role for clinicians, filling the space between life and death. Mohammed and Peter (2009) describe this as a 'social performance' in the transition from curative treatment to dying. From an ethical perspective, a possible emotional benefit for doctors and nurses is a weak justification for futile treatment that is of little or no benefit to patients and is potentially harmful.

There is inconclusive supporting evidence for continuation, or otherwise, of certain treatments in dying patients, such as clinically assisted hydration (Baillie et al., 2018). It is therefore understandable that the default position is often the continuation of certain interventions, especially given the uncertainty and known difficulties clinicians have in differentiating between dying and other reversible causes of deterioration. This was reflected in a recent ethnographic study on an acute elderly care ward which found that in an undercurrent of uncertainty, any deterioration was treated by doctors as potentially reversible. This meant that dying people were often subjected to futile and burdensome interventions (Green et al., 2023). There is considerable scrutiny of decisions about continuation or withdrawal of treatment and the possible hastening of death following the investigation into the Liverpool Care pathway (Neuberger et al., 2013). The official Liverpool Care Pathway investigation report was highly critical of the arbitrary withdrawal or withholding of certain treatments and interventions. This highly influential report is likely to have impacted practice and clinical confidence in determining futility and acknowledging that a person is dying.

Reasons for continuation of futile treatments are multi-factorial, with patient and family requests being a main reason given by doctors (Willmott et al., 2016). Other reasons include poor communication skills, being ‘trained to treat’ and prognostic uncertainty. Organisational and system factors also play a part, including medical hierarchy and out-of-hours arrangements, for example, the senior consultant being relied upon to determine futility and out-of-hours doctors not being empowered or confident enough to do this (4.5.5). My literature review (Chapter 2) similarly found that waiting for a consultant to confirm dying could be problematic due to the relative infrequency of their presence on the ward and timings of ward rounds. In my empirical findings, I found nurses’ opinions were often not heeded. Nurses, and internationally educated nurses in particular, did not feel they could question or challenge doctors (4.5.5). I found, similarly to Kirby et al. (2014), time pressures and workload impacted nurses' communication with doctors, for example, they often felt too busy to attend ward rounds, hence limiting their opportunity to contribute to decisions. Empowerment of nurses is known to improve quality of care, hence, valuing their views and opinions and creating empowering structures that enable nurses to contribute to decision-making is crucial (Goedhart et al., 2017).

The interval between when nurses believed a person was dying and their being officially recognised as a dying patient, or 'P-CEL patient', was an uncomfortable place for nurses. Nurses' unease was exacerbated when they recognised that a person was dying, but doctors did not agree and wished to continue active treatment. This transition period involved negotiation between clinicians and often involved disagreement between doctors and nurses about the goals of care. Higginson et al. (2016) found that where patients' conditions fluctuate and the approach to care waivers between active treatment and comfort-focused care, there is increased conflict between clinicians and families, as well as within and between teams. Treatments were often prescribed by doctors and were framed as, for example, 'let's do another 24 hours of antibiotics' or 'just once daily observations' - in hope rather than expectation. This transition period eventually concluded with the patient being recategorised from acutely deteriorating, or 'not for escalation', to dying. This occurred when the irreversible deterioration of the patient could no longer be ignored or denied. The high NEWS score was reinterpreted to mean dying, and there was consensus between doctors and nurses that the person was dying. This recognition brought about an immediate change of course under which the main focus of care was comfort.

The seeking of absolute certainty before classifying the patient as a dying patient meant that the change to comfort-focused care often occurred very close to the time of death. This can prolong the period of suffering and mean there is limited time for the patient and family to adjust to a different pace and care emphasis, where comfort and the quality of living and dying is prioritised. A culture where comfort measures and active treatment are seen as mutually exclusive exacerbates this problem (4.5.5). In keeping with the findings of my literature review (Chapter 2), rather than seeking certainty, a more helpful strategy would be to acknowledge the possibility that a patient is dying.

Nurses found the involvement of palliative care nurses helpful in supporting decision-making, reflecting the findings of a study where specialist palliative care involvement was found to be particularly helpful where there is greater prognostic uncertainty (Higginson et al., 2016). However, Bajwah et al. (2020), in their systematic review, found only very low, to low quality evidence to support the benefit of hospital palliative care team involvement on quality of life, symptom burden and satisfaction with care. Indeed, the evidence for early palliative care overall is inconclusive (Groenvold et al., 2017). A recent study showed that early palliative care improved quality of life in the last seven days of life but only when combined with additional palliative care, particularly in a hospice setting. However, no difference was found on quality of death and dying (Mah et al., 2023). In addition to supporting decision-making, it is plausible that the involvement of palliative care teams and a concurrent palliative approach with active management would ease the transition to comfort-focused care. Further research is needed into the role of palliative care teams in the hospital setting, including as to the timing of specialist palliative care involvement and in relation to different diagnoses.

5.8 Ritual and transition

Rituals of social transition occur in every culture and mark the transition of an individual from one status to another (Leach, 1976). Circumcision of male Jewish babies and christening ceremonies are examples of social birth rituals shortly after physiological birth. These rites of passage mark boundaries from one life stage to another. Van Gennep (1960) described the ritual of transition from one life stage to another as a state of liminality. The period where there is uncertainty about whether a person may recover and be discharged and their being officially classed as dying can be described as a ritual of social transition (Helman, 2007). The space between boundaries causes unease and discomfort (Leach, 1976), which may partly explain nurses' discomfort before a person's status was changed to the P-CEL patient.

The time when a person does not respond to treatment as intended in acute settings has been described in various ways. Kaufman (2005) refers to the period when a patient fails to improve as the 'zone of indistinction'. Chapple (2010) describes this in terms of a ritual and calls it the 'ritual of intensification'. During this period, there are attempts to create order amongst the chaos to resolve the uncertainty. Although this is about attempts to reverse physical deterioration and stabilise patients, it is also about clinicians becoming comfortable and coming to terms with the inevitability of death (Chapple, 2010). Chapple (2010) suggests that the 'ritual of intensification' is a framework in which death can eventually be permitted and justified. My findings suggest that this period forms part of a rite of passage in which, eventually, once the patient has been officially designated as a dying patient, an alternative narrative of comfort-focused care is permitted.

Like Leach (1976), Van Gennep (1960) suggests that there are three stages in rites of passage. This model can be used to explain and understand the transition to comfort-focused care for dying patients in the acute setting. The first stage of these rites of passage is separation, when the individual is separated from their usual social life. This happens when a person is admitted to hospital and becomes a patient with the associated paraphernalia: a bed space, a diagnosis, gowns, identity labels and separation from their usual social place and position. This stage symbolises a person assuming the patient role and emphasises their vulnerability (Wolf, 1988). If the person does not recover and re-enter their usual place in society, they enter the second stage. This is a period of liminality – between living and dying. In this stage, interventions and treatments take place in order to determine which direction the patient is heading – to live or die. Life prolonging interventions in acute settings can extend this liminal stage (Van Gennep, 1960). The situation I observed, where an attempt to remove non-invasive ventilation was abandoned until after a bank holiday weekend, was an obvious example of this prolongation (4.5.3). The third stage is reincorporation. This is where end-of life care deviates from Van Gennep's model, as it does not conclude with reincorporation into society and life returning to normal (Chapple, 2010). Once a person was designated as dying they were further separated, ideally in a side room, so as not to interrupt the hospital flow or upset other patients. This separation was an attempt by nurses to re-establish life as normal for everyone else. The alternative to reincorporation was the instigation of the P-CEL care plan and the change to comfort-focused care.

Dying is not only a physical process where the heart stops and respiration ceases. It is the conclusion of a life within a cultural and social context (Glaser & Strauss, 1968; Neuberger et al., 2013). Social death is said to occur sometime after physiological death and after the completion of rituals such as funerals and wakes. However, social death can also occur before physiological death, when a person is separated and loses connection with the society in which they previously lived (Helman, 2007). Dying in the acute hospital setting is an example of this.

Once a patient has been categorised as dying, the removal of the tools of active treatment and the segregation of the patient represents social death. In the acute setting, the interval between social death and ultimate biological death may be only a few days or hours.

Once a person was officially recognised as dying and the P-CEL care plan was implemented, nurses were more comfortable (4.5.6). There was no longer a state of flux, and uncertainty had been resolved. Nurses would initiate a series of actions, such as moving the patient to a side room, providing food and bedding for families, allowing unrestricted visiting hours and the removal of technical equipment from the bedside. The nurses' actions and behaviours at this stage, although having functional purposes, were also ritualistic in nature. The use of a butterfly symbol to signify the presence of a dying patient and as a means of communication between the ward staff was also an attempt to find and attach meaning at this stage of care (4.5.4). There are variations of this practice in many UK hospitals and hospices (Ford, 2018; Oxford University Hospitals, 2019; Stewart-Lord et al., 2022). However, symbols are culturally specific and can convey different beliefs and sentiments in different cultures (Helman, 2007). This means that the messages they convey may not be interpreted as intended. A study investigating the use of symbols in hospitals to denote patients with dementia found that the symbols did not benefit patient care as intended. Rather than enhance care, it was found that symbols can lead to misidentification, routinisation of care, a narrow understanding of individual patients' needs and reduced expertise of staff (Featherstone et al., 2020). Further research is needed into the use of symbols as communication tools in end-of-life care and the impact of their use on patient care.

Rituals are symbolic activities and behaviours that may or may not also have a functional purpose, and which represent the values of the culture they are situated in; they can only be understood within a specific cultural context and by those who are part of the culture (Helman, 2007). The butterfly symbols and the P-CEL care plan I encountered in my research were examples of this. Only those who were part of the specific ward culture understood their significance. Rituals are made up of symbols that may involve physical objects, including special clothing, but may also consist of other components such as actions, words, or gestures, and are usually performed in a particular order. Rituals provide structure, familiarity and comfort in a particular set of circumstances (Fahey, 2017). Indeed, once the P-CEL care plan was initiated, the nurses knew what to do and how to act and were visibly more comfortable (4.5.6). From this point on, the doctors were only minimally involved in patient care, with nurses leading proceedings. Willis et al. (2021) suggest that clinicians are managers of the ritual process. In many cultures, ritual specialists are healers who are responsible for overseeing rituals of transition and conducting the ceremonies (Büster et al., 2023). Nurses, in their role by the patient's side and in overseeing the transition from living to dying, are modern day ritual specialists (Büster et al., 2023).

Rituals play a part in nursing care from handovers to medication rounds to care after death (Büster et al., 2023; Fahey, 2017; Walsh & Ford, 1989). In fact, the main signposts of the ward day were the handovers and medication rounds. These activities may have technical and functional purposes, but the context and manner in which they are performed suggest a ritualistic role too. Indeed, Helman (2007) suggests that the technical and ritualistic aspects of nursing activities are intertwined. Nursing rituals may have a role in helping nurses enact beliefs and values of nursing that are less visible (Wolf, 1988). However, discussions about nursing rituals are often derogatory. Particularly around thirty years ago, negative views expressed and published about nursing rituals and their association with poor practice predominated (Thomlinson, 1990; Walsh & Ford, 1989). This negative association ran concurrently with an increased drive towards evidence-based nursing care and academic nurse education. There was a rejection of nursing rituals and a disregard for any value that they might serve. Evidence that is of a positivist and measurable nature, with a focus on technical knowledge, has historically been most highly regarded. This marginalises a large part of nursing knowledge and values that are centred on holistic care of the person and on the therapeutic relationship (Strange, 1996).

Further understanding and exploration of the role of rituals in nursing through a contemporary lens is needed to understand the potential value and contribution these make to patient care. Rituals can provide familiarity and a type of 'standard operating procedure', which can be undertaken semi-automatically and which in turn reduces anxiety (Fahey, 2017; Helman, 2007). The commencement of the P-CEL care plan was an important ritual of the transition to comfort-focused care. Many of the nurses expressed the view that once the patient was on the P-CEL care plan they knew what to do and they felt more confident (4.5.6). Though the emotional impact of looking after a dying person may remain, the uncertainty and anxiety dissipated.

5.9 Strengths and limitations

My research has several strengths. The literature review (Chapter 2) helped to situate it within current literature and provided preliminary insights into the themes as they developed. The findings of the literature review revealed that recognising dying, which is a key part of the process of transition to comfort-focused care, has multiple contextual and cultural influences. These findings informed my decision to adopt an ethnographic approach so I could examine how the cultural context of the acute hospital setting shaped the transition to comfort-focused care. Through this approach, I was able to gain a deep understanding of the perspectives of nurses, whilst observing behaviours and interactions in the reality and context of their practice. The ethnographic design enabled me to discern any differences in what nurses told me and what I observed in practice. It enabled me, by triangulating the observational and interview data, to gain insights that otherwise would not have been possible. Perspectives were gained from nurses from a range of backgrounds, seniority and experience that was representative of the range of nurses on the wards. This gave the multiple perspectives I needed to answer the research question.

The hospital where the ethnography was carried out was a broadly typical medium sized NHS hospital. Detailed contextual information has been provided that will enable the reader to judge its relevance and transferability to other settings.

There are also potential limitations to this research. Conducting a focused ethnography in the NHS was challenging. The frenetic pace and busyness of the wards meant that finding time and locations for interviews was sometimes difficult. This did, however, reflect the reality of this acute hospital setting, and the tension and exasperation that, at times, was evident in the interviews was an authentic representation of these nurses' reality.

Whilst I undertook observational episodes across the 24-hour period and all days of the week, a higher proportion of my observational episodes fell on the day shift and weekdays. Observational sessions more evenly spread across the 24-hour period and weekends may potentially have allowed additional insights. A further limitation of this research was its proportional representation of internationally educated nurses; whilst 60% of individual participants were internationally educated nurses, internationally educated nurses represented around 77% of the overall nursing workforce of the wards I studied.

To answer the research question, I studied the perspectives of nurses; future research exploring the perspectives of other clinicians, such as doctors and healthcare assistants, may provide further insights into the transition to comfort-focused care. In addition, studying the perspectives of patients and their families may add further understanding.

Most of the current literature on the transition to comfort-focused care is drawn from a westernised perspective. I, myself, come from a westernised background, which inevitably will have impacted the lens I viewed the data through. Greater understanding of multiple cultural perspectives would strengthen understanding further.

5.10 Final reflections

As a palliative care nurse, I am part of a hospital culture. To an extent, I was an 'insider'. I empathised with the stress and tensions the nurses experienced as they carried out their work. As a researcher, my challenge was to balance my insider perspectives with detachment to allow me to experience and understand through fresh eyes. Adopting an outsider perspective enabled me to be curious and to ask questions about the 'taken for granted' culture of the hospital. It was only by doing this that processes, beliefs and attitudes were revealed, and I could gain the understanding I was seeking.

I brought my own cultural perspectives to my research, including those of palliative care, the nursing profession and the broader UK culture. There were no rules or fixed boundaries as to when I took the role of an insider or outsider, and it required me to be constantly aware and vigilant to navigate any potential impact of this and to monitor my own responses to what I observed. However, my prior knowledge and experience also provided a 'fast track' to understanding of some aspects, such as professional dynamics, illness trajectories and medication knowledge, which otherwise would not have been possible within the timeframe of the research. I understood much of the routine, terminology and other context as well as the underlying context and processes of the UK NHS. My professional background gave me credibility when I initially approached the hospital and helped me to negotiate and gain entry to the setting.

In the early days of my field work, I felt very awkward, not quite knowing where to position myself on the ward. I had read in the ethnographic literature to expect this, but it was unsettling all the same. However, as time went on, I felt more comfortable, and the nurses became more relaxed around me, volunteering their perspectives on what was happening at the time or pointing me in the direction of activity they thought I would be interested in. The relationships I built with the nurses meant they became more open to me. They were interested in my research and wanted to help. They asked my advice about their own academic studies. I began to feel more comfortable, and my role shifted more from ‘observer’ to ‘observer participant’ as I began naturally to interact more with staff and to participate in some minor activity, such as passing messages on and collecting meal trays. By the end of the ethnography, I was sad to leave the field, and I remain immensely grateful to the hospital staff, especially the participants, for their generosity in sharing their thoughts and perspectives.

5.11 Contributions to knowledge

My research makes several contributions to the body of knowledge on how the culture of the acute hospital setting shapes the way nurses manage the transition to comfort-focused care for dying patients. The detailed contextual information and description I provide may enable the findings to be transferable to other settings.

- A finding of this research is that within the culture of the acute setting, dying people were deprioritised due to the competing needs of acutely deteriorating patients who were being actively managed. Dying patients’ needs took second place to those of patients who were expected to recover and leave hospital. This was explicitly stated by the nurses.

- It is known that a task-oriented approach prevails in the acute setting and that nurses favour this approach. This research revealed that this extends to end-of-life care. The end-of-life care plan (P-CEL), whilst intended to be guidance, was in practice used as a check list. This also revealed that the findings from the investigation into the Liverpool care pathway regarding the routinisation of end-of-life care are still an issue.
- There is a need to understand more about how specialist palliative care nurses impact the agency and the confidence of ward nurses. Nurses value and rely on the support of specialist palliative care nurses; however, at times comfort-focused care was delayed until they had reviewed the patient.
- An important finding of this research is the large degree to which nurses are disempowered in influencing the transition to comfort-focused care for dying patients. This builds on existing research that found that nurses' agency to influence decisions around end-of-life care can be limited by hierarchy and lack of confidence.
- This research highlights the significant discomfort and distress internationally educated nurses experience regard providing end-of-life care, especially in the context of the cultural differences they experience. Lack of confidence and discomfort towards dying was particularly marked in internationally educated nurses. These nurses experienced similar challenges to UK educated nurses, but the challenges were magnified.
- Other research has positioned the move to the last stage of life as a developmental transition. However, my research frames the transition to comfort-focused care for dying people as a rite of passage. This may enlighten and demystify the transition process and therefore enable nurses to be consciously aware of their acts and behaviours in the context of this rite of passage.

- Rituals and symbols played a prominent role in the transition to comfort-focused care. Rituals, such as the P-CEL care plan and butterfly symbols, had some benefit for nurses, and, whilst they serve some functional purpose and are well intended, the impact on patient care is unclear.
- The change to comfort-focused care is often abrupt and very close to the time of death due to the apparent need to have absolute certainty that a person is dying, and active treatment and a palliative approach being seen as mutually exclusive.

5.12 Recommendations

5.12.1 Practice and policy

- A change in organisational culture is needed to enable a person-centred approach. Despite rhetoric around person-centred care in healthcare, in practice a task-oriented approach dominates, and this extends to end-of-life care. Nurses are constrained in how they can act by the organisational culture. Achieving and sustaining cultural change is known to be complex. However, cultural change needs to start at the top of the organisation with leaders that have clear vision and commitment to the change (Johnson et al., 2016). The culture of an organisation shapes the behaviours and attitudes of those within it and has a critical role in the effectiveness of an organisation, including the quality of patient care and staff morale and performance.
- Structured multidisciplinary meetings should be implemented to foster collaboration, allowing different professions to contribute their perspectives while ensuring all professional groups are equally valued. Consensus between the multidisciplinary team is crucial for a successful transition to comfort-focused care. For teams to be effective,

it requires psychological safety where individuals are listened to and are free to speak openly (Khan et al., 2021).

- Joint professional education, induction and other joint events, such as Schwartz rounds and reflective sessions, which include nurses, doctors and other disciplines, to support mutual understanding of roles and perspectives and to support multidisciplinary decision-making (Flanagan et al., 2020; Lown & Manning, 2010).
- Preparation of internationally educated nurses should include end-of-life care education and recognise and address the cultural differences they may encounter. However, education alone is not sufficient, other measures such as mentorship should be considered.
- To facilitate a smoother transition and to help avoid an abrupt change to comfort-focused care close to the time of death, a concurrent active management and palliative care approach should be considered. Increased and earlier proactive involvement of palliative care teams, including at multidisciplinary meetings, may help to support earlier decision-making around limits of interventions in the event of patient deterioration, as well as with symptom management and psychosocial support.

5.12.2 Research

- Research is needed into the role, benefits and effectiveness of specialist palliative care teams in supporting ward-based nurses.
- Further research is needed into the design, timing and effectiveness of palliative care interventions in the acute setting and how specialist palliative care teams integrate with the ward teams in supporting end-of-life care.

- Further research is recommended into the experience and perceptions of internationally educated nurses in end-of life-care and how they can be prepared and supported in caring for dying patients.
- Further research is needed into the possible benefits or potential harm of the use of rituals in end-of-life care, such as the use of symbols to indicate a dying patient.
- Further evaluation and research are needed into the use and effectiveness of end-of-life care plans in supporting clinicians in caring for dying patients.

5.13 Final conclusion

I carried out this focused ethnography over twenty-three weeks on two acute medical wards. The focused ethnographic design of the research enabled me to gain new understandings and to build upon the body of existing knowledge as to how nurses manage transitions to comfort-focused care for dying people within the culture of the acute hospital setting. Through a combination of observation and interviews, I gained insights that would not otherwise have been possible. Whilst observation enabled me to understand how nurses acted and behaved, interviews meant unobservable aspects of the nurses' experiences and possible contradictions between what was observed and what was said in interviews could be explored. Through analysis of the data, I constructed six explanatory themes: Denial, Competing priorities, Discomfort, Moral dissonance, Nurse agency and Delay.

The transition to comfort-focused care happens within a culture where dying is not openly talked about, where there is a tension between curative care and end-of life care and where dying people are deprioritised. There is a conflict between the task-oriented culture and person-centred care. The transition to comfort-focused care can be emotionally burdensome for nurses, especially when care conflicts with their beliefs and values. Nurses are disempowered in their influence of the transition, however, when the patient is officially categorised as dying they then take the leading role.

The transition to comfort-focused care is often a fraught and stressful process until the official recognition of dying. This is often delayed to very close to the time of death. Accepting unavoidable uncertainty is necessary, and adopting a parallel active management and palliative approach may enable a more seamless transition to comfort-focused care, but further research into the role of palliative care teams in supporting this is needed. The final change to comfort-focused care often happens abruptly. This matters as it leaves little time to implement comfort measures and to focus on what is most important to the dying person and their family.

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Appendix 1. Published literature review

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How clinicians recognise people who are dying: An integrative review

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ABSTRACT

Background: Timely recognition of dying is important for high quality end-of-life care however, little is known about how clinicians recognise dying. Late recognition is common and can lead to futile treatment that can prolong or increase suffering and prevent a change in the focus of care.
Aim: To explore how clinicians caring for dying people recognise that they are in the last days or hours of life, as well as the factors that influence the recognition of dying.
Design: A systematically constructed integrative review of the literature.
Methods: Medline, Scopus, Cumulative Index to Nursing and Allied Health Literature, PsycInfo and Allied and Complementary Medicine were searched in July 2022. Papers were included if they were original research, discussed how clinicians recognise dying, available in English language and published in 2012 or later. A constant comparison approach was applied to the analysis and synthesis of the literature.
Results: 24 papers met the inclusion criteria. There were 3 main categories identified: 'Clues and signals' refers to prompts and signs that lead a clinician to believe a person is dying, incorporating the sub-categories 'knowing the patient over time', and 'intuition and experience'. 'Recognition by others' is where clinicians come to recognise someone is dying through others. This can be through a change in the context of care such as a tool or care plan or by communication with the team. 'Culture, system and practice' refers to the cultural beliefs of a setting that influences awareness of dying and denial of death as a possibility and avoidance of naming death and dying directly. System and practice of the setting also impact on recognition of dying. This involves work pace and intensity, shift systems and timing of senior reviews of patients. Uncertainty and its impact on recognition of dying are evident throughout the findings of this review. The seeking of certainty and the absence of the possibility of dying contributes to late recognition of dying.
Discussion: Recognition of dying is a complex process that occurs over time, involving a combination of intuition and gathering of information, that is influenced by contextual factors. A culture where dying is not openly acknowledged or even named explicitly contributes to late recognition of dying. A shared language and consistent terminology for explicitly naming dying are needed. Uncertainty is intrinsic to the recognition of dying and therefore a shift to recognising the possibility of dying rather than seeking certainty is needed.
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What is already known

- The recognition of dying is complex and can be challenging.
- Recognition is often very close to the time of death which prevents a timely change in the focus of care to implement comfort measures.
- There are no definitive criteria for the diagnosis of dying.

What this paper adds

- Recognition of dying is influenced by a complex intersection of contextual factors including setting, profession and seniority of the clinician as well as diagnosis.
- A cultural landscape where dying is not openly acknowledged or talked about contributes to the late recognition of dying.
- Clinician uncertainty about reversibility and potential recovery remains an inherent feature of recognising dying.

1. Background

Recognising dying is essential so that care can be modified to focus on patients' changing goals and values and aid the delivery of high-

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quality end-of-life care (Department of Health, 2008; Leadership Alliance for the Care of Dying People, 2014). There is limited evidence to inform clinicians' recognition of dying patients. Such recognition is known to be challenging, even for experienced clinicians, and often occurs very close to the time of death (Kennedy et al., 2014; Taylor et al., 2017). The consequence of late recognition of dying can be the continuation of potentially burdensome interventions and treatments. This can increase or prolong suffering (Gibbins et al., 2009; Gunasekaran et al., 2019). Terms used for the end-of-life stage are often ambiguous and this can contribute to the challenges associated with lack of clarity around recognising dying and adjusting goals of care (Hui et al., 2014; Kennedy et al., 2014).

A previous literature review exploring what factors influence how healthcare professionals recognise dying in hospital, hospice, community and care home settings included papers from 2001 to 2011 (Kennedy et al., 2014). Kennedy et al. (2014) defined dying as the final hours or days of life. They identified an overarching theme of uncertainty and recommended that uncertainty should be incorporated into decision-making. Uncertainty can lead to the default continuation of futile treatments and interventions even when death is very imminent. A consequence of this can be unnecessary suffering and limited time to focus on other priorities. Two sub-themes were also identified. The first was 'characteristics of dying' where it was found that characteristics of dying were social, spiritual, and psychological as well as physical. Physical signs often received more attention which may result in the continuation of biomedical interventions. The second was 'treatment orientation' where decision-making around diagnosing dying was focussed on biomedical interventions. Kennedy et al. (2014) also found that the type of diagnosis impacts on recognising dying and that dying is often clearer in cancer when compared to other life limiting conditions. They recommended further research into contextual factors that influence the recognition of dying including the culture of the care environment.

Due to the period of time elapsed since the review by Kennedy et al. (2014) and the extent of new literature, it was appropriate to update this review. Late recognition of dying remains an important issue and recognising dying continues to be challenging (Gunasekaran et al., 2019). A synthesis of new literature could further enlighten how clinicians recognise a person who is dying and the contextual factors influencing this. The aim of this literature review was to explore how clinicians caring for dying people recognise they are in the last days or hours of life, as well as the factors that influence the recognition of dying. In this literature review the term dying is used to describe someone thought to be in the last days or hours of life. The term clinician is used to describe paid staff who provide direct health and social care, including doctors, nurses, allied health professionals, healthcare assistants and care workers.

2. Methods

The review question: How do clinicians recognise people are dying and what are the factors that influence this recognition?

2.1. Design

An integrative review design was chosen as it can accommodate diverse designs. Integrative reviews enable capturing of the complexity and breadth of perspectives (Hopia et al., 2016). The integrative review design developed by Whittemore and Knafl (2005) was selected to enhance the rigour and transparency of combining diverse designs by outlining explicit and systematic methods for each stage of the review. It includes five stages: problem identification; literature search; data evaluation; data analysis and presentation of findings. Given the aims of this review a constructionist approach was taken to the synthesis (Burr, 2015). This approach incorporates culture and context to generate knowledge. The review protocol is published with PROSPERO (CRD42022360900). Registered September 2022.

Table 1
Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Population of interest: Clinicians – paid staff who provide direct health and social care including doctors, nurses, allied health professionals and healthcare assistants and care workers.	Papers exploring the recognition of dying of those under the age of 18 years.
Dying refers to when a person is thought to be in the last days or hours of life.	
Phenomenon of interest: How clinicians recognise that a person is dying, and what influences this.	Papers focussing on the transition from curative treatment to palliative care. Studies about development of prognostication tools unless including data about how clinicians recognise dying.
Any setting	
Dates of publication: from 2012 to July 2022.	
Empirical studies of any design	Systematic reviews, review articles, and opinion articles. The reference lists of any such papers identified in the search were interrogated to identify papers that met inclusion criteria.
Full text available	
Papers written in English	

2.2. Search strategy

Predefined inclusion and exclusion criteria enabled the identification of relevant literature (Table 1).

The search aimed to be comprehensive to identify all relevant papers. Subject or MeSH headings were used when available and were enhanced by free text terms related to end-of-life care. The search strategy was adapted from the search filters developed by Rietjens et al. (2019) and tailored to each database. Guidance was given by Lancaster University information specialists. Search strings combined variations of the following terms and subject headings (Table 2).

Five databases were searched: Medline, Scopus, Cumulative Index to Nursing and Allied Health Literature, PsycInfo and Allied and Complementary Medicine Database. These searches were performed in July 2022. Detailed search strings are presented in supplementary material, file 1. Reference lists of included papers were examined for further potential papers. In addition, whilst reviews identified in the search did not form part of the included papers, their reference lists were examined for potentially relevant papers (Bruun et al., 2022; Eychmüller et al., 2013; Kennedy et al., 2014). Backward citation tracking was performed (Zwakman et al., 2018).

2.3. Data evaluation

Search results were imported to Endnote to assist with managing a large number of references and to record where and when database

Table 2
Search terms.

Search terms		
Palliative care terms		Decision making terms
(MH "Palliative Care" OR MH "Terminal Care" OR MH "Hospice and Palliative Care Nursing" OR MH "Palliative Medicine" OR MH "Terminally Ill" OR MH "Hospice Care") **OR** "end of life care" OR "end-of-life care"	**AND**	(recogni* OR diagnos* N4 "end of life" OR end-of-life OR death OR dying) **OR** (MH "Decision Making" OR MH "Clinical Decision-Making" OR MH "Prognosis" OR MH "Diagnosis" OR MH "Attitude to Death")

references were found. Rayyan software was used to remove duplicates and to manage screening and selection of papers. Titles and abstracts were first screened by the first author to exclude papers that obviously did not meet the inclusion criteria. A second reviewer AB screened 10 % of the papers. Petticrew and Roberts (2008) suggest that a second reviewer screens 10 % of papers to ensure papers are not missed and that inclusion/exclusion criteria are not misapplied. There was 100 % consensus on papers to be included, excluded and where there was uncertainty. Uncertainty was resolved through discussion amongst all the authors. Full text was obtained for papers that were not excluded thorough screening of titles and abstracts and they were examined to confirm their relevance to the review question. A proportion (10 %) of full text articles were screened by AB. The appraisals and analysis were performed by the first author with oversight and discussion with the other authors. Any uncertainties were discussed by all authors to reach consensus.

2.4. Quality appraisal

The Hawker Tool was used to appraise the quality of included papers as it is suitable for methodologically diverse studies (Hawker et al., 2016). Papers were appraised by the first author. No paper was excluded based on methodological quality or assigned scores, however, the impact of the strengths or weaknesses of papers on the analysis and synthesis was considered (Aveyard et al., 2016). All papers were appraised as high quality other than two which were appraised as medium quality; however, these papers were of sufficient quality with no major flaws that would negatively affect the review findings. See supplementary material, file 2 for details of appraisal of included papers.

2.5. Data analysis

A constant comparison approach was adopted to convert data into categories and to identify patterns, themes, relationships and variations (Charmaz, 2006; Whittemore and Knafl, 2005). This method is recommended by Whittemore and Knafl (2005) as it can enable analysis of a variety of data from diverse methodologies. It consists of four phases:

- *Data reduction*: Data were extracted mainly from the finding sections of papers. However, presentation of findings can vary, hence extracted data were also found in abstracts and discussion sections. Some articles presented data pertaining to non-clinicians and different timeframes but only data that met the inclusion criteria were extracted. Selected papers were coded line by line using NVIVO. Initially qualitative and quantitative data were coded separately. Qualitative data were coded first followed by quantitative data as the majority of the data were qualitative. Qualitative data explained and confirmed quantitative data. NVIVO was used for organisation and structure of developing concepts and categories.
- *Data display*: Data extracts were displayed in tables to indicate how categories and sub-categories were developed across sources and designs. Data were interrogated to understand if there were patterns detected depending on setting and clinician type, however the heterogeneity across studies precluded meaningful within-setting, or clinician type analysis.
- *Data comparison*: An iterative process of data comparison to identify patterns, themes or relationships to develop a conceptual map. Codes from quantitative data were compared and integrated with codes from qualitative data. See supplementary, file 3. To enable quantitative data to be incorporated into a synthesis with the qualitative data, relevant data from the narratives in findings sections of quantitative papers (and other sections as applicable) were coded. Data comparison was an iterative process that involved categorising and grouping and going back and forth through the data as codes, categories and concepts were developed and refined (Charmaz, 2006). Pearson et al. (2015) suggest converting quantitative data into qualitative data is more reliable and less subject to errors than assigning numerical values to qualitative data. Developing concepts and categories were discussed with all authors and checked for accuracy against the original papers.
- *Conclusion drawing and verification*: An inductive process of moving from description of patterns, themes and relationships to a higher level of abstraction. All patterns, categories and concepts were verified with the primary data sources to ensure accuracy (Miles et al., 2018). Interpretations were discussed between all authors and any differences were explored until consensus reached.

3. Results

24 papers met the inclusion criteria and were included in the synthesis (Fig. 1).

3.1. Data summary of selected papers

Details of the 24 papers that met the inclusion criteria are summarised in supplementary material, file 4. There were six quantitative papers, three mixed methods papers and 15 qualitative papers. Of the 15 qualitative papers most involved some form of individual or group interview approach, only two involved observation. The quantitative papers included one Delphi study, four retrospective surveys and one prospective observational study. The main focus of 10 papers was how clinicians recognise dying. The remaining papers were partly about how clinicians recognise dying or about end-of-life care more generally.

Terms associated with dying varied, for example dying state, impending death, imminent dying. Only four papers specifically gave a timeframe. A timeframe of the last few days or hours of life was clearly inferred by the remaining papers.

All studies were based in Western countries: UK ($n = 10$), Australia ($n = 3$), Canada ($n = 2$), New Zealand ($n = 1$) or Europe ($n = 6$), USA ($n = 1$), multi-country ($n = 1$). Participants ranged from doctors only ($n = 6$), nurses only ($n = 3$), allied health professionals only ($n = 1$), to mixed professional groups ($n = 14$). Of the 14 mixed professional groups all contained nurses ($n = 14$), doctors ($n = 10$), healthcare/care assistants ($n = 5$), various allied health professionals ($n = 5$). 13 papers were in the acute setting, five in long-term care facilities, one in a geriatric rehabilitation setting and four were surveys which included participants from multiple types of settings.

3.2. Findings

The analysis and synthesis produced three main categories: Clues and Signals; Recognition by others; and Culture, System and Practice.

3.2.1. Clues and Signals

Clues and signals refer to the prompts and signs that lead a clinician to suspect or believe a person is dying. These include physical signs, as well as psychological signs and changes in behaviour. There was considerable variation in the range of signs, symptoms, tests and observations that prompted clinicians to recognise dying (Domeisen Benedetti et al., 2013; Taylor et al., 2017; Vrijmoeth et al., 2016a) and the evidence associating these signs with the time of death is sparse (Taylor et al., 2017). Clues and signals of dying that featured prominently across studies included breathing changes, reducing consciousness, reduced oral intake, skin changes and 'general deterioration' which include mobility and general function. See Table 3 for a presentation of the clues and signals a clinician perceives via sensory information - mainly visual, auditory, or tactile.

Many studies identified breathing changes as a strong sign of dying (Åvik Persson et al., 2018; Domeisen Benedetti et al., 2013; Gerber et al., 2022; Van Der Werff et al., 2012). Clinical measurements such as oxygen saturation, blood pressure and blood tests were not widely used in recognising dying and were only found to be influential in

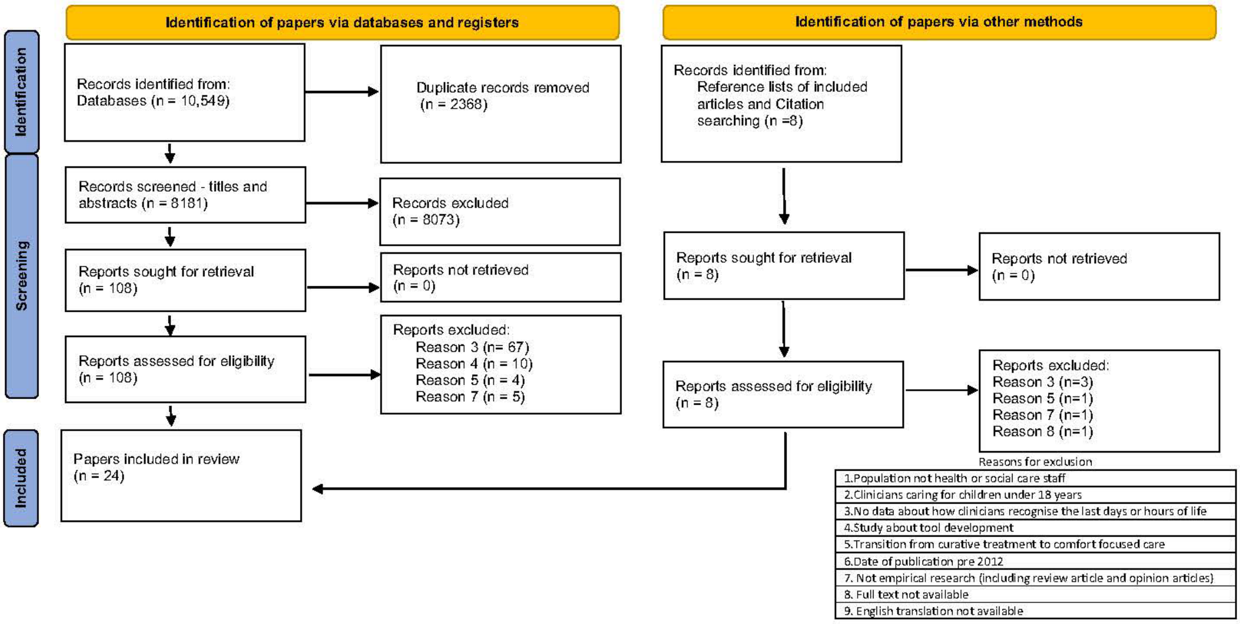

Fig. 1. PRISMA diagram.

three studies (Cowey et al., 2015; Taylor et al., 2017; Van Der Werff et al., 2012). Across papers many different terms were used to describe similar clues or signals, for example breathing changes included Cheyne Stoke or irregular breathing (Åvik Persson et al., 2018; Domeisen Benedetti et al., 2013; White et al., 2018) noisy secretions (Domeisen Benedetti et al., 2013; Sahlberg-Blom et al., 2013; White et al., 2018) and shortness of breath (Gerber et al., 2022; Waldrop et al., 2015). Skin changes were described as mottling (Cable-Williams and Wilson, 2014; Waldrop et al., 2015), peripheral cyanosis (White et al., 2018), or cold extremities (Domeisen Benedetti et al., 2013).

Behavioural and psychological changes such as fatigue, withdrawal, existential distress, restlessness and agitation were also common (Cable-Williams and Wilson, 2014; Domeisen Benedetti et al., 2013; Sahlberg-Blom et al., 2013; White et al., 2018). There is no definitive list of visible signs that inevitably indicate dying as often they are also indicative of reversible illness, have low specificity for dying within hours or days, and can depend on context and the experience, knowledge and role of the clinician (Taylor et al., 2017).

One study found that the palliative performance scale, which measures functional status and decline, was the most influential factor in how palliative medicine doctors recognised dying (White et al., 2018). However, generally prognostic tools and prompting questions were not considered helpful and were rarely used (Cable-Williams and Wilson, 2014; Gerber et al., 2022). Although most clinicians knew about the 'surprise question' – "Would you be surprised if this patient died within the next 12 months/6 months/this admission?" – only geriatricians found it useful, whereas nurses and allied health professionals did not use it due to lack of confidence (Gerber et al., 2022). Also pointing to differences between professional groups, doctors were more likely to use clinical information such as trajectory, diagnosis and changes in clinical measurements for example observations and blood tests, in recognising dying. However, nurses and others relied

Table 3
Sensory signals and clues.

Signals	Participants profession	Breathing changes	Levels of consciousness	Reduced/no oral intake	General deterioration/ function	Skin changes	Agitation/restlessness/ emotional changes	Fatigue/lethargy
Signals and clues from quantitative data								
Domeisen Benedetti et al. (2013)	1, 2, 4	✓	✓	✓	✓	✓		
Vrijmoeth et al. (2016a, 2016b)	1		✓	✓	✓		✓	✓
Waldrop et al. (2015)	3	✓				✓		
White et al. (2018)	1	✓			✓(Palliative Performance Scale)	✓	✓	
Signals and clues from qualitative data								
Åvik Persson et al. (2018)	2, 3, 4	✓	✓	✓		✓	✓	
Cable-Williams and Wilson (2014)	2, 3, 4	✓	✓	✓		✓		✓
Cowey et al. (2015)	1, 2, 4	✓	✓					
Gerber et al. (2022)	1, 2, 3	✓	✓	✓	✓	✓	✓	
Sahlberg-Blom et al. (2013)	2	✓		✓	✓	✓	✓	✓
Taylor et al. (2017)	1, 2	✓	✓	✓	✓	✓		
Van Der Werff et al. (2012)	2	✓	✓	✓	✓	✓	✓	✓

Key: Doctors = 1, Nurses = 2, Allied Health professionals = 3, Psycho-social professionals = 4.

on more visual clues such as skin changes but struggled to describe this (Gerber et al., 2022).

Context such as care setting and type of clinician was also a factor found to influence the clues and signals that alerted clinicians to the possibility a person may be dying. For example, one study found that learning disability physicians identified more signs compared to general practitioners, however the learning disability physicians had received more palliative care education and were generally caring for people with more severe learning disability (Vrijmoeth et al., 2016b). Another example of contextual differences is in a study involving emergency pre-hospital clinicians. It was found that the most common signs indicating imminent dying were apnoea, shortness of breath and skin mottling (Waldrop et al., 2015). However, breathing difficulty, which is closely associated with apnoea and shortness of breath, is a prompt for emergency interventions and the training and focus of emergency care clinicians are the management and stabilisation of acute illness and resuscitative measures. These factors may account for differences in the importance of reported signs.

3.2.1.1. Knowing the person over time. A sub-category of Clues and signals is *knowing the person over time*. Unfamiliarity with a person contributes to late recognition of dying (Reid et al., 2015) and knowing the person over a period of time in both acute settings and long-term care settings is a supporting factor (Bloomer et al., 2018; Cable-Williams and Wilson, 2014; Lee et al., 2017; Taylor et al., 2017). See Table 1 in supplementary material, file 5 for excerpts illustrating this sub-category. In long-term care settings 'knowing' the person was as a result of close relationships built over time, meaning staff recognise small changes in behaviour that differ from the person's norm (Åvik Persson et al., 2018; Fryer et al., 2016; Lee et al., 2017; Sahlberg-Blom et al., 2013). These changes could be subtle and multifaceted and include physical, social, psychological, and existential changes requiring close attention and knowledge of the person in order to notice them (Åvik Persson et al., 2018). However, one study found that in long-term care settings daily contact with residents may make recognising incremental changes more difficult compared to clinicians with more occasional contact (Cable-Williams and Wilson, 2014). Subtle signs could be vague and harder to define such as facial changes, an expression, or a different smell (Sahlberg-Blom et al., 2013; Van Der Werff et al., 2012). Similarly, a positive association was found between more frequent physician visits and recognition of dying in people living in long-term care settings (Oosterveld-Vlug et al., 2019). This suggests that increased frequency of visits, and by implication knowing the patient over time, is conducive to recognition of dying. The amount of time spent with patients is related to seniority and profession, often with nurses, healthcare assistants and junior doctors spending most time with patients (Reid et al., 2015; Sahlberg-Blom et al., 2013; Taylor et al., 2017). However, paradoxically, as discussed in the next category, it is the senior doctors who are looked to to confirm a patient is dying (Bloomer et al., 2013).

Recognising dying is an iterative process of seeking more information (Gerber et al., 2022; Taylor et al., 2017, 2020). It occurs over time rather than being a decision at one particular point in time (Taylor et al., 2017). Information used, especially by experienced clinicians, includes response to treatment, manner and rate of change, clinical deterioration, and reversibility (Cowey et al., 2015; Taylor et al., 2017). This suggests that recognising dying, and patient management are not separate processes or mutually exclusive (Taylor et al., 2020). However, in one study in nursing home settings, dying was not seen as a process but as an event or a 'happening' and this could result in recognition of dying being delayed (Åvik Persson et al., 2018). In another study in long-term care settings, recognition of dying was described as a two-stage process; the first characterised by generalised awareness of mortality in old age and the inevitability of death and the second being when clinicians noticed changes indicating imminent death. Generalised awareness was not associated with dying and was not accompanied by active seeking of information to inform decision-making (Cable-Williams and Wilson, 2014).

3.2.1.2. Intuition and experience. Recognition of subtle signs is associated with a further subcategory of *intuition and experience*, see Table 2, file 5 in supplementary material. Intuition plays a prominent role in recognising dying (Domeisen Benedetti et al., 2013; Gerber et al., 2022; Taylor et al., 2017). It is described as a 'gut feeling' and is presented as participants not being able to describe what they are seeing and how they came to know (Bloomer et al., 2013; Sahlberg-Blom et al., 2013; Taylor et al., 2017; Van Der Werff et al., 2012). In hospital settings clinicians described recognition of dying as being predominantly an intuitive process which they found difficult to communicate to others in the team (Gerber et al., 2022; Taylor et al., 2017). Clinicians were aware of their intuition being founded on experience (Gerber et al., 2022; Johnson et al., 2014). This included recognising patterns which could be matched to their experience of previous patients (Taylor et al., 2017). Junior doctors who had undertaken a dedicated palliative care post found this experience increased their expertise in recognising dying (Morrison and Forbes, 2012). However, lack of feedback on the accuracy of their assessment after a patient had been discharged limited the opportunity to learn from experience (Gerber et al., 2022).

3.2.2. Recognition by others

As well as dying being recognised by individual clinicians, to enable clarity of goals and a change in focus of care, consensus is needed by the team involved in the patient's care (Bloomer et al., 2018; Cowey et al., 2015; Morrison and Forbes, 2012; Vrijmoeth et al., 2016a). See Table 3 in supplementary material, file 5 for excerpts illustrating this category. Recognition of dying by others can be a consequence of a cascade effect. This could be described as secondary recognition as someone will have already recognised the patient is dying. For example, an individual clinician who recognises dying will communicate their assessment in some way and in doing so alerts other clinicians to the possibility a patient is dying. A study of emergency pre-hospital clinicians' perceptions of end-of-life care illustrates how clinicians come to recognise someone is dying through the context of care. It was found that they were prompted in their awareness of dying by hospice involvement (Waldrop et al., 2015). Use of tools, such as care pathways or treatment limitation forms, was how some clinicians were made aware a patient was dying (Bloomer et al., 2018; Cable-Williams and Wilson, 2017; Lee et al., 2017; Taylor et al., 2017). Opioid administration, a care plan or a symbol outside the room to indicate a dying patient are also examples of contextual changes in care prompting others to recognise dying (Cable-Williams and Wilson, 2014; Cable-Williams and Wilson, 2017; Johnson et al., 2014; White et al., 2018).

> *In the absence of clear information to inform their understanding, participants described other ways in which they could ascertain when a patient might be deteriorating towards death, or what other members of the treating team, such as medical staff, might think, including relying on documents (such as treatment limitation form) in the medical record that were not intended to be the first indicator that a patient was dying (Bloomer et al., 2018 p. 1621).*

As well as being prompted by other clinicians and changes in context of care patients themselves may purposefully signal they think they are dying (Gerber et al., 2022; Sahlberg-Blom et al., 2013; Taylor et al., 2017; Van Der Werff et al., 2012). At times this was explicitly verbalised by patients expressing their readiness to die (Cable-Williams and Wilson, 2014; Sahlberg-Blom et al., 2013; Van Der Werff et al., 2012). Gerber et al. (2022) found that clinicians were also influenced in their recognition of dying by the views of families.

Effective communication within the team is essential for recognition of dying patients, though this can be challenging (Bloomer et al., 2018).

Opportunities for communication include discussion with the larger team, for example in handover meetings, as well as with individual colleagues (Lee et al., 2017; Morrison and Forbes, 2012; Redman et al., 2017; Taylor et al., 2017). Newly qualified doctors perceived handover meetings and 'accurate and specific' documentation in the clinical records as being particularly helpful (Redman et al., 2017). Written documentation was an important means of communication between teams that a patient is dying (Gerber et al., 2022; Lee et al., 2017; Redman et al., 2017; Reid et al., 2015). However, poor documentation can be a barrier with unclear and ambiguous language leading to uncertainty and reluctance to make decisions (Bloomer et al., 2018; Gerber et al., 2022; Reid et al., 2015).

Nurses in acute settings can find it difficult differentiating between deteriorating patients where there is potential for reversibility, and patients who are dying. Nurses frequently recognise dying first but depend on doctors for confirmation. This can contribute to curative management continuing until dying is confirmed (Bloomer et al., 2013; Gerber et al., 2022), with senior doctors making the final decision despite them knowing the patient less well (Cable-Williams and Wilson, 2014; Reid et al., 2015; Taylor et al., 2017). However, Reid et al. (2015) found that doctors believed it was a nurse's role to recognise dying as they spend more time with patients, revealing a lack of clarity and uncertainty as to whose role it is. Similarly in long-term care settings palliative measures could also be delayed until a doctor confirms dying (Cable-Williams and Wilson, 2014; Johnson et al., 2014).

Nurses used several strategies to inform other clinicians when they felt that dying was not being recognised by the treating team. These strategies ranged from seeking support from senior nurses, writing their assessments and opinions in notes, as well as escalating to medical emergency teams (Bloomer et al., 2018). This reveals intrinsic challenges nurses have in communicating a person may be dying and implies cultural influences which are explored in the next category. However, doctors also rely on nurses and other clinicians in order to identify dying and senior doctors consult with other members of the clinical team to gain the information needed (Cowey et al., 2015; Gerber et al., 2022; Morrison and Forbes, 2012; Vrijmoeth et al., 2016a). This suggests a co-dependency between members of the team for dying to be recognised but with doctors being the author of the final decision.

3.2.3. Culture, system and practice

Underpinning the process of recognising dying by both individual clinicians and by the clinical team are the culture, system and practice of the care setting, see Table 4, file 5 in supplementary material for data excerpts illustrating this category. Cultural beliefs influence awareness of dying, including deeply held beliefs that some settings, such as long-term care settings, are for living and not dying (Cable-Williams and Wilson, 2017). This leads to resistance to acknowledging that a person is dying. Clinicians found it challenging to unambiguously name dying, using words such as 'decline' as a way of softening the impact (Cable-Williams and Wilson, 2014, 2017; Johnson et al., 2014). There is also a strong belief in the importance of recognising dying so that people do not die alone or in pain, so that someone can be with the dying person and palliative measures implemented (Cable-Williams and Wilson, 2017). This reveals an inherent conflict between a culture of denial of dying and death as a possibility and the high value placed on attentive high-quality end-of-life care.

In acute settings a culture of denial was particularly apparent. This led to an avoidance of directly referencing death and dying, with the use of euphemisms such as 'guarded prognosis' and 'not appropriate for escalation' (Gerber et al., 2022). Medical and nursing staff across a range of grades, perceived that there was a culture of active management in which dying was rarely openly discussed. This led to avoidance of explicitly acknowledging dying. Some doctors referred to requiring courage to openly declare that someone is dying, and that not actively managing a patient was seen by some as 'letting them die' (Reid et al., 2015). Higginbotham et al. (2021) found that some doctors perceived that to recognise dying was failure and therefore this justified continuing curative treatment.

> *Staff explained that the hospital culture was rarely to discuss or acknowledge death or dying and to treat all patients actively, assuming that active treatments and investigations are always in a patient's best interest. Some spoke of the 'bravery' required to state that a patient was dying (Reid et al., 2015, p. 492).*

Cultural differences between different specialities within the acute setting were found to influence the decision-making process of recognising dying (Redman et al., 2017; Reid et al., 2015; Taylor et al., 2017). Junior doctors perceived surgical specialities as being particularly poor at recognising dying (Redman et al., 2017). In addition, it was found that individual senior doctor's attitudes to end-of-life care varied, which junior doctors found challenging and influenced their decision-making as they felt they had to concur with the senior doctor's decisions (Reid et al., 2015).

System and practice in the acute setting were found to impact on the recognition of dying. This included the intensity and pace of the work (Bloomer et al., 2013), the need to vacate beds for new admissions and the movement of patients to different wards (Gerber et al., 2022; Reid et al., 2015). These factors could result in staff being unfamiliar with patients which impacted on their ability to recognise dying.

> *System pressures also played a role, especially in hospital settings where there is often a perceived mantra of active treatment and high pressure to vacate beds to free up space for new admissions (Gerber et al., 2022, p. 13)*

Shift systems also meant doctors could be unfamiliar with patients resulting in them not having the confidence or information needed to recognise dying. Frequency and timing of senior doctors' reviews and ward rounds were found to contribute to delayed recognition of dying as both nurses and doctors looked for confirmation by senior doctors (Bloomer et al., 2013; Reid et al., 2015). Senior doctors could feel they were not familiar enough with patients to be confident in recognising dying which meant it may not happen at all (Reid et al., 2015). This often resulted in the continuation of futile treatment, sometimes despite nurses' distress or discomfort. An absence of attempts to influence the focus of care revealed a culture of passivity amongst nurses (Bloomer et al., 2013), though Reid et al. (2015) found that nurses continued to request patient reviews.

In one study nurses and allied health professionals made surreptitious attempts to influence a better outcome for the patient by being deliberately slow to assess patients for residential care so they could remain in hospital rather than be transferred only to survive for a short time (Gerber et al., 2022). Indirect and circuitous ways of communicating with other clinicians points to a hierarchy that was seen across settings. Hierarchy was also apparent by the contributions of healthcare assistants being undervalued leading to negative consequences for the recognition of dying (Fryer et al., 2016). In one study, junior doctors found their role in recognising dying to be unclear and that at times this part of their role was not recognised by others (Redman et al., 2017). A hierarchical dynamic was present between doctors, allied health professionals and nurses but also between different grades of nursing staff, and between nurses and healthcare assistants (Bloomer et al., 2018; Fryer et al., 2016; Gerber et al., 2022; Redman et al., 2017).

3.2.3.1. Uncertainty. Uncertainty and the impact it has on recognition of dying and subsequent care are threaded throughout the findings of this review (See Table 5, file 5 in supplementary material). The need to be certain and the absence of the possibility of reversibility was found to be a contributory factor in late recognition of dying in several studies and across different settings (Cable-Williams and Wilson, 2014; Higginbotham et al., 2021; Reid et al., 2015; Taylor et al., 2017).

> *In heart failure patients this lack of certainty in recognising dying and referring them for palliative care often delayed the patient's transfer and consequently the patient died unnecessarily in a hospital bed. The cardiology doctors often referred to this as being the 'vicious cycle' (Higginbotham et al., 2021, p. 3148).*

In long-term care settings, although clues and signals for dying were viewed as 'ominous', they were not seen as certain predictors of dying (Cable-Williams and Wilson, 2014). This was explained by having prior experience of witnessing residents who 'rallied to life' when death had seemed certain. Johnson et al. (2014) described unpredictability in long-term care facility residents as 'bounce back' – where they are thought to be near to certain death one day only to improve significantly on other days. Dying was not acknowledged if there was any possibility of a 'rally', however this often resulted in late recognition.

In acute settings, as well as uncertainty as to whose role it is to recognise dying, several studies found lack of confidence was a barrier to openly voicing recognition of dying (Gerber et al., 2022; Higginbotham et al., 2021; Reid et al., 2015). In the UK a care plan for dying people known as the Liverpool Care Pathway was discontinued following controversy and concerns about its use (Neuberger et al., 2013). In one study it was found that lack of clear guidance following the discontinuation of the Liverpool Care Pathway had contributed to lack of confidence in recognising dying (Higginbotham et al., 2021). When a patient had been fit and well prior to admission to hospital clinicians found it particularly hard to acknowledge a patient was dying (Reid et al., 2015). As well as the difficulty in differentiating between reversible deterioration and dying (Bloomer et al., 2013, 2018), contributing to uncertainty is the variability of signs and symptoms indicating dying and the trajectories of different conditions (Higginbotham et al., 2021; Johnson et al., 2014; Lee et al., 2017; Taylor et al., 2017).

> *Several of the nurses noted that marking 'the turning point' is difficult and that the combination of signs and symptoms may differ from patient to patient. Hence, nurses may feel uncertain about how to diagnose the onset of the dying phase (Van Der Werff et al., 2012, p. 148).*

Clinicians use multiple strategies in order to recognise dying (Cowey et al., 2015; Gerber et al., 2022; Lee et al., 2017; Taylor et al., 2017), however this can be challenging especially when there are conflicting messages received from patient documentation, other team members and from the patient themselves (Gerber et al., 2022).

4. Discussion

The findings of this synthesis are that timely recognition of dying matters as it enables the focus of care to be adjusted, meaning futile and potentially burdensome interventions are avoided. Despite similarities in clues and signals associated with dying across studies, there is a lack of a definitive list of clues and signals that indicate or are exclusive to the last few days or hours of life. In addition, they may also be associated with signs of reversible illness and the absence of these signs does not rule out dying (Chu et al., 2019). These factors contribute to uncertainty. Further prospective studies are needed to validate the accuracy of clinicians' perceptions of the clues and signals indicating the last days or hours of life. However, uncertainty is intrinsic to recognising dying and should be incorporated into decision-making.

Potentially tools can support the nuanced and subtle ways that clinicians predict the onset of dying with more objective measures. A UK report into the Liverpool Care Pathway recommended more use of evidence-based tools for recognising dying and further research into their development (Neuberger et al., 2013). A number of validated prognostic tools have been developed; however, few have been shown to be better than clinical prediction alone at determining when death will occur. This is despite research showing that clinicians' predictions tend to be inaccurate and overestimate survival (Chu et al., 2019). Many of these tools have been developed for prognostication in advanced cancer and therefore may have less applicability to patients with non-malignant conditions. However, it is suggested that the palliative performance scale is the most suitable for predicting the last days of life (Chu et al., 2019). The iterative nature of recognising dying over time has implications for the use of tools which are used at a particular point in time (Taylor et al., 2017). Whereas Kennedy et al. (2014) recommended acknowledging the inherent uncertainty associated in recognising dying, a new finding of this review is that repeated measures whilst recognising uncertainty may improve their use in practice. In long-term care settings staff may not recognise dying until very late and view dying as an event rather than a process. However, on questioning it was found that staff were able to report earlier clues and signals that could be indicative of dying (Åvik Persson et al., 2018), hence using tools at repeated time points may be helpful in this setting to support staff in recognising dying. In addition, prospectively designed studies are required in order to develop tools to provide objective methods for the recognition of dying alongside intuition and clinical judgement.

Intuition is an important contributor to how clinicians recognise dying and this was evident in all settings. Intuition is known to increase with experience (Melin-Johansson et al., 2017). Knowing the patient over time and the quality of the relationship between the clinician and patient is also an important factor in making intuitive judgements and has been found to enable identification of changes in patients' conditions (Melin-Johansson et al., 2017; Smith et al., 2004). In acute settings it was found that clinicians used a combination of intuition and more methodical and analytical reasoning, reflecting dual process theory (Pelaccia et al., 2011; Reid et al., 2015; Taylor et al., 2017). These two components of decision-making are not competing but are both integral and parallel parts of a holistic process (Sicora et al., 2021). Uncertainty, lack of confidence and beliefs about whose role it is to recognise dying may also undermine intuition and prevent it being used to its full potential. However, in the included papers intuition was not validated by the actual death of the patient. In retrospective studies clinicians would have been aware of the outcome (death) and therefore confirmation bias may have influenced their perceptions and views. Further prospective longitudinal studies are also required to investigate the accuracy of clinicians' intuition.

As well as recognition of dying by individual clinicians there must be recognition and consensus by the team looking after the patient to enable a change in the approach to care. Effective communication is essential in facilitating the process of recognising dying, however, there are inherent challenges evident in the findings of this review. Though Kennedy et al. (2014) allude to cultural influences on recognising dying, this review gives further depth and insight into how cultural, organisational and system factors impact on recognising dying. Dying is not openly talked about and euphemisms and ambiguous language is used to describe it. As well as dying not always being directly referenced in documentation, challenges included inadequate opportunities for face-to-face communication and organisational factors such as timing of senior ward rounds. Written documentation has an important role in communication between clinicians that a patient is dying and using standardised documentation and terminology may help with this. Nurses' difficulty in differentiating between acute deterioration and dying means they wait for doctors to confirm dying. Generally confirming dying is not within nurses' scope of practice. Along with lack of confidence, uncertainty and a knowledge deficit, this may contribute to nurses not attempting to influence the focus of care until confirmation by a doctor. In addition, the contributions of clinicians who have lower status within health and care settings are not heard, suggesting a hierarchical culture. This is important because it can lead to futile treatment and interventions and delay a change in the focus of care. Despite this, a co-dependency exists in recognising dying between different professional groups and different levels of seniority within professions, for example, senior doctors rely on nurses and junior doctors as they are more familiar with patients.

The cultural context and beliefs of the setting also impacts on the individual clinician, for example, doctors can feel they are somehow responsible for the death of a patient by recognising dying or believe that to recognise dying equals failure (Higginbotham et al., 2021; Reid et al., 2015). Nurses can feel distressed when treatment and interventions continue despite their belief a person is dying (Bloomer et al., 2013; Reid et al., 2015). These factors suggest that support for clinicians in recognising dying needs to extend beyond learning how to do it or tool development. Clinicians need to be empowered in a supportive cultural climate that acknowledges dying as a possibility.

Kennedy et al. (2014) found that contextual factors such as diagnosis and experience of the clinician influence recognition of dying. This review gives further insight into contextual factors such as profession and seniority of the clinician, type of setting and knowing the patient over time. System pressures both in long-term care settings and the acute setting and the subsequent effect on end-of-life care is an inherent problem for recognition of dying with complex organisational causes. Contributing to this problem is that end-of-life care is not the main focus and may not be openly acknowledged as a role of the setting at all, even though patients commonly die in these settings. These factors contribute to the intrinsic uncertainty in recognising dying. In the period of time since the review by Kennedy et al. (2014), recognising uncertainty and incorporating it into decision-making remains an issue. Reflecting the findings of Kennedy et al. (2014), this suggests rather than an emphasis on recognising dying, recognition of the *possibility* of dying is likely to be more helpful. This switch in emphasis embraces the possibility of recovery and allows for uncertainty.

5. Strengths and limitations

This review has several strengths. The search strategy was comprehensive and methods have been recorded in detail which will allow replicability. The inclusion of diverse designs allowed the review question to be comprehensively explored. The findings from the qualitative and quantitative papers reflect each other and consistent patterns were found in the data.

There are also some limitations including the varying definitions of terms such as 'end of life' and 'imminent dying' that do not consistently refer to the same timeframe (Hui et al., 2014). Inconsistent terminology added a challenge to searching the literature and determining relevance to the review question. However, where it was not possible to determine this from the title and abstract, the full text was obtained. Although there was 100 % congruence between the first and second reviewers in the screening of papers, a greater proportion reviewed by the second reviewer may potentially have reduced any bias. Most qualitative studies involved either interviews or a combination of interviews and focus groups. More studies involving observation would add more depth and perspective on how clinicians recognise dying. Furthermore, prospective longitudinal studies are needed to investigate the accuracy of clinicians' intuition and their perceptions of clues and signals indicating dying.

All studies were based in developed westernised countries meaning that perspectives of clinicians in other cultures and countries may not be represented.

6. Conclusion

Through undertaking an integrative review and synthesis of the literature, evidence on how clinicians recognise dying, including influencing factors, has been gathered. Clinicians recognise dying using a combination of intuition and an analytical, objective process over time. Other factors include communication within the team and various contextual influences. However further research is needed to validate clinicians' intuition and perceptions of the clues and signals indicating dying with the eventual outcome (death). A cultural landscape where dying is not acknowledged or talked openly about contributes to late recognition of dying. Further research into recognising dying in different contexts such as care setting, profession and diagnosis is needed. There is also an imperative for consistent terminology to be used when referring to the last days and hours of life – not only in the clinical and care settings, but also by researchers and in study reports so that the findings can be more easily assessed by the reader.

Organisational changes are required to support recognition of dying such as improving opportunities for senior review of patients thought to be dying. Written documentation has an important role in communication between clinicians that a patient is dying and using standardised terminology for talking about dying may help with this. Recognising the role of staff in different professions and levels of seniority and formally recognising their role in recognising dying would help to empower staff. Nurses spend most time with patients and so are well positioned to recognise dying, therefore acknowledging their role and supporting them to do this is vital.

Further research is also needed into development and use of prognostic tools that use measurable and objective parameters to support clinicians' intuition as well as research into the use of tools in varying trajectories associated with different conditions. Tools that assist with specifically determining the likelihood of the last few days or hours of life are also needed, however a focus on the possibility of dying that acknowledges and tolerates inevitable uncertainty would be more helpful to clinicians in recognising dying than the seeking of absolute certainty.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix 2. Search strategies

Table 1: Medline search strategy

S1	(MH "Palliative Care") OR (MH "Terminal Care") OR (MH "Hospice and Palliative Care Nursing") OR (MH "Palliative Medicine") OR (MH "Terminally Ill") OR (MH "Hospice Care")	Search modes - Find all my search terms
S2	TI (“end of life care" OR "end-of-life care”) OR AB (“end of life care" OR "end-of-life care”)	Search modes - Find all my search terms
S3	TI ((recogni* OR diagnos* N4 ("end of life" OR end-of-life OR death OR dying)) OR AB ((recogni* OR diagnos* N4 ("end of life" OR end-of-life OR death OR dying))	Search modes - Find all my search terms
S4	(MH "Decision Making") OR (MH "Clinical Decision-Making")) OR (MH "Prognosis") OR (MH "Diagnosis") OR (MH "Attitude to Death")	Search modes - Find all my search terms
S5	S1 OR S2	Search modes - Find all my search terms
S6	S3 OR S4	Search modes - Find all my search terms
S7	S5 AND S6	Search modes - Find all my search terms
S8	S7	**Limiters** - Date of Publication: 20120601-; English Language; Human

Table 2: CINAHL search strategy

S1	(MH "Palliative Care") OR (MH "Hospice and Palliative Nursing") OR (MH "Palliative Medicine") OR (MH "Terminally Ill Patients") OR (MH "Hospice Care")	Search modes - Find all my search terms
S2	TI ("end of life care" OR "end-of-life care") OR AB ("end of life care" OR "end-of-life care")	Search modes - Find all my search terms
S3	TI ((recogni* OR diagnos* N4 ("end of life" OR end-of-life OR death OR dying)) OR AB ((recogni* OR diagnos* N4 ("end of life" OR end-of-life OR death OR dying))	Search modes - Find all my search terms
S4	(MH "Decision Making, Clinical") OR (MH "Decision Making") OR (MH "Prognos*") OR (MH "Diagnosis") OR (MH "Attitude to Death")	Search modes - Find all my search terms
S5	S1 OR S2	Search modes - Find all my search terms
S6	S3 OR S4	Search modes - Find all my search terms
S7	S5 AND S6	Search modes - Find all my search terms
S8	S7	**Limiters** - Published Date: 20120601-; English Language; Human

Table 3: PsycINFO search strategy

S1	TI (“end of life care" OR "end-of-life care”) OR AB (“end of life care" OR "end-of-life care”)	Search modes - Find all my search terms
S2	TI ((recogni* OR diagnos*) N4 ("end of life" OR end-of-life OR death OR dying)) OR AB ((recogni* OR diagnos*) N4 ("end of life" OR end-of-life OR death OR dying))	Search modes - Find all my search terms
S3	(((DE "Decision Making") OR (DE "Prognosis")) AND (DE "Diagnosis" OR DE "Medical Diagnosis")) OR (DE "Death Attitudes")	Search modes - Find all my search terms
S4	((DE "Palliative Care") OR (DE "Terminally Ill Patients")) OR (DE "Terminal Cancer")	Search modes - Find all my search terms
S5	S1 OR S4	Search modes - Find all my search terms
S6	S2 OR S3	Search modes - Find all my search terms
S7	S5 AND S6	Search modes - Find all my search terms
S8	S7	Search modes - Find all my search terms
S9	S8	**Limiters** - Publication Year: 2012-; Published Date: 20120601- **Search modes** - Find all my search term

Table 4. AMED

S1	TI (palliat* OR "end of life care" OR "end-of-life" OR terminal* OR hospice* OR dying) OR AB (palliat* OR "end of life care" OR "end-of-life" OR terminal* OR hospice* OR dying)	Search modes - Find all my search terms
S2	TI (“decision-making" OR prognos* OR diagnos* OR "attitude to death”) OR AB (“decision-making" OR prognos* OR diagnos* OR "attitude to death”)	Search modes - Find all my search terms
S3	TI (recogni* N4 (“end of life" OR end-of-life OR dying) OR AB (recogni* N4 (“end of life" OR end-of-life OR dying)	Search modes - Find all my search terms
S4	S1 AND (S2 OR S3)	**Limiters** - Published Date: 20120601-; Language: English Search modes - Find all my search terms

Table 5: Scopus search strategy

(TITLE-ABS-KEY ((diagnos* OR recogni* OR identif* OR determin* OR prognos* OR "decision making") W/5 ("end of life" OR end-of-life OR dying)) AND TITLE-ABS-KEY ("attitude to death" OR hospice* OR palliati* OR terminal*)) AND (LIMIT-TO (PUBYEAR , 2022) OR LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012)) AND (LIMIT-TO (LANGUAGE , "English"))

Appendix 3. Results of appraisal using the Hawker tool

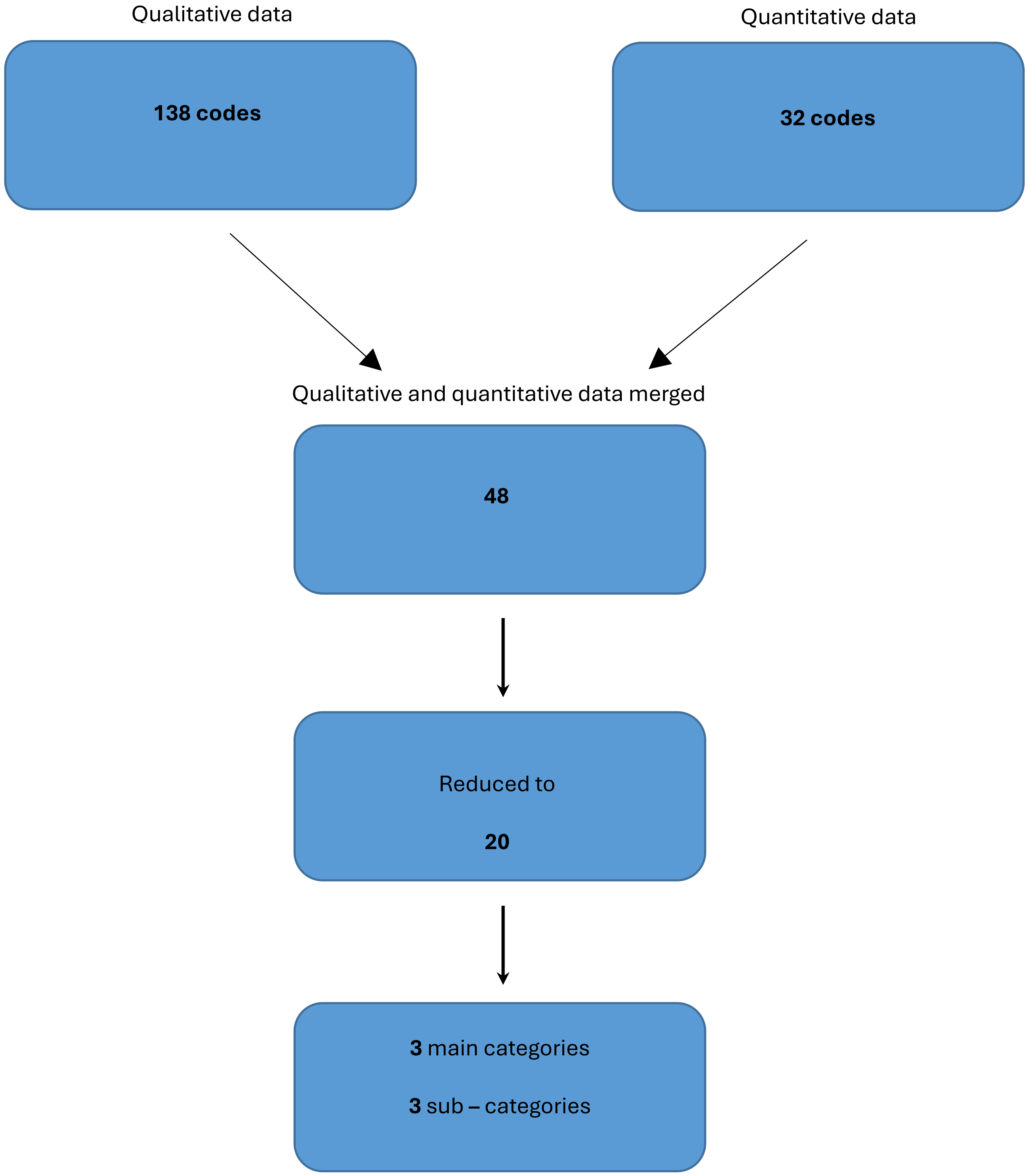
	Abstract/ Title	Introduction/ Aim	Methods/Data	Sampling	Data analysis	Ethics/Bias	Results	Transferability/ Generalisability	Implications/ Usefulness	Score
Avik Persson et al., 2018	4	4	4	4	4	3	4	4	4	35
Bloomer et al., 2013	4	4	4	4	3	4	4	4	3	34
Bloomer et al., 2018	4	4	4	4	4	4	4	4	4	36
Cable-Williams and Wilson.,2014	4	4	4	4	3	4	4	4	4	35
Cable-Williams and Wilson., 2017	4	4	4	4	4	4	4	4	4	36
Cowey et al., 2015	4	4	4	4	4	2	4	4	4	34
Domeisen Benedetti et al., 2013	4	4	4	4	4	4	4	4	4	36
Fryer et al., 2016	4	4	4	4	4	4	4	4	4	36
Gerber et al., 2022	4	4	4	4	3	4	4	4	4	35
Higginbotham et al., 2021	4	4	4	4	4	4	4	4	4	36
Johnson et al., 2014	4	3	4	3	2	4	3	3	2	28
Lee et al., 2017	4	4	3	4	2	2	4	3	3	30
Morrison and Forbes., 2012	4	4	4	4	3	3	4	4	4	34
Osterveld-Vlug et al.,2019	4	4	4	4	4	4	4	4	4	36
Redman et al., 2017	4	4	4	4	3	4	4	4	3	34
Reid et al., 2015	4	4	4	4	4	4	4	4	4	36

Sahlberg-Blom et al., 2013	3	3	3	3	4	3	4	3	3	29
Taylor et al., 2017	4	4	4	4	4	4	4	4	3	35
Taylor et al., 2021	4	4	4	4	4	4	4	4	2	35
Van Der Werff et al., 2012	2	4	4	4	4	3	4	3	4	32
Vrijmoeth, Christians, Festen, Groot, Tonino, et al., 2016	4	4	4	4	4	4	4	4	4	36
Vrijmoeth, Christians., Festen, Groot, Van der Heide, et al., 2016	4	4	4	4	4	4	4	4	4	36
Waldrop et al., 2015	3	4	4	4	3	3	4	3	3	31
White et al., 2018	4	4	4	4	4	4	4	4	4	36

🟩 High Quality

🟧 Medium Quality

Appendix 4. Process of comparing, grouping and categorising patterns and themes



Appendix 5. Summary of included papers

Table 1. Quantitative papers

Author **Date** **Country**	**Setting**	**Population** **Sample Size**	**Aims & Objectives**	**Research design**	**Data collection analysis**	**Findings**
Domeisen Benedetti et al., 2013 **International**	Mixed care settings in Italy, Netherlands, Sweden, Germany, UK, Argentina, New Zealand and Slovenia	Health care professionals (physicians, nurses, psychosocial spiritual professionals, laypersons/ volunteers. Laypersons/volunteers were not included in cycle 3. Cycle 1 : (n=252) Cycle 2 : (n=36) Cycle 3 : (n=78)	To provide expert consensus on phenomena for identification and prediction of the last hours or days of a patient's life	**Design**: Delphi techniques consisting of 3 cycles. Questionnaire to collate phenomena that identify and predict the last hours and days of life	**Data collection:** Questionnaire in each cycle **Analysis:** Statistical analysis – Parametric and nonparametric methods. Data were dichotomised into high relevance and low relevance	Seven categories found to be highly relevant to predict someone would die within the next few hours/days. The categories were: 'Breathing', 'consciousness/cognition', 'emotional state', 'general deterioration', 'intake of fluid, food, other', 'non-observations/expressed opinions/other' and 'skin'
Waldrop et al., 2015 **USA**	Emergency Medical service	Pre-hospital providers employed by a single Emergency Medical Service (n=178)	To explore prehospital providers' perceptions of the frequencies of different types of end-of life calls, the signs and symptoms of dying	**Design**: Cross-sectional survey: Twenty-seven questions were asked about 3 domains of end-of-life care: (1) frequencies of various emergent end-of-life calls	**Data collection:** Survey **Analysis:** Statistical analysis – Nonparametric and descriptive statistics	The 2 objective factors that were the most frequently endorsed indicators that a patient is dying: diagnosis and hospice involvement. The most frequent signs and symptoms of dying were diagnosis, hospice involvement, apnea, mottling, and shortness of breath

			and medical orders for life sustaining treatment (MOLST)	(e.g., home, nursing home, ALFs), (2) signs and symptoms of dying, and (3) advanced directives		
Vrijmoeth, Christians, Festen, Groot, Tonino, et al., 2016 **Netherlands**	Home, hospital, hospice, community residential home	Learning Disability Physicians (n=81) General Practitioners (n=16)	To explore when and based on which information sources and signals physicians recognised that a patient with learning disability would die in the foreseeable future.	**Design:** Retrospective survey about their last patient with learning disability that had a non-sudden death	**Data collection:** Online survey **Analysis:** Statistical analysis – Parametric and nonparametric methods	More than 20% of all physicians foresaw death not until the last week of life. There are 40 different signals that lead to physicians' foreseeing death. Results indicate that the physicians' ability to foresee death is a result of a process of growing awareness in which multiple signals from different information sources converge
Vrijmoeth, Christians., Festen, Groot, Van der Heide, et al., 2016 **Netherlands**	Home, hospital, hospice, community residential home	Learning Disability Physicians (n=81)	To determine the prevalence rates of physician-reported symptoms from the Edmonton Symptom Assessment System at moment that physicians recognized patient's death in the foreseeable future. To explore interventions as reported in the period between	**Design:** Retrospective survey about their last patient with learning disability that had a non-sudden death	**Data collection:** Online survey **Analysis:** Statistical analysis – Parametric and nonparametric methods	On average, patients suffered from three of the eight ESAS symptoms. Fatigue (83%), drowsiness (65%), and decreasing intake (57%) were most reported

			physicians' recognition of death and time of death			
White et al., 2018 **UK**	Mixed settings	Medical doctors. Members of the Association of Palliative Medicine Phase 1: (n=99) Phase 2 (n=14)	To identify how palliative care doctors, who perform well on a prognostic test, make predictions about which patients are imminently dying	**Design:** Prospective observational study and two cross-sectional online studies	**Data collection:** Phase I: an online prognostic test, Phase II: an online judgement task **Analysis:** Phase 1- The accuracy of each doctor's prognostic estimate was determined by calculating the Brier score. Phase 2- Statistical analysis - Parametric methods	This study identified six clinical signs and symptoms which influenced the judgement policies of palliative care doctors. It was found that for hospice in patients with end-stage malignancy the PPS was the most influential factor, followed by the presence of Cheyne-stokes breathing, decline in overall condition. Noisy respiratory secretions and peripheral cyanosis
Osterveld-Vlug et al.,2019 **Netherlands**	239 long-term facilities in 6 European countries	Residents of long-term care facilities (n=1094)	To describe the relation between physician visits and physicians' recognition of a resident's terminal phase in long-term care facilities	**Design:** Cross-sectional survey	**Data collection :** Questionnaire **Analysis :** Statistical analysis – Parametric methods	Positive associations were found between the number of physician visits in the last 3 months of life and the recognition of the resident's terminal phase, and between the number of physician visits and the resident having palliation as the main treatment goal in the last week of life

Table 2. Mixed methods papers

Author **Date** **Country**	**Setting**	**Population** **Sample Size**	**Aims & Objectives**	**Research design**	**Data collection analysis**	**Findings**
Cable-Williams and Wilson., 2014 **Canada**	Three long-term care facilities	Staff (multi-professional) (n=29) Family members (n=12) Residents (n=9)	To explore awareness of impending death for very old persons in long-term care facilities	**Design:** Mixed methods	**Data collection:** Qualitative – interviews, focus groups, artefact review. Quantitative – data gathered through review of charts **Data analysis :** Qualitative – Constant comparison. Quantitative – Statistical analysis – Descriptive methods	A 2-stage layered awareness of impending death was identified: Generalised awareness, and clinical awareness when health status changes that suggested that death was likely within a few hours or days
Cowey et al., 2015 **UK**	Four acute stroke units in Scotland	Healthcare professionals (doctors, nurses, speech therapists, nursing assistants (n=23) Relatives (n=17)	To identify family and health-care worker perceptions of an end-of-life care pathway for patients who die after acute stroke. To determine	**Design:** Mixed methods	**Data collection:** Qualitative – interviews. Quantitative - Case note review	Clinicians used multiple factors to identify that patients were likely to die within hours or days including clinical indicators, clinical trajectory, intuition and discussion with the clinical team

			patients with fatal stroke judged to require an end-of-life care pathway differ from patients with fatal stroke who die without introduction of such a pathway		**Data analysis:** Qualitative data - Thematic analysis. Quantitative - statistical analysis - Parametric and descriptive methods	
Taylor et al., 2020 **UK**	Acute hospital trust which is a tertiary referral centre for both oncology and cardiology	Qualitative: Clinicians (doctors and nurses) (n=19) Quantitative: Data collected from patients with heart failure (n=81) and patients with cancer (n=102)	To explore the ability of clinical staff to recognise end of life in hospital in-patients dying as a result of cancer and heart failure, and to generate new hypotheses for further research	**Design:** Mixed methods	**Data collection:** Qualitative – Interviews. Quantitative – Retrospective cohort study **Data analysis:** Qualitative arm - Thematic analysis. Quantitative analysis – Multilevel modelling. Mixed methods analysis – Parallel convergent design	The decision process described was time-dependent, ongoing and iterative, and relies heavily on intuition. Clinicians also described a process that seeks data over time, allowing time for a more analytical, methodical component. Managing and recognising dying is blurred, repeated assessments are a key component of the decision process. Uncertainty is a defining characteristic of the overall process, and objective parameters only have a limited role in predicting end of life.

Table 3. Qualitative papers

Author **Date** **Country**	**Setting**	**Population Sample Size**	**Aims & Objectives**	**Research design, as described by study authors**	**Data collection analysis**	**Findings**
Morrison and Forbes., 2012 **UK**	Doctors undertaking posts palliative medicine or palliative medicine with oncology, in two acute hospitals	Foundation year doctors (n=10)	To explore doctors' experiences in foundation year1 (F1) palliative medicine posts	**Design:** Interpretive phenomenological analysis	**Data collection:** Interviews **Analysis:** Interpretative phenomenological analysis	Experience improved skills in recognising dying. The doctors learnt from experienced palliative care nurses
Van Der Werff et al., 2012 **Netherlands**	Four nursing units (oncology, internal medicine, pulmonology and neurology) in a hospital	Nurses (n=18)	To explore hospital nurse' perspectives of the signs and symptoms that mark the start of the dying phase in oncology patients	**Design:** Focus group design	**Data collection:** Focus groups **Analysis:** Constant comparative method	Nine categories of signs and symptoms that indicate onset of dying were identified: Changes in respiratory function, blood circulation, psychological condition, conscious levels spiritual experience, deterioration of physical condition, reduced oral intake and pain. Several of the nurses noted that marking 'the turning point' is difficult and that the combination of signs and symptoms may differ from patient to patient
Bloomer et al., 2013 **Australia**	Two acute medical wards	Nurses (n=25)	To explore nurses' 'recognition of' and 'responsiveness to'	**Design:** Qualitative approach	**Data Collection:** Observation, focus groups and	Nurses took a passive role in recognising dying, providing active care until a medical

			dying patients and to understand the nurses' influence on end-of-life care		individual semi-structured interviews **Analysis:** Observation data - qualitative content analysis. Table summary design to code the focus group and interview transcript data	officer's declaration of dying. Nurses found it difficult differentiating between acute deterioration and dying. Nurses demonstrated varying degrees of discomfort, indicating that they were underprepared for this role
Sahlberg-Blom et al., 2013 **Sweden**	Two nursing homes	Nurses (n=8)	To describe assistant nurses' experiences of signs of dying among older people in nursing homes	**Design:** Qualitative manifest content analysis	**Data collection:** Individual and group interviews **Analysis:** Manifest content analysis	Signs of imminent dying are described as 'manifest' - more obvious (fatigue, pain, breathing issues) and subtle - smell, withdrawal, desire to see family
Johnson et al., 2014 **UK**	Two nursing homes	Registered nurses, healthcare assistants, managers) (n=28), relatives (n=6) and residents (n=9)	To examine aspects of end-of-life care as it was perceived by stakeholders in two nursing homes	**Design:** Qualitative methodology	**Data collection:** Individual and group interviews, Observation **Analysis:** Thematic analysis	Key themes were diagnosis and awareness of dying in which there is no substitute for experience. Death was not talked about directly
Reid et al., 2015 **UK**	An acute hospital	Doctors, nurses, healthcare assistants) (n=28)	To explore healthcare professionals' views on delivering EOL care within a study examining the implementation	**Design:** Qualitative design	**Data collection:** focus groups, interviews and 'questerviews' - interviews with participants as they	Two major themes identified: delays in diagnosing dying (due to difficulty, avoidance, and cultural and structural issues, and the end-of-life tool providing support for staff

			and impact of a simple EOL tool on the dying experience in a large acute teaching hospital		completed the end-of-life checklists **Analysis:** Framework approach	
Fryer et al., 2016 **New Zealand**	Seven residential aged care facilities	Healthcare assistants (n=26)	To explore the experiences of healthcare assistants caring for imminently dying residents in aged care facilities and to identify barriers and facilitators to their work in this area	**Design:** Qualitative approach	**Data collection:** Focus groups **Analysis:** General inductive approach	Healthcare assistants provide the majority of hands-on care to dying residents and believed they had a valuable role to play due to their familiarity with the patient. There was a lack of value placed on their knowledge and experience by others. There was a lack of opportunity to share information about a resident's condition
Cable-Williams and Wilson., 2017 **Canada**	3 long-term care facilities	Residents (n=9) Staff (multi-disciplinary) (n=29) Family members (n=12)	To identify the influence of the culture in Canadian long-term care facilities on the awareness of impending death and initiation of a palliative approach to care for residents aged 85 years and older	**Design:** Focussed ethnography	**Data collection:** interviews, focus group observation, review of artefacts **Analysis:** Constant comparison	Four cultural influences on the awareness of impending death and consequent initiation of a palliative approach to care were identified: Care demands and resources, and the beliefs that long-term care facilities are for living, no one should die in pain; and that no one should die alone
Lee et al., 2017 **UK**	Stage 1: Range of services across England.	Service managers (n=33) and Staff involved in frontline care (n=54),	To explore the views of service managers and frontline care staff	**Design:** Qualitative design	**Data collection:** Qualitative interviews and focus groups	Recognition of end-of-life in people with dementia required both technical skills and personal, ongoing knowledge

	Stage 2: 8 sites across England	including doctors, nurses, nursing and care home managers, service development leads, senior managers/directors, care assistants/team leads	on key aspects of good EOLC for people with dementia		**Analysis:** Thematic analysis	observing and interpreting signs of deterioration and systematic approaches to acting on this information
Redman et al., 2017 **UK**	5 acute hospitals in England	Foundation year doctors (n=47)	To explore the experiences of foundation year doctors in caring for the dying, using the Priorities for Care of the Dying Person as a conceptual framework, to identify areas for improvement in education and clinical practice	**Design:** Qualitative design	**Data collection:** Semi-structured interviews. 8 group interviews and 21 individual **Analysis:** Framework method for coding with comparison across transcripts	Recognition of dying was one of the five main themes. Participants found it difficult to recognise dying but this became easier with experience. They described differences between specialities. Also described was lack of clarity to whose role it is and fear of uncertainty. Importance of communication including documentation.
Taylor et al., 2017 **UK**	Acute hospital trust which is a tertiary referral centre for both oncology and cardiology	Clinicians (doctors and nurses) (n=19)	Qualitative study: To answer the question: ‘What factors influence medical and nursing staff when recognising dying in end-stage cancer	**Design:** Qualitative study	**Data collection:** Qualitative interviews **Analysis:** Thematic analysis	Six themes were generated: information used; decision processes; modifying factors; implementation; reflecting on decisions and related decisions. The decision process described was time-dependent, ongoing and iterative, and relies heavily on intuition

			and heart failure patients?			
Avik Persson et al., 2018 **Sweden**	Four nursing homes	Healthcare Professionals, (n=24): Assistant nurses (n=5), nurses (n=3), occupational therapists (n=4), physiotherapists (n=4), social worker (n=2), manager (n=2)	To explore the experiences of early and late signs preceding dying in older persons in nursing homes from the multidisciplinary team's perspective	**Design:** Qualitative approach	**Data collection:** Focus groups **Analysis:** Focus group method developed by Krueger and Casey	Participants experienced dying as a happening, not a process, and found it difficult to identify early signs. There were two main categories "Going into a bubble" and "The body begins to shut down".
Bloomer et al., 2018 **Australia**	Geriatric inpatient rehabilitation care	Medical, nursing and allied health clinicians (n=19)	To explore how end-of-life care goals and decision-making are communicated in a geriatric inpatient rehabilitation setting	**Design:** Qualitative descriptive design	**Data collection:** Semi-structured individual and group interviews **Analysis:** Inductive content analysis	Clinicians described finding it challenging identifying patients who were dying, with some relying on others to inform them. How patient deterioration and decision-making was communicated among the team varied. Some clinicians relied on documentation, such as commencement of a dying care pathway to indicate when a patient was dying
Higginbotham et al., 2021 **UK**	Acute Medical Department in a 524 bed District Hospital	Registered nurses: (n=16) Doctors (n= 15) Patients (n=16)	To explore how healthcare professionals in an acute medical setting make decisions when managing the care of patients	**Design:** Grounded theory approach	**Data collection:** Interviews. Focus Groups. Field notes, diaries, memos **Analysis:** Constant comparison	The healthcare professionals perceived that heart failure was difficult to prognosticate and that the unpredictability of the disease could lead to unexpected death. The barrier to expert end-of-life care was perceived by some doctors involved to be the lack of

			diagnosed with end stage heart failure, and how these decisions impact directly on the patient's end of life experience.			clear guidance. A core theme was ‘A vicious cycle of care’.
Gerber et al., 2022 **Australia**	Two hospitals in Melbourne, Australia	Aged care assessment team members - Geriatricians/registrars (n=7) Nurses (n=10) Allied health Professionals (n=3)	To examine hospital aged care assessment teams’ experiences, strategies and challenges in identifying patients at risk of dying	**Design:** Qualitative design	**Data collection:** Interviews **Analysis**: Thematic analysis	Clinicians used analytical thinking, intuition, assessments from others, and pattern matching. Prognostic tools were rarely used. Barriers to recognition of dying included: diffusion of responsibility regarding whose role it is to identify patients at end-of-life; lack of feedback about whether a prognosis was correct; system pressures to pursue active treatment and vacate beds; avoidance of end-of-life discussions; lack of confidence, knowledge and training in prognostication and pandemic related challenges

Appendix 6. Excerpts from the literature

Table 1. Knowing the person over time

Excerpts from the literature
Qualitative
Others reported relying on their understanding of the patient's situation and attending to subtle cues in patients' behaviours and physiology to provide a subjective assessment that they may be dying (Bloomer et al., 2018, p.1618) *Increased knowledge of the patient was also important, in terms of assessing patterns of change over time (Taylor et al., 2017, p.8)* *"We see them each time we work, yes. We get to know them really well. That's why we see all the signs that show a change, because we see them so often. So we notice pretty quickly, we're the ones who see it perhaps clearest of all, that are closest to them..." (Sahlberg-Blom et al., 2013, p.21)* *Many staff members spoke about the importance of close long-term relationships with residents for noticing a mortal turn in their health condition, for instance, one Registered Practical Nurse said: "We know the little norms of people. We pick up on all the very small signals [because we have] very close relationships with these people" (Cable-Williams and Wilson, 2014, p.174)*
Quantitative
….. positive associations were found between the number of physician visits in the last 3 months of life and the recognition of the resident's terminal phase, and between the number of physician visits and the resident having palliation as the main treatment goal in the last week of life (Oosterveld-Vlug et al., 2019, p.696)

Table 2. Intuition and experience

Excerpts from the literature
Qualitative
“I couldn’t operationalise how I do it because some of it is just intuitive and sometimes you just get a feel, which isn’t scientific, I realise. But I suspect that’s how a lot of people work, actually. Although everyone’s aware of the things that are very strong predictors of the end of life, I think there’s always a little bit of gut feeling about it” (Cowey et al., 2015, p.253) *Clinicians described that their intuition was crafted through experience, but sharing gut feelings were a difficult foundation for discussions with team members or families. Hence many struggled with communicating their suspicions to others (Gerber et al., 2022, p.10)* *“… but you know on intuition: you just know don’t you? And after being a nurse for some time you do get to know and I went, ‘No, I really want pathway drugs for this lady” (Helen, Senior Nurse) (Johnson et al., 2014, p.100)* *Doctors also reported their palliative care experience helped them to make professional judgements, for example when it was no longer appropriate to intervene (Morrison & Forbes, 2012, p.854)*
Quantitative
In addition to these phenomena, palliative care experts rated intuition/gut feeling as clinically relevant (Domeisen Benedetti et al., 2013)

Table 3. Recognition by others

Excerpts from the literature
Being informed by others
As well as discussing the use of intuition or 'sixth sense' and pattern matching, all staff interviewed discussed decision making in teams. This included assessing/discussing cases with individual colleagues, sharing information in larger teams (Taylor et al., 2017, p.7) *At the beginning and end of some shifts, doctors have the opportunity to give their colleagues written and verbal information about patients that the following doctor needs to be aware of. It was noted as particularly important to include information about deteriorating patients and expected deaths in that handover process:(Redman et al., 2017, p.1030)* *Geriatricians often relied on nurses' assessments as nurses spent more time with the patient and were able to notice subtle changes (Gerber et al., 2022, p.9)*
Informed by other means
In the absence of clear information to inform their understanding, participants described other ways in which they could ascertain when a patient might be deteriorating towards death, or what other members of the treating team, such as medical staff, might think, including relying on documents (such as treatment limitation form) in the medical record that were not intended to be the first indicator that a patient was dying (Bloomer et al., 2018, p.1621) *"… when the butterfly finally goes up (a symbol posted on a resident's door to indicate that death is imminent) I think they get everything they need, but it could have been picked up days before and we could have started measures earlier" (Cable-Williams & Wilson, 2017, p.8)* *Participants indicated that diagnosis and the involvement of hospice strongly indicates that someone is dying (Waldrop et al., 2015 p.202)*

Table 4. Culture, system and practice

Excerpts from the literature
Culture
Long term care settings *Staff members were particularly anxious to portray living in contemporary LTC (Long Term Care) facilities as being in sharp contrast to the grim reputation of nursing homes in years gone by when they were places of death as illustrated by these quotations: 'It's an old stigma that this is a place to come to die ... '(Administrator); and 'The generation of people that are coming in now still have that nursing home stigma in their minds from their parents and grandparents. We haven't got over that yet' (Director of Care) (Cable-Williams & Wilson, 2017, p.6)* *Nevertheless, speaking directly about death as such remained relatively rare in these nursing homes. Rather, euphemisms were used, not with intent to deceive, but to 'soften' the emotional impact of the information. Senior Nurse John explained how 'poorly' was used to portray a deterioration, which might result in a resident's death (Johnson et al., 2014, p.101)* *Registered Nurses also expressed their concerns about the consequences of staffing ratios and qualifications on the quality of care in such comments as: 'The Registered Practical Nurses are so tied up on the floor they often don't get back to do the assessment [of resident condition or the impact of interventions]' (RN) (Cable-Williams & Wilson, 2017, p.5)*
Acute settings *Staff acknowledged that the diagnosis of dying was often made late; this was partly due to prognostic uncertainty but compounded by a culture that did not acknowledge death as a possible outcome until death was imminent (Reid et al., 2015, p.490)* *Staff explained that the hospital culture was rarely to discuss or acknowledge death or dying and to treat all patients actively, assuming that active treatments and investigations are always in a patient's best interest. Some spoke of the 'bravery' required to state that a patient was dying (Reid et al., 2015, p.492)*

Providing ideal care for the dying, while also caring for other acutely ill patients appeared to be challenging; at times, nurses resorted to a 'task focus' to get the work done: (Bloomer et al., 2013, p.760)

Another hospital system that did not facilitate good EOL (end of life) care was the frequency of senior reviews of patients. Junior doctors and nursing staff described needing validation of the diagnosis of dying by the senior medical staff (usually the consultant), and thus asked for this confirmation on the ward round. However, senior staff felt that they did not see patients frequently enough to be confident about diagnosing dying (Reid et al., 2015, p.492)

"... it's not done well at all ... especially on the weekend ... if the team on Friday, they know that a patient's going to be end of life over the weekend ... they need to at least document into the notes that if this patient is deteriorating, they're for end of life care" (Redman et al., 2017, p.1032

Table 5. Uncertainty

Excerpts from the literature
Acute settings *During observation, it became apparent that recognition of dying was difficult, that is, nurses had difficulty differentiating between an acutely ill patient and a dying patient, most often deferring to, or waiting for, medical staff to make the distinction (Bloomer et al., 2013, p.759)* *Staff acknowledged that the diagnosis of dying was often made late; this was partly due to prognostic uncertainty but compounded by a culture that did not acknowledge death as a possible outcome until death was imminent (Reid et al., 2015, p.490)* *The focus group moderator specifically asked the participants to focus on the signs and symptoms that herald the onset of the dying phase. Several of the nurses noted that marking 'the turning point' is difficult and that the combination of signs and symptoms may differ from patient to patient. Hence, nurses may feel uncertain about how to diagnose the onset of the dying phase (Van Der Werff et al., 2012, p.148)*
Long-term care settings *Staff members noted these observations as ominous, but not as certain indicators of immediately impending death. All had witnessed residents who had rallied to life when death had seemed certain as portrayed in the following quotation of a staff member: 'We see many people cheat death. We think they're close to that time, but then they bounce back' (Cable-Williams & Wilson, 2014, p.175)* *The phenomenon of 'bounce back' is commonly experienced in nursing homes when someone whose death is expected with virtual certainty appears to rally and defies realistic planning for death (Johnson et al., 2014, p.100)*

Appendix 7. Letter of invitation

12/1/2023

Hello

My name is Elizabeth Flannery and I am undertaking a PhD in Palliative Care at Lancaster University. I will be undertaking research on [redacted] from 23/1/23.

I will be shadowing individual registered nurses carrying out their role whilst caring for patients who may be dying. I will also be interviewing nurses to ask about their experiences and views about caring for patients who are dying in the acute setting.

I am writing to invite you to take part in the research. You may agree to be shadowed or interviewed, or both. Participation is entirely voluntary and you will be asked to give written consent.

If you would like to participate or have more information, please contact me using my contact details below or let your ward manager know.

Kind regards

Elizabeth Flannery

Post-graduate Researcher

Tel: 07818434989

e.colquhoun-flannery@lancaster.ac.u

[redacted] NHS
Hospitals
NHS Foundation Trust

Lancaster University

Appendix 8. Participant information sheet

Participant Information Sheet

How do nurses in the acute setting care for people who may be dying?

Study location: __________ hospital, __________ ward.

My name is Elizabeth Flannery and I am conducting this research as a student in the PhD Palliative Care programme at Lancaster University, Lancaster, United Kingdom. Lancaster University is the sponsor for this project.

What is the study about?

The purpose of this study is to explore how nurses care for people who may be dying in the acute setting. Recognising dying is known to be challenging, but it is important because it begins the change to comfort-focused care. When it has been recognised that a person is dying a change may take place from treatments and investigations where the intention is to prolong life, to where the main priority is comfort. Nurses are the healthcare professionals who spend most time with dying patients but little is known of how they manage the change to comfort-focused care.

Why have I been approached?

You have been approached because you are a Registered Nurse who works in the acute hospital setting.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part you will be invited to be observed by me as you go about your work in caring for patients who may be dying. You will be individually observed on one occasion for a maximum of one shift. You will also be invited to participate in an

interview which might take up to around 60 minutes. You may consent to both or one of these.
You will be able to choose whether the interview takes place virtually using Microsoft Teams, or in-person at a convenient place for you. In-person interviews will be recorded using a portable audio recorder and virtual interviews will be recorded using the recording function of Microsoft Teams.

Will my data be Identifiable?

The information you provide is confidential. All the data (audio, visual and text) collected for this study will be securely stored at Lancaster University and only the researcher will have access to this data.

- Audio recordings will be deleted once the thesis has been examined.
- Virtual interviews via Microsoft Teams will be deleted once the thesis has been examined.
- All data collected for this study will be stored securely only on Lancaster University OneDrive and will be password protected. The computer itself will be password protected.
- At the end of the study, data will be stored securely in Lancaster University data repository for ten years, after which the data will be deleted.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this study.
- All your personal data will be confidential and will be kept separately from your interview responses and audio and virtual recordings.
- Personal identifying details will be deleted when the research has been examined.
- There are some limits to confidentiality: if during the interview I think that you, or someone else, may be at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The study findings will be anonymised and summarised, and then reported in a thesis. The findings may also be presented at academic conferences. Papers on the findings may also be submitted for publication to peer reviewed academic journals and other professional journals. A report of the study findings will be sent to all participants.

Are there any risks?

The subject matter of this research is sensitive and therefore it is possible that you may feel distressed. If you experience any distress during or following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet. There are no other risks anticipated with participating in this study.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University and the Health Research Authority.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the researcher:
Elizabeth Flannery: e.colquhoun-flannery@lancaster.ac.uk
You may also contact: Professor Catherine Walshe (academic supervisor):
c.walshe@lancaster.ac.uk

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban Tel: +44 (0)1524 595133
Director of Research
Email: f.lobban@lancaster.ac.uk
Department of Health Research
Lancaster University
Lancaster LA1 4YG

If you wish to speak to someone outside of the Palliative Care Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 595133
Ethics Chair for Research for the Faculty of Health and Medicine
Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

- XXXX Staff Wellbeing Hub gives you access to a qualified counsellor 24/7 for confidential listening support, signposting and options for 6 weeks counselling or online CBT. Staff can access Health Assured (HA) by calling XXXX XXXXXX and choosing Option 1. Additional Employee Assistance Programme services are also available via this route or by emailing staffwellbeing[redacted]
- National Helpline from NHS England on 0300 131 7000 (07:00 –23:00)
- Project5 - Free Wellbeing Service for NHS staff and healthcare workers: https://www.project5.org/
- Royal College of Nursing - Counselling Service. Tel: 0345 772 6100
- Unison Welfare thereforyou@unison.co.uk.   Tel: 020 7121 5620

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

NHS
[redacted] Hospitals
NHS Foundation Trust

Lancaster University

Appendix 9. Consent form

How do nurses in the acute setting care for people who may be dying?

I am asking if you would like to take part in a research project about how registered nurses care for people who may be dying in the acute setting. Before you consent to participating in the study, please can you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the researcher – Elizabeth Flannery

Please respond to each statement.

1.	I confirm that I have read the information sheet V2_22.8.22, and fully understand what is expected of me within this study.	
2.	I confirm that I have had the opportunity to ask any questions and to have them answered.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
4.	I consent to being interviewed and understand that my interview will be audio recorded or video recorded (in the case of virtual interviews) and then made into an anonymised written transcript.	
5.	I understand that audio or video recordings will be kept until the research project has been examined.	
6.	I consent to being observed carrying out my role in caring for patients who may be dying and understand that the researcher will make notes and records of observations.	
7.	I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.	

8.	I understand that information will be pooled with responses and observations of other participants. It will be anonymised and may be published; all steps will be taken to protect the anonymity of the participants involved in the project.	
9.	I consent to information and quotes from the study being used in reports, conferences and training events.	
10	I understand that the researcher will discuss data with their supervisor as needed.	
11	I understand any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with their research supervisor.	
12	I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.	
13	I consent to take part in the above study.	

Name of Participant___________________ Signature_____________________ Date ___________

Name of Researcher ___________________Signature _____________________Date ___________

If you do decide to take part you will be given a copy of your signed consent form to keep. A copy will be kept by the researcher

Appendix 10. Posters

NHS
[redacted] Hospitals
NHS Foundation Trust

Lancaster University

Research

A study will start on this ward on / /2023

- The research involves observing day to day staff activity in the ward environment

- It is being undertaken as part of a PhD at Lancaster University

You have the right to opt-out of being observed. If you do not wish to be observed please inform the nurse in charge or the researcher using the contact details below

For more information contact: Elizabeth Flannery

E.Colquhoun-Flannery@lancaster.ac.uk

NHS
[redacted] Hospitals
NHS Foundation Trust

Lancaster University

Research

TAKING PLACE TODAY!

- The research involves observing day to day staff activity in the ward environment

- It is being undertaken as part of a PhD at Lancaster University

You have the right to opt-out of being observed. If you do not wish to be observed please inform the nurse in charge or the researcher using the contact details below.

For more information contact: Elizabeth Flannery

E.Colquhoun-Flannery@lancaster.ac.uk

Appendix 11. Patient information trifold leaflet

IRAS_309655_v1.0_9.3.22

NHS
[redacted] Hospitals
NHS Foundation Trust

Lancaster University

Research

How do nurses in the acute setting care for people who may be dying?

About the researcher

My name is Elizabeth Flannery. I am a post-graduate researcher from Lancaster University. This study is part of a PhD in palliative care.

Background

The purpose of this study is to explore nurses understanding of, and role in, the transition to comfort-focused care for patients in the last days or hours of life in acute hospital settings. I am interested in the knowledge and experiences of nurses, and how these may be shaped by the culture of the healthcare setting.

Transition to comfort-focused care involves a change from treatments and investigations where the intention is to prolong life to where the main focus of care is comfort.

Comfort-focused care refers to where the plans and all treatment prioritise the comfort of the patient at the end of life, rather than the primary aim of care being to prolong life. However comfort-focused care may at times involve the continuation of some treatments such as antibiotics and parenteral fluids if they contribute to the patient's comfort and symptom management.

Recognising dying begins the process of the refocusing of goals and a change to comfort-focused care, rather than on treatment and investigations that are potentially burdensome to the patient with the goal of prolonging life. However, recognising dying is known to be challenging at times, even for experienced clinicians.

In the acute hospital setting there are additional challenges including the competing priorities of curative treatments with the accompanying investigations and interventions alongside the needs of dying patients.

Why is this important?

Transition to comfort-focused care is complex and often difficult, however a successful transition can enable the dying person to receive end-of-life care in alignment with their wishes and values, and where professionals, families as well as the patient, have a shared purpose.

Nurses are the healthcare professionals who spend most time with dying patients therefore the role of nurses in recognising dying and the subsequent shift in approach and goals of care is likely to be significant.

What is involved

Observation will take place in the ward environment. Meetings and events such as ward rounds, nurses' handovers and multi-disciplinary team meetings will be observed. Individual registered nurses will also be observed carrying out their role and activities in caring for patients who are thought to be dying, have advanced or end-stage illness or where recovery is uncertain. In addition, registered nurses will be invited to take part in an interview about their role, perceptions and attitudes about transition to comfort-focused care. Nurses who are interviewed or individually observed will need to give written consent. Otherwise, an opt-out process will be in place. If you wish to opt-out of observation please let me know using the contact details below or let your ward manager know.

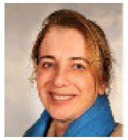
Taking part

If you are a Registered Nurse and are interested in taking part, please contact me using the contact details below or let your ward manager know. I will then forward participant information and a consent form. You may also contact me if you have any questions, concerns or comments.

Elizabeth Flannery

Tel: 07818434989

e.colquhoun-flannery@lancaster.ac.uk



Appendix 12. Topic guide for interviews

Topic Guide for interviews

How do nurses working in acute hospital settings manage transition to comfort-focused care in people who are dying? – a focused ethnography.

- Can you describe a time when you have been involved in the care of someone who is dying?
- Can you describe what makes you believe or judge that a patient may be dying? It may help to recall a particular patient. Please do not identify specific patients in any way.

Probes: Experience, intuition, knowing the patient, clinical results, diagnosis

- What do you do when you think a patient may be dying?
- How do you convey your observation or assessment that a patient may be dying to other members of the multi-disciplinary team?
- How easy or difficult do you find it to talk to other members of the MDT about your observation or assessment that a patient may be dying? If difficult: Why do you think this might be? What would make this easier?

Probes: Role boundaries, seniority, MDT working, time, knowledge, differences in opinion, uncertainty

- How easy or difficult do you find it to talk to the patient's family about the possibility that a patient may be dying? If difficult: Why do you think this might be? What would make this easier?

Probes: Family dynamics, taking away hope, taboo subject, concern about their reaction, sadness, advocacy role.

- Have you ever talked to the patient themselves about dying? If you have, how confident were you to do this? How did you feel?

Probes: worried about upsetting the patient, sufficient knowledge, saying the wrong thing, whose role?

- What do you feel the challenges are in caring dying patients in the acute setting?
- Is there anything that would help make this easier?
- Is there anything that makes this more challenging?

Do you have any final thoughts, or would you like to follow up upon anything I haven't asked you?

Appendix 13. University ethics approval

From: donotreply@infonetica.net <donotreply@infonetica.net>
Sent: 21 July 2022 15:57
To: Colquhoun-Flannery, Elizabeth (Postgraduate Researcher) <e.colquhoun-flannery@lancaster.ac.uk>
Cc: Walshe, Catherine <c.walshe@lancaster.ac.uk>
Subject: [External] FHM-2022-0842-IRAS-2 Ethics Approval from FREC

Name: Elizabeth Colquhoun-Flannery

Supervisor: Catherine Walshe

Department: Health Research

FHM **REC Reference:** FHM-2022-0842-IRAS-2

Title: How do nurses working in acute hospital settings manage transition to comfort-focused care in people who are dying? - a focused ethnography

Dear Elizabeth Colquhoun-Flannery,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).

- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

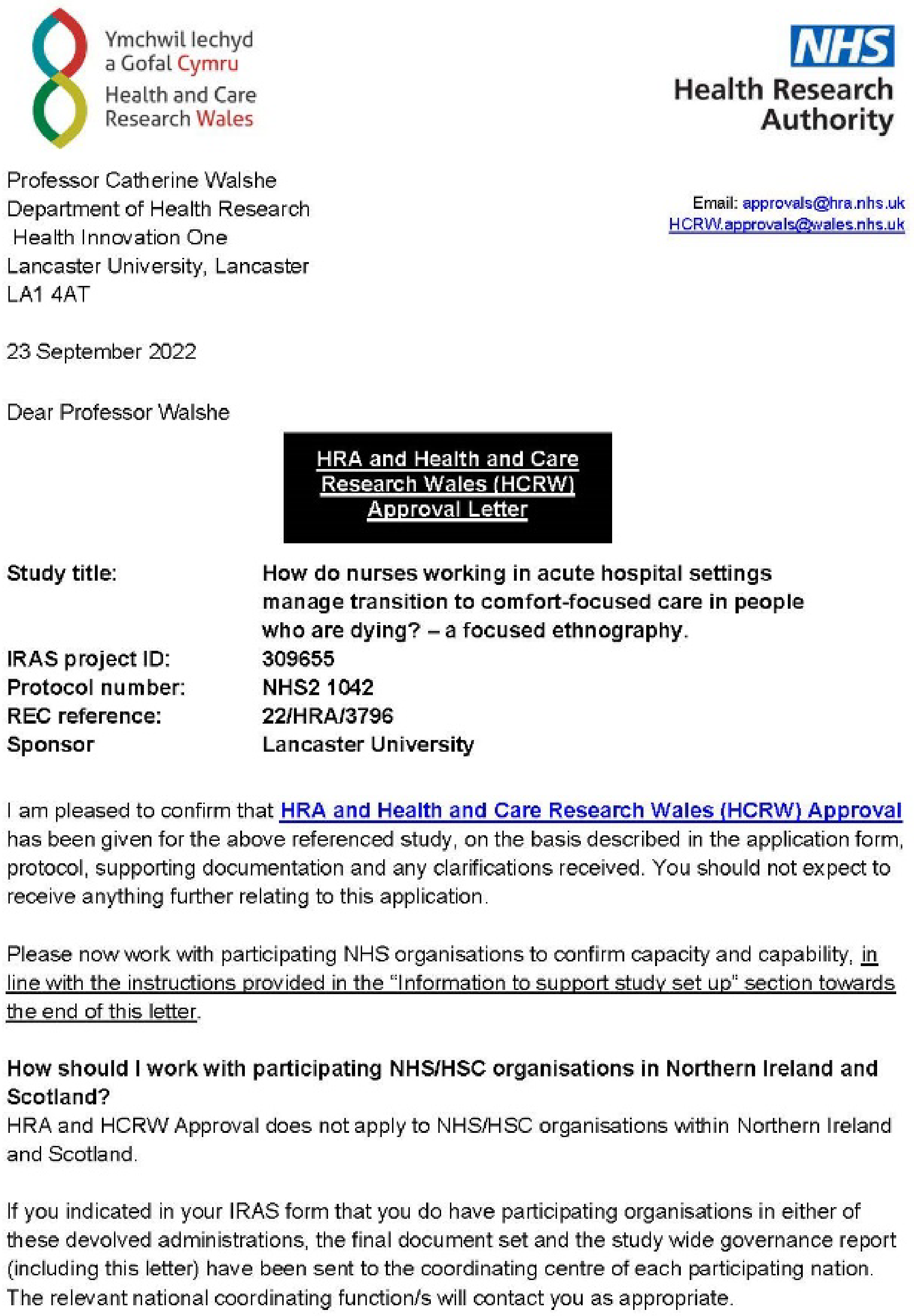
Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk

Lancaster University

Appendix 14. Health Research Authority approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Professor Catherine Walshe
Department of Health Research
Health Innovation One
Lancaster University, Lancaster
LA1 4AT

23 September 2022

Dear Professor Walshe

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **How do nurses working in acute hospital settings manage transition to comfort-focused care in people who are dying? – a focused ethnography.**
IRAS project ID: **309655**
Protocol number: **NHS2 1042**
REC reference: **22/HRA/3796**
Sponsor **Lancaster University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The "*After HRA Approval – guidance for sponsors and investigators*" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **309655**. Please quote this on all correspondence.

Yours sincerely,
Kelly Rowe

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Becky Gordon*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Lancaster University Indemnity]	V1	01 August 2022
Interview schedules or topic guides for participants [Topic guide for qualitative interviews]	V2	22 August 2022
IRAS Application Form [IRAS_Form_01092022]		01 September 2022
Letter from sponsor [University approval letter]	V1	21 July 2022
Letters of invitation to participant [Letter of invitation]	V1	15 March 2022
Organisation Information Document [Organisation Information Document]	V2	22 August 2022
Other [Distress protocol]	V1	15 March 2022
Other [Risk Assessment]	V1	20 March 2022
Other [Poster]	V2	22 August 2022
Other [Poster observation days]	V2	22 August 2022
Other [Tri-fold information leaflet cover]	V1	09 March 2022
Other [Tri-fold information leaflet]	V1	06 March 2022
Other [CV Dr Dawn Goodwin]	V1	21 September 2022
Participant consent form [Consent form]	V2	22 August 2022
Participant information sheet (PIS) [Participant Information Sheet]	V2	22 August 2022
Research protocol or project proposal [Protocol]	V2	22 August 2022
Schedule of Events or SoECAT [Schedule of events]	V2	22 September 2022
Summary CV for Chief Investigator (CI) [CV CI]	V1	22 July 2022
Summary CV for student [CV ECF]	V1	22 July 2022
Summary CV for supervisor (student research) [Catherine Walshe CV]	V1	22 July 2022

IRAS project ID	309655

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	**Expectations related to confirmation of capacity and capability**	**Agreement to be used**	**Funding arrangements**	**Oversight expectations**	**HR Good Practice Resource Pack expectations**
All activities will be conducted at the one participating NHS organisation	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type.	The sponsor has detailed its proposals with respect to whether any study funding will be provided to participating NHS organisations of this type in the relevant Organisational Information Document. This should be read in conjunction with the relevant Schedule of Events/SoECAT which details the cost implications of the study for participating NHS organisations.	In line with HRA/HCRW expectations a Local Collaborator should be appointed at participating NHS organisations of this type.	Where an external individual is conducting only research activities that are limited to access to staff, or staff data (in either identifiable or anonymised form), or anonymised patient data then a Letter of Access is required only if these activities will take place in NHS facilities. Where these activities will not take place in NHS facilities then no arrangements under the HR Good Practice Pack are required. This should be issued be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio. The Caldicott Guardian from the participating NHS organisation confirm that the research does not breach common law of confidentiality.

Appendix 15. Letter of access

[redacted]

[redacted]

Elizabeth Colquhoun-Flannery

Friday 21st October 2022

Dear Elizabeth,

Letter of access for research

This letter is to confirm that we are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer, and to confirm your right of access to conduct research through [redacted] Hospitals NHS Foundation Trust, the purpose and terms and conditions which are detailed below. Your employer is responsible for ensuring all necessary checks have been carried out.

This right of access commences on **01st October 2022** and ends on **01st October 2023** unless terminated earlier in accordance with the clauses below. You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to [redacted] Hospitals NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee. While undertaking research through [redacted] Hospitals NHS Foundation Trust you will remain accountable to your employer but you are required to follow the reasonable instructions of your nominated manager Dr [redacted] in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third-party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings. You must act in accordance with [redacted] Hospitals NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [redacted] Hospitals NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation, and to take reasonable care for the health and safety of your self and others while on Hampshire Hospitals NHS Foundation Trust premises.

Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times. You are required to ensure that all information regarding patients or staff remains secure and **strictly confidential** at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence, and such disclosures may lead to prosecution.

[redacted]

[redacted]

[redacted] Hospitals NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property. We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

[redacted]
Recruitment Advisor

cc: Dr [redacted] Consultant

Appendix 16. Distress protocol

Distress Protocol adapted from Draucker et al. (2009) and Haigh and Witham (2015)

Distress: A participant indicates that they are experiencing distress, **or** the participant exhibits behaviours indicating distress, for example crying or physical symptoms such as feeling faint.

Stage 1 response: Stop the interview. Offer immediate support. Assess level of distress, for example ask: How are you feeling? Do you feel safe? Do you feel able to continue with your day? The Interviewer will be a health care professional who has advanced communication skills training.

Review: If participant is willing and feels able to continue, resume the interview. **If not** go to stage 2.

Stage 2 response: Discontinue interview. Encourage the participant to contact their GP or mental health support. If the participant consents the researcher can offer to do this for them. Give contact numbers for support organisations (already included in participant information).

Follow up: Follow up call if participant consents **or** encourage the participant to call researcher or seek support from GP or mental health support if they experience distress or have concerns in the hours or days following the interview.

Appendix 17. Sample interview

I= Interviewer P= participant

I: Thank you very much. Do you confirm that you consent to talking to me?

P: Yes that's fine absolutely fine.

I: To start can you tell me how long you have been a nurse for?

P: Ah so coming up to August it will be two years.

I: And did you train here?

P: I didn't, no, I trained in xxx (UK)

I: So what I'm interested in are really your views and opinions about looking after people who might be dying, or who have got advanced illness and you think they may be approaching end of life, and your experiences of that.

It might be helpful to think of someone you have looked after recently.

P: Yes, I think probably a couple of months ago actually, it was a lady we had on our ward and you could clearly see after multiple attempts at trying different things, trying IV antibiotics and you know trying to correct all the blood results, you could just tell that there wasn't any movement and you could just physically see from the patient and also just their family the distress they were going through and you could clearly see that the patient had had enough. They, you know, I can recognise the signs, you know. The blood pressure was going down, peripherally she was very cold, you could just (pause), signs and symptoms of (pause) recognising that someone was dying, you could just tell so I went and spoke with doctors and I said look what are we doing here, what is actually going on because this patient is clearly dying and I think all this treatment that we're doing is actually making her worse off and the family are very distressed as well.

The doctors didn't really seem keen to be listening to me. So I actually went and contacted palliative care myself and I asked them, 'can you please review this patient, they are under you already', I think more for symptom management to begin with. And I asked them if they can review her and they actually agreed with me. Yes. And end of life care was commenced, and you could just tell that the patient seemed a lot more comfortable and the family were all in agreement with it as well. I didn't want to have to go behind, I felt like I kind of went behind the doctors back, but in the sense, I knew that me going to palliative care was the right thing for my patient.

I: So you went to them for support?

P: Yes. They were coming up to see somebody else on the ward I think and I just grabbed them in the corridor and said do you mind just going to have a chat with the family and have a look at the patient for me. Yeah, they were in agreement with what I was saying.

I: What did they do then?

P: Yes, they want to speak to the reg and said look this patient is actively dying. I think we need to start them on end of life medications and get them comfortable.

I: So you were talking about blood pressure and things like that, but also you said you 'just know'.

P: Yeah you can just, you just, you just look at someone you just, the colour of their skin or you notice that the way they are breathing has changed or you go to touch them and it's just like an ice block everywhere or patients are fluid overloaded to the point where the skin is just leaking fluid all the time and their skin starts to breakdown and then they get sores and then yeah, you can just sort of tell from that. Just looking at someone, of the colour of their skin and things like that, you know. And if the patient's awake enough I'm sure they will probably be able to tell you as well, you know, 'I don't want anything else, I want to, you know', and I think we should be able to give them that respect. That decision at the end of the day, it is still them and it's still their care. If they choose they don't want more treatment and they know and that they feel it would be better for them, then I think you need to respect that.

I: Can you tell me more about that?

P: I think a lot of times people do get ignored cos (sic) I mean as medical people we always want to do the best that (pause) we don't want to have to put someone on (pause) end-of-life care, but I think sometimes for the patients, you know, sometimes it can be better than pushing all these, you know, dying obviously isn't the best thing in the world, but at the same time it, it does happen and if we can make that the most comfortable thing for someone rather than, you know, pushing all this, all these medications clearly noticing that the patient's not getting any better. And then we've wasted say a couple of days or even just hours that we could have made them comfortable. And then there are times on the ward when we've had patients that doctors have made the decision to put someone on end of life and then they've died within the hour or they've died within... sometimes that just makes me think how long have they just sat there though when we could have been doing pain control, pain management or, you know, the family could have seen him a bit more comfortable.

I: Have they been having active treatments until then?

P: Yes. Yeah they had. Yeah. So we keep doing treatment, obs, but I think doctors still, they push everything most of the time. If it's to do with antibiotics they'll say 48 hours, if nothing's changed, if blood results haven't changed then. .... It will be up until the point that someone is completely on end of life you still have to actively treat what you're seeing so if they were, if I can see that a patient is clearly dying, that they've probably got hours or even days, if they're newsing (sic) a 12, I still have to escalate that, because they've not told me to stop.

I: So you need the recognition from the doctors?

P: Yeah exactly.

I: The okay from the doctors.

P: Yeah so it's like I had another time as well, I was looking after a lady, clearly documented on the plan was that if patient loses access then they will be for end of life and the patient's cannula was clearly tissued. And I was like, yeah. I need to let the doctors know that this is the plan from the day team, I was on a night shift so but I think I was waiting about three or four hours for a doctor to finally come up and make that decision. So she was saturating like in the 60s. So I was putting on a rebreathe, we were doing obs every 15 minutes. It was sort of like if that decision was (pause), if someone had come to me sooner or been able to come up to ward a bit sooner, then I feel like those three to four hours could have been a lot better for that patient and also for the family as well, because it's annoying enough getting every 12 hours someone putting a blood pressure cuff on you or sticking a mask on you, let alone every 15 minutes. Because they were newsing (sic), every 15 minutes I was having to go in there disturb the patient and it's, yeah that that frustrated me a little bit too.

I: You talked about making the patient end of life. Can you tell me about P-CEL?

P: Yes. It's P-CEL … individuals' priorities of care. P-CEL yeah, individual priorities of care. So it's the end-of-life paperwork and pathway.

I: And how would you describe P-CEL?

P: It's just yeah, I guess it's. It's more like a template, kind of on EPR or like a template that we use in hospital that sets out our criteria for I guess why you're placing someone on end of life. And it's what then, you still want the patient to have, when they're on this end of life, they'll (Doctors) put on there (P-CEL) oxygen for comfort, like if they're a patient that has been on say CPAP or BIPAP or a really high amount of oxygen, it can be quite traumatising to completely take that off, because then you get the respiratory symptoms, the gasping and sometimes it can be quite distressing for the patients and their family. Sometimes on there they will say like oxygen for comfort, or pop on nasal specs just for comfort. Or sometimes they still want us to do blood sugars. I know there's a lot of, there's a lot of grey area when it comes to blood sugars, I think, because although the patient is dying. I've heard a lot of people say, well, you don't want them to die from a hypo. So there is a yeah, I know for a lot of staff on the ward it's a grey area, are we doing the blood sugars? Do we still do them at least once a shift or do we not? I think a lot of the time now we just go by what the doctor said, So if they have said check the BMs we check them.

I: I think you said that sometimes the decisions are made very late.

P: Yes.

I: Is that for P-CEL too?

P: Yes definitely. I think sometimes it's (pause) it could have been a lot of the sooner. And I'm not saying that, you know, it's an enjoyable thing for people to put people on P-CEL, you know what I mean, it's traumatising for the patients and the family, and for doctors as well because as nurses we don't make that decision. We can, we can advise and we can say well I think – but we're officially not the ones that do that and I think it can be difficult for doctors to (pauses) especially over night as the doctors don't know the patients. People are very very reluctant to overnight to place someone on end-of-life care because they don't know that patient. They see numbers and they see, I think a lot of the time, it's numbers. Figures that they look at rather than actually taking a look at the patient and being like ok like realistically, looking at them.

I: How do you find communicating your opinions? You know when like you said you 'just know'?

P: It can be hard sometimes I think they just kind of look at you and go what do you know kind of thing but I feel like as nurses we know our patients best. Doctors get their information the majority of the time from us because we're with patients for 12 and a half hours, like we get to know them. We get to know what their normal is, we get to know how they feel and (pause). Sometimes it can be difficult, just like (pause), oh I don't know (exasperated). I just. I just feel – and it's. It's very much like I think, like I said, I think they like to see the figures and the numbers, things like that. You do get some that are really good and they go yeah I do agree with you. Sometimes it can be a bit of a battle.

I: What about out of hours or at night? And Bank holidays like today?

P: It can be a battle because none of our regular doctors are around who have seen the patient Monday to Friday, who know what they look normally look like or what their normal ranges are. It's very difficult for someone who's never met the patient before to come over and be like - I understand, I do get it, but I think at the same time we also just need to do what's right for the patient.

I: How much does documentation help if the normal team doctors have documented the plan?

P: Yeah, I mean it does help. if they have clearly documented or patient is to be on (pause) carry on with IV antibiotics for the next 48 hours, if numbers haven't increased or decreased if it's in regard to inflammatory markers, then patient will be for (pause) P-CEL, I think that does give them a clear sign that OK, right, well, we've looked at the numbers, no they've not changed. But yeah, if it's not been clearly documented or anything like that, it can be really difficult but palliative care (palliative care team) in the hospital are very good because obviously they are nurses. They have just specialised in palliative care. So I think from our perspective they do really get it and I think a lot of the time they will agree with what we've said.

I: Can you tell me more about the doctors and your working relationship with them?

P: It honestly varies. Sometimes with the doctors constantly changing from when they do, their rotations you'll have ones that are really, really good and then they'll go elsewhere and you get new ones and it's like. But yeah to be fair I have to say most the doctors, our doctors up here our regular doctors are pretty good. Cos they know that we know what we're doing, and if we suggest something they'll normally take that into consideration, but I don't think it's the same everywhere.

I: So am I hearing correctly that it's easy with doctors that you have an existing (interrupted)...

P: ...working relationship with because they know how you work, you know how they work and it's, you both have a common ground, a common interest that you wanna do what's best for that patient and like I said, they would have looked after the patient for the last say couple of months and they know what the patient's originally come in with, they've seen them from the start. They've now seen them, OK, done all of this yet nothing's really working and then it'll be a case of – yeah, definitely.

I: Going back to the first patient you were talking about. How much difference, if any, does knowing the patient possibly over repeated admissions or over a period of time, does it make?

I: I think, I think it does help. You get to know them, you know, you know what they've come in with every time. You sort of know when they started to get unwell, you know when they're starting to get better and then once you then start to recognise what you're doing isn't really working and you know when they a lot of the patients get here when they start coming more frequently you know that there is something's going on. Something's not working anymore. Sometimes that can make it a lot harder because you've got to know them. You've built that nurse/patient relationship; it can be very difficult at that point. Yeah, I think definitely for us as nurses I definitely think it makes it a lot easier.

I: So am I right on hearing when you think patients are dying either the doctors agree and they maybe they start P-CEL or they don't?

P: I mean well until they're officially on that P-CEL, that decision's been made, we still will treat them as any other deteriorating patient, we escalate the news score. If we need to, you know if they're still – cos (sic) sometimes I mean their ReSPECT form will say that they're not for CPR but they might still be for ITU or something. So you know it's then getting outreach involved as well but a lot of the time they can also seem ok, 'why have we been contacted', but we have to follow protocol that if it was someone that was newsing (sic) 13 or 14 who necessarily wasn't for resus but would have still been for intubation or they would have been for ITU, we still have to get in contact with them and it's just making sure we do that and still escalating NEWS score to doctors

I: So once it's agreed that the patient is end of life or dying, and P-CEL is started, what other things happen then at that point?

P: So obviously the family will have been notified or sometimes the family would have probably been there to make that decision with the doctors, and the patient obviously if they are still alert enough. And then it's just a case of making them comfortable. So it's checking, ok are they on just in case medications, do they need to be on a syringe driver and it' s just making sure, the main thing is pain relief and comfort. Definitely, then it's regular turns obviously because then if they've been started on certain medication, that can make them quite drowsy, they'll be lying in the bed for long periods of times so it's making sure we're doing proper pressure area care. As nurses, we have a part of the P-CEL paperwork that we fill out and it's kind of like a table and it's every two hours you fill that out and you go and check on your patient. Check if they're still passing urine and opening their bowels or if they're comfortable or do they need any pain relief, are they agitated, yeah, I like the fact, I mean every patient who is immobile should be checked every 2 hours anyway. But I think it's good that we go and check them every 2 hours. If they are very, very close to their end of life then you never know in those last two hours that they've been placed on P-CEL, they may have passed away already. So I think it's definitely good to check, but yes it's just checking in on the family as well. I know we can be quite good up here for making sure that the family are, the family feel supported enough. You know we notice if the pain relief the patient's now on has not really done much. Then it's getting palliative care involved, it's getting them to come and review.

I: Can you tell me about some of the challenges that you might experience looking after a patient who is end of life, on an acute ward like this?

P: So I think the main difficulty we might come across is the nature of the patients that we get up here. They can be fine one minute and within, the next, the second part of the shift they could be deteriorating. So it's then if you've got a lot, all of that going on in your bay, as a nurse it's, so I've got someone who's literally screaming out in pain who's dying who doesn't have the right pain relief at the moment, or I've got someone who is also NEWsing 14 who's still for full escalation. I think sometimes it can be very difficult with it being an acute ward and a ward this acute, with the fact they do just get so unwell so quickly, um I think it can be very, very difficult to then not make the decision but it's like, what do I quickly sort out ft, what's more important? I feel like it's not, it's just, it can be a really difficult decision you know although you know this patient's dying, they are still your patient up until they take their last breath. We still have to actually do everything you can to make that patient comfortable and you know, but then you've also got a patient who is still, for that full escalation who you know, you can give a chance to be able to make a difference and get them better. Sometimes that can be very difficult, if you've got a lot going on in one day, that would definitely be a struggle.

I: Does the location of the patient, make a difference?

P: Yes definitely, because sometimes we don't always have a lot of staff, so sometimes as a nurse you'll be taking a bay and two side rooms, I know that I definitely feel like my main focus is always in a bay and sometimes I do feel like the side rooms can get neglected sometimes. But at some point, you think oh I've got two more patients. I think. I think it's better for patients who are actually under end-of-life care to have their own private room, because I felt like it gives the family that time alone with them, you know, coz sometimes the memories can be quite private. And you know, if you've got someone that's quite agitated, say someone who's detoxing in that bay at the same time, they're screaming their head off, they're getting agitated, getting aggressive. I think that can be quite difficult for them. For the family and the patient as well, you know when you're trying to let your body do its natural thing and you know. It can be very disturbing, I think more for the family, if someone is screaming their head off or causing havoc.

I: So ideally you give the dying patient a side room?

P Yes

I: Am I hearing correctly that that can be tricky having a patient in a side room because you are busy in the bay?

P: It can be. It can be yeah, but we do try to prioritise it, the main issue we have is actually the site team not letting us use the side rooms for dying patients because, you know it might be a case that they've had a massive break of norovirus or you know they've got C diff patients and unfortunately, to them that takes priority of needing to isolate them first. But I know that up here we'll always try to, even if it means that they have to go to another ward. If we think that they could make it with enough time to go somewhere else to have a side room we also try to do that as well. But if we think it’s going to be hours, we don't want to risk then you know if they are travelling up to say x ward there’s a chance they could pass away in the corridor which is just not very dignified.

I: You’ve already talked about the palliative care team supporting you. What other sort of support do you get or don’t get in this part of your role?

P: Mainly the support comes from palliative care (team), sometimes it’s just our colleagues who have more experience than you, sometimes they know a little bit as well. Sometimes outreach as well, sometimes they can come up and if you know you’re sort of, they agree with you yeah, this patient, normally they’ll guide you a little bit but the main port of call is palliative care. The palliative care team definitely.

I: How do you find talking to families about dying and end of life care?

P: It can be challenging especially if you know they haven't known, that is quite sudden like the patient’s come into hospital, they were unwell but they were ok. Then all of a sudden, they’re not doing ok, this isn’t going to change, this isn’t going to get better, I think the best thing to do is this. It can be difficult because then they get all emotional, sometimes it can be really difficult, because they’re not taking in any information. And yeah, it's definitely something that (pause), it never gets easier and I think it does just take having those conversations frequently, not frequently but you know, when you can - do it, don't shy away from it because, you know, it does need to happen. You need to have those conversations with the family. Yes sometimes it can be difficult especially if, - say you come on shift you’ve not met this patient before. You understand that they’re unwell, you’ve noticed that the doctors have agreed and said ok we’re approaching end of life and then you've never met that patient, you’ve never met their family, and then to be part of the team that has to then tell them, that can be quite difficult as well. On the other spectrum you've known the patient a long time, they know you as a nurse, you know the patient, you know the family, that can be really difficult as well. I think it's using the right terminology. Because I feel at that time, they'll really focus on what you're saying. I think if you say one wrong thing or one wrong word it can spiral.

I normally like psyche myself up beforehand but like can we go through it, what am I going to say, how am I going to say it. Because I don't want to be that person who ends up telling them something wrong. Because they'll remember that for the rest of the time., that was the nurse who told us one thing and then this ended up happening. Yes sometimes it can be really supportive I mean, I know I always like if the doctors are going to, because the doctors on the ward are going to have that first conversation with the patient. What I would normally like to do is then go with them. And go with the doctors to go speak with the patient and the family and then I can hear what they've said and then if they have any further questions then I can feel, ok I have a little bit of information now, I'll be able to sort of say something.

I: Have you had training in end of life care – formal training.?

P: None really. It's sort of what I've just learnt from placement, what I've learnt on the ward. What I've learnt from others really. I know they've had palliative care study days, but I just haven't been able to get on them. Yeah a lot it's just from what I learn on the ward really.

I: You've been talking about some of the challenges of looking after dying patients alongside deteriorating patients. Is there anything that could make that easier?

P: I guess just levels of staffing, I guess. Yeah, if you have that extra person that can, you know, if you're really needing to go, turn your patient who is actively dying or your actively dying patient needs PRN medication. Even if it's just oh if there's a spare person who, okay, can you quickly just give that person this for me or I'll give that patient their medication or can you ring the doctor about my patient over there; just working as a team really. I guess just having more people to be able to or just grabbing a colleague to help, I guess.

I: You've mentioned staffing and talked about other things. Is there anything else that you can tell me that makes end of life care on this ward more challenging? More difficult?

P: I would definitely just say it's just the types of patients we get, because we are a gastro ward we get a lot of people that come in with detoxing. So if you've got someone that's on a day three detox, which is normally the day where they start to get the agitation, although you know they'll start, sometimes they get aggressive or verbally abusive, I think, yeah, that definitely can be quite difficult.

I: So types of patients like the detoxing patients?

P: Yeah definitely yeah.

I: I've noticed, particularly today actually, you have a lot of patients with mental health problems.

P: Yeah, definitely. A lot of the time the patients that do come in they detox, they do have a mental health background, there's a reason why they started drinking. We then obviously get our eating disorder patients who have existing mental health background as well. It's time consuming, mental health is not something you can rush. It's not something that's going to fix on its own. It takes a lot and takes a lot of input. A lot of your time as well.

I: Can you tell me who supports you with this aspect of your work - end of life care?

P: Senior nurses definitely, I think we do. You know, I was a senior nurse not that long ago. I felt like I was able to support the team when I could obviously, now I've gone back down.

I: Were you doing a secondment?

P: I was doing a secondment, yeah but I definitely know before I was doing that I definitely felt that they did support us enough if they were able to as sometimes as the senior nurse you were in charge you were also trying to take a bay of patients yourself as well. But when they weren't and they were that sort of floating person that can go do the little bits and bobs that you're not able to do. That was really helpful yeah definitely.

I: Is there anything else that I either haven't asked or you'd like to expand on about your experiences or your views about end of life care on this ward, or more generally?

P: I just think. My main thing is that … it's just recognising it early enough, to be able to get that patient exactly what they need, cause like I said before, I think sometimes it can be left too late, to the point where I feel like you could have done so much more, you could have made that patient so much more comfortable if it was just recognised a bit sooner. I just think people need to not be as scared as they are sometimes, especially the doctors making that decision but I do understand from their perspective, especially if it's overnight, they don't know that person and to make such a big decision, to decide to stop treatment for someone is a big thing.

I: Thank you. Thank you so much

Appendix 18. Coding trees

Codes: Denial	Codes grouped and combined	Theme
'Nurse back to health, not to death'	End of life care contradicts what nurses believes their role to be	Denial
No time for dying		
'Not giving up'		
P-CEL – last resort		
'If you can stop someone dying you should'		
'Our patients are not meant to die'		
End of life care is last resort.		
Preference for nursing patients who get better		
P-CEL, a euphemism for dying	Dying not spoken about directly	
Euphemisms used for dying		
Afraid to say the words death and dying		
It is better not to say 'dying'		
No language for dying, only scores and numbers	Difficulty even articulating a patient is dying	
Difficulty expressing intuition		
Not having the 'right' words to talk to families about dying		
Doctors only interested in NEWS scores and blood results.		
Nurses express side rooms are better for dying patents	Hiding dying from view	
It is upsetting for other patients having dying patients in a bay		
Dying patients are forgotten about in side rooms		

Codes: Competing priorities	Codes grouped and combined	Theme
Competing needs of patients	Nurses deprioritise dying patients	Competing priorities
Acutely deteriorating patients take priority		
Deteriorating patent v dying patients		
Neglect of dying patients		
Nurses admit they prioritise acutely ill patients		
Avoiding dying patients.		
'The nature of patients on ward mean other patients take most of our attention'		
Side rooms prioritised for patients with infections	Organisational/system factors	
Difficulty discharging patients for end-of-life care – slow process.		
Lack of availability of hospice/care home beds		
Short staffing/skill mix		
Nurses perceive lack of understanding from managers		
Nurses moved to other wards, leaving short staffed		
High proportion of newly arrived IEN and newly qualified staff, inexperienced in end-of-life care		
Task oriented approach.	Task oriented approach dominates	
Routine tasks prioritised		
Nurses unable to give care that want to give		
'Tick box' and task completion		
Task oriented care/ person-centred care conflict		
Time critical tasks prioritised		
Ward routine continues around dying patients.	'Busyness'	
'We are so busy, patients in side rooms are forgotten about'		
Number and acuity of patients – dying patients are attended to last		

Nurses talked constantly about being busy		

Codes: Discomfort	Codes grouped and combined	Theme
Concern about talking to families	Discomfort talking to families	Discomfort
Fear of saying the wrong thing		
Leave to others to talk to families		
Wish for more training in talking to families about dying		
Lack confidence in end-of-life care	Experience and knowledge	
Avoiding dying patients		
Fear of precipitating dying		
Ethical concerns		
Concern about giving opioids		
Inexperience in end-of-life care		
Lack of knowledge		
Rely on palliative care team		
End of life care a new concept	Discomfort around dying of internationally educated nurses	
No experience of end-of-life care before coming to UK.		
Differences in country where nurse educated		
Feel ill-prepared for end-of-life care		
Discomfort when active management ceases.		
Patients are not meant to die		
No formal education in end-of-life care.		
Support from senior nurses	Sources of support	
Supported from palliative care team		
Support from palliative care team not always timely		
Wish for more education in end-of-life care		
Supported from colleagues		
Concern about giving opioids	Ethical concerns	
Fear of precipitating dying		

Codes: Moral dissonance	Codes grouped and combined	Theme
Empathising with patients and families	Sadness	Moral dissonance
Knowing the patient makes it harder		
'Too young to die'		
Concern interventions are adding to suffering		
Sadness at not giving the care that feel they should be		
Dealing with families' emotions		
Frustration at concerns/views and opinions not being listened to	Constrained	
Conflict with nurses' beliefs in what role should be		
Feelings of guilt at not giving care nurse feels they should be giving		
Feelings of being constrained by routine tasks.		
Required to carry out 'futile' interventions.		
Disagree with focus of care		
No time to reflect		
Relief at change to comfort-focused care	Motivation and care	
Importance of showing respect.		
Marking significance		
'They are still our patients'		
Want to get it right		
Concern for family		
Respecting patient's wishes		
Sense of duty/obligation		

Codes: Nurse agency	Codes grouped and combined	Theme
Lack of trust from doctors	Doctor/Nurses relationships	Nurse agency
'More trust with doctors who know us'		
Consultants trust nurses more		
More challenging with out of hours doctors		
Frequently changing doctors		
Doctors only interested in NEWS scores and blood results		
Nurses' views not heeded		
Deferring to doctors		
Dr/Nurse game		
Aware of doctor's challenges		
Documentation important		
Too busy to attend ward rounds		
Not being allowed	Hierarchy	
'We keep going until they tell us not too'		
Senior nurses may challenge		
'We need to be braver'		
'Nurses should challenge'		
Feel undervalued		
'Not my place to challenge doctors'		
Seeking alternative support		
'Getting into trouble'		
Unable to make decisions (even when plan documented)		
Internationally educated nurses reluctant to challenge doctors		

Codes: Delay	Codes grouped and combined	Theme
Type of diagnosis	Uncertainty	Delay
Younger patients		
Looking for certainty		
Uncertain trajectories		
Active treatment continues if any chance of recovery		
Intuition – difficult to articulate	Recognition of dying - often late	
Inexperienced nurses rely more on measurable parameters		
Knowing patients over time helps		
Patients tell you		
Recognised very near to time of death		
Gathering information		
Lack of response to treatment		
Recognising futility		
Nurses recognise dying before doctors		
Doctors confirm dying		
Reliance by doctors on scores		
Poor documentation – plans unclear		
Nurses’ views not being heeded		
Lack of availability of senior doctor to confirm dying		
Changing doctors, shift systems, Doctors don’t know patient		
Abrupt change to comfort-focused care	Late change to comfort-focused care	
Doctors keep treating		
Change very close to time of death		
Active treatment until death		
Active management and palliative care mutually exclusive		
P-CEL - change in status of patient		

P-CEL - Nurses relieved when transition is made to comfort-focused care		

Appendix 19. Theme overview - Discomfort

I analysed the interview transcripts and field notes in the order the data were collected. Many of my interviews took place on the same day I observed the same nurse, which allowed me to directly explore my observations during the interview. However, in cases where this was not possible, memoing helped me keep track of key points to explore in subsequent interviews. Interviews also provided valuable insights into key issues and highlighted areas I should pay closer attention to during future observations.

The approach I used to analyse the data was based on the framework for analysing ethnographic data described by Roper and Shapira (2000). I began by coding for descriptive labels. My observations and informal conversations were converted into field notes, and I coded both the interview transcripts and field notes line by line using NVivo. This initial coding helped me begin identifying patterns in the data and organising it into meaningful groups. The process was iterative, involving continuous grouping and regrouping of data.

The next stage, as described by Roper and Shapira (2000), is termed *sorting for patterns*. In this stage, I sorted the initial codes into a smaller number of groups that contained similar and related codes. This was also an iterative process, with groups being refined as patterns became more apparent. Throughout this phase, I was also looking for outliers, such as contradictions within the data. The combination of interviews and observations particularly helped me to identify these outliers.

The next stage is *Generalizing: Constructs and Theories*, where I refined and developed the themes from the data. In ethnographic research, this stage involves linking the emic meanings of the participants to my etic interpretations to create explanations based on the data. Throughout this process, I recorded my reflections and any insights or analytical ideas, a process Roper and Shapira (2000) call *memoing*. Memoing was essential in helping me make connections and identify patterns in the data.

In this appendix I provide an illustrative example of the theme ‘Discomfort’, which highlights the key aspects of this theme. See also Figure 3.

Theme: Discomfort

Of the initial descriptive codes, 160 eventually contributed to the theme of ‘Discomfort’. Through an iterative process of identifying patterns in the data, these codes were then grouped and regrouped, with the groups being further refined as the analysis progressed. Ultimately, this process resulted in five key groups that contributed to the final theme of ‘Discomfort’. Below I will outline these groups and provide illustrative data.

Cultural differences

Observational data

> *Field notes: It was 11.30 in the morning. The student was becoming increasingly frustrated that the staff nurse [Participant 13. Africa] had not yet entered the room [the patient needed two people to carry out personal care]. Eventually, when the staff nurse was ready to go into the room, she looked visibly uncomfortable and stayed for the shortest time possible. She took me aside and explained her conflicting thoughts, saying, 'I want to care for dying patients because I want to become more confident, but then I don't want to'. She went on to explain that although she was uncomfortable, she realised she needed the experience to become more confident. The patient’s family were waiting outside the room, looking understandably distressed. She avoided eye contact with them. There was no attempt by the nurse to engage with them. It was left to the student nurse to comfort the family.*

Interview data

Participant 13, p.3. Staff nurse, Africa: Where I come from, they just never give up on anybody. Not until the person takes his last breath. In my country it's totally different. ... we don't do the whole helping the patient to die peacefully, put the patients on syringe driver, prioritise comfort. No. I think they look at it like mercy killing because you're helping this person die. I don't know how to explain it, but I was never involved in end-of-life care in my country because traditionally in my country people die at home.

Participant 16, p.6. Senior nurse, UK: This lady died and I had to go do last offices [when she had newly arrived in the UK and working as a health care assistant prior to nurse training]. Each day for three days, each time I closed my eyes that lady come to mind; I could see her face. Because I'd not been exposed to that before, things like comfort care, or syringe drivers, or end of life medication. Some of our internationally Educated Nurses have no experience of end of life care in their own countries - in their work life or even personal life. They're young.

Participant 13, p.6. Staff nurse, Africa: Where I come from, they just never give up on anybody. Not until the person takes his last breath.

Experience and Knowledge

Observational data

Field notes: The nurse (Participant 10, Staff nurse, UK) was shaken and looked upset at what she thought was poor management of the withdrawal [of non-invasive ventilation]. I asked her if she was ok. She replied, 'sort of'. I was concerned that the patient remained unsettled and appeared agitated. Whilst I was aware I did not have access to all the patient information and was conscious of my role as researcher and not palliative care nurse, I asked the nurse whether the 'end-of-life meds' were prescribed, in an attempt to

> *support the nurse in helping the patient in an exceptional situation. 'Oh, which one do you think?' she said. I suggested medications and advised she spoke to the ward sister for guidance. 'Good call' she said. [The nurse looked anxious and appeared to not know how to manage the situation].*

Interview data

> *Participant 10, p.4. Staff nurse, UK: I was really uncomfortable at was happening, I felt helpless. But I didn't know what to do to make it better. I wasn't sure which of the end of life meds to give.*

During interview, when asked what would improve nurses' confidence a senior nurse said:

> *Participant 1, p.7. Senior nurse, Europe: They're starting to talk about making things like deteriorating patients study days mandatory, and that's absolutely the right thing to do because a deteriorating patient is massive. But if you are not acutely treating a deteriorating patient then most likely you're looking at end-of-life care, and those are the two choices that you have for somebody who's that level of unwell. You fix them or you decide to make them comfortable. What can you do? So one shouldn't be more important than the other because it's one of two options for people at that point in their life.*

When asked what would help her feel more prepared for caring for dying patients, a staff nurse said:

> *Participant 15, p.6. Staff nurse, UK: Experience I think, to be honest, as I said, I'm a lot better now than I would have been like nine months ago and it's just about building up your confidence and having knowledge, knowledge as well. So input from palliative care team, you know I've also listened in with, you know, the consultant and the palliative*

care, I've listened to these difficult conversations being had about ReSPECT forms and things. So that's kind of built up my confidence. But yeah, I think experience and yeah knowledge is the only thing really that will help you know.

Participant 16, p.7. Senior nurse, UK: I have nurses who have never done end-of-life care. This is their first experience, so it's all going to be daunting. We try and buddy them up so that they can experience it with support and we do a lot of debriefs after death.

Ethical concerns

Observational data

Field notes: There was a patient in the final stages of dying in the bay. The nurse (Participant 17) and healthcare assistant were very attentively caring for the patient. The patient was restless and they were discussing whether to give medication to help settle the patient. The nurse appeared worried and reticent. I asked about her thoughts on this – she explained she was uncomfortable about giving 'end-of-life' medications as they 'suppress' the patient and she had not had experience of using these medications in the country she trained in. Despite her apprehension she did administer medication. The patient died soon after. I wondered if this would reinforce her beliefs.

Field notes: The night nurse handed over to the day nurse that the doctors had asked that they switch from 15 litres oxygen via a rebreathe mask to four litres via nasal cannulae on a dying patient. The day nurse said to her colleagues she was not happy to do this because she was worried the family would have 'the perception we are killing him'. The family were on their way into the hospital. The nurse looked visibly uncomfortable and unhappy.

Interview data

> *Participant 17, p.6. Staff nurse, Africa: Death should be natural, not we nurses being the cause of the death. So, it's something we should worry about ... we have to be very careful because there is just a thin line between it as well. ... Because, you know, definitely we don’t want to overdose the patient, because it might lead to sudden death, which we don't want*

> *Participant 18. P.3. Staff nurse, Africa: ... you have to just gather yourself together, try and think it through like you're not responsible for the death of this patient. You're not responsible for the patient dying. The patient is dying. ... we are trying our best.*

Support

Observational data

> *Field notes: The nurse went behind the curtains to see the dying patient and to speak to his family. Afterwards, the nurse again told me she was not going to reduce the oxygen in case she was blamed for his death. A senior nurse then came to offer support and give guidance. The senior nurse said she would contact chaplaincy, advised lots of mouth care and that she would try to get a side room. She then explained how to wean the oxygen. The nurse was reassured and changed the mask to nasal cannulae.*

> *Field notes: During the handover, the staff nurse said she thought a dying patient was agitated. The sister told her to ask the palliative care team to come and see the patient and to advise. I thought the nurses seemed very reliant on the palliative care team. The end-of-life medications were prescribed to be given as needed but the nurse told me she was not sure what medication to give for the patient’s symptoms.*

Interview data

Participant 12, p.1, Senior nurse, UK: So, I actually went and contacted palliative care myself and I asked them, 'can you please review this patient?' …. and they actually agreed with me. Yes. And end-of-life care was commenced you could just tell the patient seemed a lot more comfortable and the family were all in agreement with it as well.

Participant 11, p.1. Senior nurse. UK: So firstly I think we just talk to the patients and the family and once the patient has consented we normally refer them to the palliative nurses. Once you escalate it to them and depending on how urgent it is, they are very good in seeing the patients. I think they work seven days a week at the moment. And the good thing is, even over the weekend, you can get the palliative nurses and if there is no one available, you can get hold of on call palliative doctors as well, depending on how the situation is. I find them very helpful because they are so expert in the end of life care and stuff like that. So when the palliative team is around, I feel it's easier to talk to the family members because obviously, there might be some things which I may not be able to answer. When the palliative team is around, I think it's much easier.

Participant.18, p.7. Staff nurse, Africa: Yes (with emphasis), they are a good help! Yeah, the reason why I say they are good help is you know, is when you are more specialised in a particular aspect of care, you tend to have a wide knowledge, wide view and more in depth understanding of that aspect. So they are a very special team that are trained, they have adequate trainings, adequate knowledge, they've added experience.

Participant 6, p.4. Staff nurse, Africa: About a year ago I had to talk to xxx (ward manager). I told her don't want to get used to people dying. She said xxx you're helping them. How am I helping people to die? That's also part of our jobs. She made me understand how I help. She said you're helping them not be in pain, making sure they are *comfortable so they die peacefully. People in my country don't have this luxury. She said to be proud of myself. Yes. That has really, it's really sunk in and it's giving me strength. The senior nurses, they're so supportive, so supportive. I probably wouldn't have been able to cope. I probably would have left. But obviously people die. If it wasn't for their support I would have worked in outpatients. They make us understand why [end of life care] it is necessary? I've enjoyed working here.*

Talking about dying

Observational data

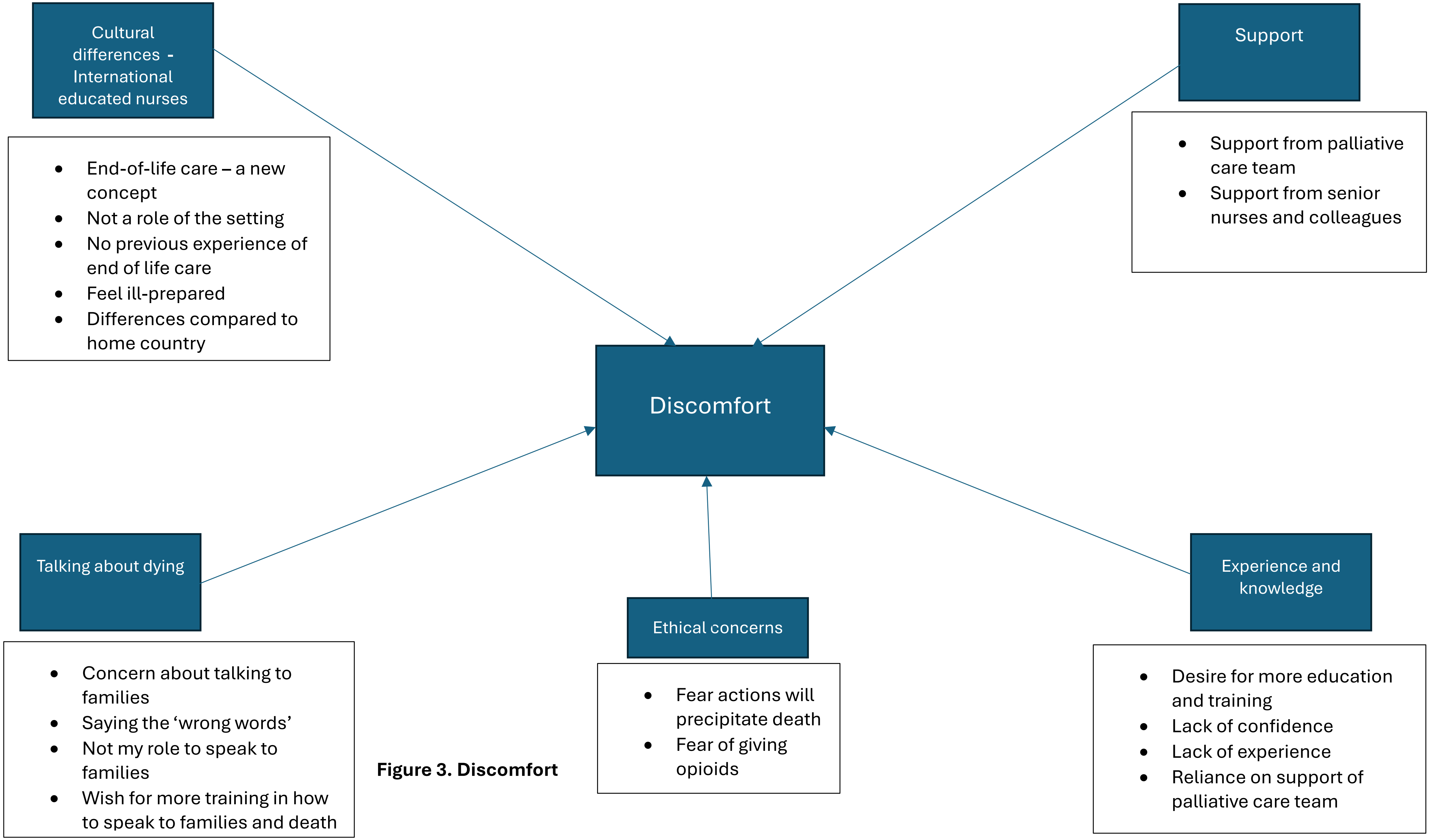
Field notes: A family member of a dying patient called the ward this morning. The ward clerk took the call and asked the nurse looking after the patient (Participant 8) to speak to the relative. The nurse looked very uncomfortable and refused. She said, 'ask Dr x' and quickly walked away in to a bay. The doctor had only just come on to the ward that morning and hadn't yet had an update so she said she didn't have the necessary information. The ward clerk then proceeded to look for the nurse in charge so the family could be updated. I later asked the nurse about this – she told me that she was not confident to talk to families, especially of dying patients.

Interview data

Participant 8, p.4. Staff nurse, Africa... they need to train us on how to speak to the relatives, ... because you know, you have to be empathetic; you should be able to say some words just for them to feel you care. ... if you're not able to put your words right, you end up saying things you're not supposed to say'

Participant 18, p.4. Staff nurse, Africa: You want to be careful to say the right words. And because we come from different background with different perceptions, you don't know what words will be suiting to their hearing. So that's the challenging part sometimes, *Participant 16, p.9. Senior nurse, UK: In my country [trained in UK but originally from an African country] nurses don't do personal care; you don't do manual handling and you don't update relatives. You give medication, you do the dressings. You don't know what they are being treated for, so there's no reason to update families, we don't talk to them about dying. So then when nurses come here [UK], we expect them to answer the phone calls and update and talk to families. I remember vividly with one of my new nurses - I walked onto the ward, I saw a relative of a dying patient wave to me, opposite the Doctor's room. The relative was waiting there. I said, 'have you been attended to'. She said 'no'. She was waiting for the nurse who was looking after her husband to give her an update. I called the nurse and I said, 'oh, I've got one of your patient's relatives, can you give her an update'. Her face – it was as if I'd asked something unimaginable, then I realised maybe she doesn't know what to do. So I took her and the relative and said, 'Do you mind if I give you an update and my junior nurse can learn', and that's how we got around it. They are not quite familiar with how to talk to relatives especially talking about dying.*

Participant 1, p.5. Senior nurse, Europe: I find all of the conversations with dying patients here will fall to the nurse in charge as opposed to the junior nurse who's looking after them. Some of them are more comfortable. I would say UK trained nurses are more comfortable because it's part of their training here and we do it with our students and we bring them into these conversations. Whereas people who've just come into the NHS from other cultures who don't do palliative care as standard probably wouldn't. They would leave that to anybody in dark blue [senior nurses].



Cultural differences - International educated nurses

- End-of-life care – a new concept
- Not a role of the setting
- No previous experience of end of life care
- Feel ill-prepared
- Differences compared to home country

Support

- Support from palliative care team
- Support from senior nurses and colleagues

Discomfort

Talking about dying

- Concern about talking to families
- Saying the ‘wrong words’
- Not my role to speak to families
- Wish for more training in how to speak to families and death

Ethical concerns

- Fear actions will precipitate death
- Fear of giving opioids

Experience and knowledge

- Desire for more education and training
- Lack of confidence
- Lack of experience
- Reliance on support of palliative care team

Figure 3. Discomfort