An exploration of how specialist palliative care nurses respond to patient-initiated conversations about assisted dying: A qualitative study utilising Reflexive Thematic Analysis.

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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.

Abstract

An exploration of how specialist palliative care nurses respond to patient-initiated conversations about assisted dying: A qualitative study utilising Reflexive Thematic Analysis

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Background

Assisted dying is illegal in the UK, although some individuals with a desire to die may consider hastening their death with the support of others, including travelling abroad to a jurisdiction where assisted dying is permitted. When patients choose to discuss assisted dying, nurses are often the first healthcare professionals they approach to explore this topic with. However, little is known about the decision-making processes that nurses engage in when determining their response to patients expressing these wishes.

Aim

The aim of the study is to explore how nurses, who work in specialist palliative care, respond to patients who wish to discuss hastening their death through assisted dying.

Methods

A qualitative evidence synthesis was undertaken utilising Thematic Synthesis exploring the experience of nurses involved with care they may perceived as death hastening. These findings informed the empirical study, which utilised Reflexive Thematic Analysis methodology. Fifteen nurses were interviewed using a clinical vignette to explore the case.

Findings

Within the empirical study, an overarching theme *providing patients with solutions to remove the desire to die* was developed. To do this, the nurses engaged with three themes relating to their own understanding of the legal status of assisted dying, the influence of the care setting to build relationships with the patient and the teams they work within, and protecting professional and public perceptions of palliative care.

Conclusion

A patient’s wish to seek an assisted death disrupts the pervasive forces that exist within palliative care services. Perceptions of palliative care, both from patients and the profession itself, have an impact on how nurses engage with patient-led discourse relating to assisted dying. Nurses are struggling to find their voice within these discussions, both within their teams and with wider society. Physical and emotional space needs to be created to enable nurses to be able to fully realise their impact on discussions relating to assisted dying.

Acknowledgements

I would like to start by thanking my supervisors, Professor Nancy Preston and Professor Laura Machin, for fostering a facilitative, supportive, and open learning environment that enabled me to explore the topic of assisted dying. I have been inspired to engage directly with feminist issues throughout this journey by these two inspiring women. I also thank all the nurses who generously shared their time and knowledge, in a variety of ways, to help create this thesis.

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Finally, I would like to dedicate this work to Wendy and Tony Seed, my parents, who died before I began this process, but have supported every step.

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Chapter 1: Introduction to the thesis

1.0 Introduction

Three hundred million people worldwide have access to assisted dying in jurisdictions with permissive legislation (Downar et al., 2024). Assisted dying is not legal in the UK, although some individuals with life-limiting illnesses may consider hastening their death with the support of others, including travelling to a jurisdiction where assisted dying is permitted. People who have a desire to die and wish to explore this option commonly discuss such matters initially with their family, but later may talk to a trusted healthcare professional (Boven et al., 2023; Gamondi et al., 2019; Variath et al., 2020).
When this occurs, nurses are often the first healthcare professional to whom patients express a desire to die and may ask for assistance with enacting this (Feijoo-Cid et al., 2025; Francke et al., 2016; Variath et al., 2020). However, nurses may express significant ethical and moral uncertainty regarding how to approach conversations related to what can be seen as a challenging and contentious topic within healthcare and wider society (Hol et al., 2023). Little is known about the decision-making process nurses enter when deciding how to address patients' requests for assistance to die.

1.1 Aim and objectives of the study

The aim of the study is to explore how nurses, who work in specialist palliative care, respond to patients who wish to discuss hastening their death through assisted dying.

Three objectives were developed to achieve this aim. These are:

- To understand how nurses within specialist palliative care may respond to a patient when they wish to discuss seeking an assisted death.
- To understand the aspects that may influence and impact upon the nurses' reactions and responses to these discussions.

- To conceptualise nurses’ process of ethical decision-making when a patient requests support in seeking an assisted death.

1.2 Background of the researcher

At the time of writing, I am the Lead Nurse for palliative care at an acute trust in the north of England, UK. The thesis is grounded in, and by, my experiences as a senior nurse working clinically and supporting other nurses through the complexities of delivering care at the end of life. Working in palliative care, it was not uncommon for my patients to express a desire to die, something my participants echoed, and while less frequent, I encountered several patients who had considered assisted dying. I was always aware of the significance of being entrusted with this information and how I needed to approach these conversations to maintain a patient’s trust. However, over time, I also realised that other healthcare professionals had varying levels of comfort and confidence in speaking to patients about these issues and how to address them with the healthcare team. This prompted me to interrogate my own stance to understand aspects that may influence how nurses approach these types of conversations.

1.3 Research design

To effectively address the research objectives, two key components were undertaken, forming the core of the thesis. First, a qualitative evidence synthesis was conducted to understand how nurses broadly experience care that may be perceived as hastening death. The review informed the empirical research by identifying factors that influence the emotional labour involved in providing care within assisted dying and other acts nurses may perceive as hastening death. Second, an empirical research study using a qualitative approach, utilising Reflexive Thematic Analysis (Braun & Clarke, 2022) was undertaken to gain a rich understanding of the phenomenon. Data, across all aspects of the thesis, were interpreted using the lens of the ethics of care, a feminist epistemological approach to ethical decision-making.

1.4 The organisation of the thesis

The thesis consists of six chapters.

Chapter Two: I explore the context for the study, outlining the current legal and ethical landscape regarding assisted dying both in the UK and internationally. Given the evolving nature of assisted dying, I also highlight the position statements and guidance issued by professional organisations relating to assisted dying that aim to provide structure for healthcare professionals to work within. The study focuses on nurses working in specialist palliative care; therefore, within this chapter, I also explore how these services are structured and how nurses are trained to manage conversations related to assisted dying. The relationship between palliative care services and assisted dying is also explored to establish the socio-cultural framework for the study.

Chapter Three: I present a Thematic Synthesis of the literature relating to nurses' experience of care when involved with acts of care that may be perceived as death hastening. Aspects that contribute to the emotional labour required to provide care across different interventions that may be perceived as death hastening, including assisted dying, palliative sedation and the withdrawal of life-sustaining treatment are identified.

Chapter Four: I discuss how I employed the methodology of Reflexive Thematic Analysis (Braun & Clarke, 2022) to address the research aim and objectives. This includes my epistemological and ontological position and how these positions influenced the decisions made within the research methodology. The feminist epistemology of standpoint theory is used to understand the data, and the overall impact that an ethics of care may have on the findings is explored.

Chapter Five: I explore the empirical study's findings. Three themes are presented, which are united by an overarching theme of nurses wishing to offer solutions to remove the desire to die. The themes are 1) using, (mis)interpreting, and (mis)representing the legal status of assisted dying to the patient, 2) the care setting influences how nurses can nurture relationships with patients and the wider team, and 3) protecting the professional and public perceptions of palliative care are presented.

Chapter Six: I discuss the findings within their theoretical context of feminist standpoint theory. At the conclusion of chapter six, I also outline the study’s unique contribution to knowledge and make recommendations for clinical practice, education, and further research.

Chapter 2: Background

2.0 Introduction

In this chapter, I outline the current legal status of assisted dying in the UK, as well as the international position in countries where assisted dying is permitted. Despite assisted dying being illegal in the UK, I also offer context for the research into why some individuals with a desire to die may view assisted dying as an option at the end of their lives. Furthermore, I discuss the socio-political and healthcare service factors that are thought to shape the professional discourse around death and dying.

2.1 Definitions of assisted dying

Ambiguity surrounding the terminology used to describe assisted dying is widely recognised in the literature (Gerson et al., 2020; Gerson & Preston, 2021; Mroz et al., 2021). A variety terms are used within legislation across jurisdictions where assisted dying has either been legalised or decriminalised (Mroz et al., 2021). In areas where assisted dying is illegal, the choice of terms often comes down to personal preference, further contributing to the lack of clarity when discussing this topic. In the context of these discussions, assisted dying refers to the active intervention undertaken with the intention of ending a patient's life, at their explicit request, either by the active administration of medication by a permitted healthcare professional or by providing or prescribing medication for a patient to administer themselves. The term euthanasia is used to define the administration of medication, usually by a doctor, to end life; a term commonly used across the Benelux countries. Euthanasia is also legally recognised in multiple countries, including New Zealand, Australia, Spain, and Canada, although different terms are used within the legislation to refer to this, such as physician-assisted suicide (PAS), voluntary assisted dying (VAD), medical aid in dying (MAiD), or assisted dying. As these countries allow for self-administration by the patient, the terms also refer to this intervention, adding to the ambiguity regarding their precise meaning. Some countries, including Switzerland, Austria, Germany, and some USA states, solely allow assisted dying for patients able to self-administer the medication; in this case, healthcare professionals' role is limited to providing the means of death to the patient. In these areas, terms such as physician-assisted dying (PAD), physician-assisted suicide (PAS), physician aid in dying/aid in dying (AiD), assisted dying, or assisted suicide may be used. The inconsistent and varied use of terminology worldwide contributes to the ambiguity, making clear definitions within this topic difficult.

It has, however, been acknowledged that selecting terminology to use to describe assisted dying is a political act influenced by socio-cultural and religious norms, alongside stigmas related to suicide (Elsner et al., 2024; Mroz et al., 2021; Overbeek et al., 2021). Ambiguity in the terminology is also noted to raise complex ethical considerations regarding what acts may be perceived as hastening death, which will be examined within this thesis. Having acknowledged that terminology choice can be personal and political, I also recognise the active choices I have made in using the term ‘assisted dying’ to encompass the interventions discussed within this thesis. The term assisted dying is argued to represent a neutral umbrella term for actions undertaken with the active intention of inducing death, in line with suggested international convention (Gerson et al., 2020; Koksvik et al., 2020; Mroz et al., 2021), and aligns with current UK terminology. I favour using the phrase ‘dying’ over 'suicide', not to evade an uncomfortable topic, but as I believe it better represents my position, offering a neutral descriptor term across all of the interventions outlined. However, I also recognise that this is my current perspective on a complex issue and remain reflexive about my position.

2.2 The legal status of assisted dying

2.2.1 International position

Internationally, certain jurisdictions have either enacted laws that support assisted dying or decriminalised the practice. Assisted dying was first decriminalised in Switzerland in 1941, provided that the person offering assistance acted with compassionate motives. Specific legislation allowing assisted dying was first passed in the state of Oregon, USA, in 1997, with Belgium and the Netherlands following in 2002. Over the past ten years, several countries have passed permissive legislation, including New Zealand, Spain, Portugal, Canada, and all Australian states. This legislative landscape is quickly evolving, with assisted dying now permitted in Ecuador, Cuba, Jersey, and the Isle of Man in more recent years. These examples illustrate the legislative developments and are not an exhaustive list of legislation.

2.2.2 Current law in the UK

Suicide, the act of intentionally ending one's own life, was decriminalised in 1961 through the Suicide Act (1961). Section 2 (a) of the Suicide Act (1961) in England and Wales states that a person can incur criminal liability for complicity in another's suicide when:

> "(a) D (the person) does an act capable of encouraging or assisting the suicide or attempted suicide of another person, and
> (b) D's act was intended to encourage or assist suicide or an attempt at suicide."

A conviction for assisting another person's death can result in a maximum sentence of up to 14 years in prison. In this context, assistance may involve encouraging someone to act, coercing them to end their life, or helping them make practical arrangements. It remains illegal regardless of whether the attempt ends in death or if the actions taken could have actually led to death, such as administering an 'underdose' of medication. Prosecution in these cases can only occur with the approval of the Director of Public Prosecutions. Northern Ireland has also implemented this legislation under Section 13 of the Criminal Justice Act (Northern Ireland) (1966). In Scotland, there is no specific offence related to assisting another person's death; rather, it is addressed under existing homicide legislation.

2.2.3 Assisted dying: a choice for some?

While assisted dying is not legal in the UK, the right to die remains available for those who have the physical means to do so. People may choose to stop eating and drinking or hoard and then overdose on medication with the intention of ending their life (this is only classed as assistance if they need help to take it). Some individuals may also choose to travel to a jurisdiction that allows assisted dying to end their lives, most commonly through the right-to-die organisation Dignitas in Switzerland. Dignitas began capturing data relating to deaths within the organisation in 2002; from 2002 until 2024, a total of 608 individuals from the UK have died at Dignitas, including 37 people in 2024 (Dignitas, 2024). The practice of travelling to areas where assisted dying is legal is colloquially referred to as ‘suicide tourism’. However, Huxtable (2009) describes the law as a suicide tourist ‘trap’, as it creates a complex and confusing legal picture for those seeking an assisted death (Brannan et al., 2010; Huxtable, 2009). It is important to note that it is not illegal for a person to travel to Dignitas to end their own life; indeed, specific guidance was issued during the COVID-19 pandemic to advise people that travel for this reason was permitted (Torjesen, 2020). The law ‘simply’ does not permit individuals to assist others in this process. However, the lack of clarity about what may be permitted could lead some to risk prosecution.

Following the case of R (Purdy) vs DPP (2009) the Director of Public Prosecutions issued decision-specific guidance as to when prosecution would be sought when someone is charged with assisting a death. While aiming to provide clarity, this guidance made an already complex legislative landscape even more challenging, as the varied application of the law contributed to the confusion for those attempting to navigate it (Wicks, 2020). In particular, uncertainty about what might be deemed assistance or encouragement has been posited as a significant concern (Wicks, 2020). Between April 2009 and March 2025, 199 cases were referred to the Crown Prosecution Service for prosecution under section 2 of the Suicide Act. Of these, 170 were not proceeded with by the Crown Prosecution Service or were withdrawn by the police; eight were referred onwards as homicide, one was charged with an offence and later acquitted, and ten cases remain ongoing (Crown Prosecution Service, 2025). Five cases were found guilty of undertaking an offence under the Act (this may include more than one person); however, at the time of writing, there have been no convictions under this Act for assisting someone in ending their life through supporting travel to Dignitas.

2.2.4 Proposed law

Throughout the process of developing and writing this thesis, the prominence of assisted dying in the media and the legislative landscape have changed rapidly. At the time of writing, proposed Bills are progressing through Parliament for England and Wales, and Scotland; these are being considered separately due to the structure of the devolved Parliaments in the UK. In Scotland, the Assisted Dying for Terminally Ill Adults (Scotland) Bill, introduced by Liam McArthur MSP, has reached the stage two committee, where the initial bill is undergoing amendments. In England and Wales, a Private Members' Bill proposed by Kim Leadbeater MP, the Terminally Ill Adults (End of Life) Bill, had its first reading in Parliament in October 2024. At the time of writing, this Bill is being debated in the House of Lords. Both Bills propose that individuals who have a 'terminal illness', with the England and Wales Bill stipulating that they must be within the last six months of life, could request to be given the means to end their life through the provision of medication, which they must self-administer. The individual must have the capacity to make the decision and be free from coercion. In some other jurisdictions, people with enduring mental illness can opt for assisted dying; neither Bills support individuals without physical life-limiting illnesses in requesting assistance. There are no current plans for the Northern Ireland Assembly to introduce a similar Bill. Legislation has also recently been passed in the Crown Dependencies of the Isle of Man and Jersey. These Bills permit both euthanasia and physician-assisted dying as a means to end someone's life.

When the Terminally Ill Adults (End of Life) Bill was first published for public viewing, my initial reading of the Bill was not from the perspective of a PhD candidate, considering how it might influence my thesis. Instead, it was as a senior nurse working in palliative care, reflecting on how this may impact my immediate practice, what support my team may need, and how the future might look if the Bill is passed. However, despite the significant role that nurses play in providing care at the end of life, the Bill does not mention nurses. There is a clear necessity to consider how nurses' involvement impacts on caring for people considering or undertaking assisted dying. The lack of consideration of the impact of nurses is a sentiment echoed in other jurisdictions as they navigate the legislative process (Hewitt et al., 2021). While the UK Bills are still under consideration, their consequences are being felt within society as part of the cultural consciousness. The underrepresentation of nurses in the proposed legislation is reflective of a significant gap in the evidence, which has informed this study. This lack of consideration and representation of nurses weaves through this thesis. The impact of the lack of representation is discussed within the findings in Chapters Five and Six, and I make suggestions as to how this can be addressed in Chapter Six.

2.3. Professional bodies' position on assisted dying

The ongoing and evolving debate surrounding the legalisation of assisted dying in the UK has prompted both professional bodies and Royal Colleges to issue position statements with the aim of reflecting the views of their professional memberships. While position statements lack legal mandate, they can mirror and influence the changing social landscape, guiding and influencing their membership, thereby shaping the debate (Inbadas et al., 2020; Inbadas et al., 2017). Historically, Royal Colleges have declared their stance as opposed to assisted dying. However, several organisations have recently surveyed their members about their views and have subsequently transitioned to neutral positions. The Royal College of Nursing acknowledged the complexity of the debate and, following a motion passed at their union congress in 2023, has updated its position statement to reflect neutrality, which they assert "rightly reflects our members' differing views on the issue" (RCN, 2023).

Nonetheless, palliative care organisations, which include a large body of nurses, including the Association of Palliative Medicine, continue to oppose a shift to a neutral position regarding assisted dying (De Lima et al., 2017; Hurst & Mauron, 2006; Radbruch et al., 2016; Sulmasy et al., 2018). Internationally, the International Association of Hospice and Palliative Care and the European Association of Palliative Care argue that assisted dying directly opposes the principles of palliative care, stating that the focus should be on the provision of universal access to palliative care (De Lima et al., 2017; Radbruch et al., 2016).

2.3.1 Professional body guidance for nurses

In the United Kingdom, nurses are regulated by the Nursing and Midwifery Council (NMC), and expected behaviours are governed by The Code (NMC, 2018). This code broadly defines the standards of practice and behaviour expected of registrants, ultimately serving as a framework for public protection. While The Code states that nurses must act lawfully at all times, it does not provide specific guidance on how to navigate requests for assisted dying or what may constitute assistance. In contrast, the General Medical Council (GMC) offers some guidance on fitness to practice issues for doctors who participate in these discussions (GMC, 2024). However, neither guidance provides explicit practical examples of how to address requests, what actions may be legally permissible, what may be regarded as assistance, and where the limits to involvement would lie.

In 2015, the Royal College of Nursing (RCN) published guidance for nurses to support them in responding to requests to hasten death (RCN, 2015). The guidance outlines practical steps that nurses should take, including specific communication skills that may support these conversations when aiming to understanding the patients' perceptions of their illness, prognosis, and dying. It also states, ‘If the patient is asking specifically for your help with assisted suicide, it is essential that you acknowledge the request and resist the inclination to ‘ignore’ or abandon the conversation’ (RCN, 2015, p. 14). It also advises nurses to inform patients about the legal implications of the request providing direct guidance that providing information relating to assisted dying organisations or supporting them to contact them would be against the law. Additionally, the guidance suggests that it is inappropriate for nurses to share their personal views with patients and their caregivers. While it does not explicitly state that sharing opinions with other healthcare professionals is unacceptable, this statement could be interpreted as positioning the topic as something that should generally not be discussed.

2.4 Assisted dying in the context of care at the end of life

2.4.1 What is specialist palliative care?

Palliative care encompasses all levels of support that individuals with life-limiting illnesses may require as they approach the end of their lives, including both generalist and specialist palliative care. In the UK, generalist palliative care refers to the integration of palliative care across all healthcare settings that support any individual with life-limiting illnesses. This can take place in various care settings, including, but not limited to, hospitals, patients' homes, hospices, care homes, and prisons. For those with more complex symptoms, specialist palliative care may become involved in the patients care to support the generalist teams in providing care. In 2023, NHS England published a service specification for specialist palliative care and end of life care for adults (NHS England, 2023). This document outlines specialist palliative care as requiring:

- specialist knowledge to assess and manage physical, psychological, social, religious and spiritual needs to reduce symptoms, suffering and distress.
- supporting analysis of complex clinical decision-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment.
- providing specialist advice, support, education and training to the wider care team who are providing direct core-level palliative care to the person.

Although there are regional variations, specialist palliative care is offered across care settings, with inclusive services delivering care wherever the patient resides. Within the UK, the role of nurses working in specialist palliative care varies due to the nature of the service structures within which they operate (Kirk, 2010; Payne et al., 2017). In hospitals and community settings, nurses are more likely to work at the level of Clinical Nurse Specialist or above, as these services provide clinical advice and support to teams providing universal palliative care (Higginson, 2015; Phillips et al., 2019). In contrast, within a hospice inpatient setting, patient care is provided solely by the hospice team, with advice from other specialists (Higginson, 2015). Due to this, nurses may work in a variety of clinical roles and levels of seniority. Whilst services across the UK will have differing service specifications and structures, as a medical speciality, nurses will commonly work within medically led teams as part of a wider multidisciplinary team.

2.4.2 Preparing healthcare professionals in palliative care to discuss assisted dying

Nurses are most commonly the healthcare professional patients initially approach to discuss their desire to die and to discuss assisted dying (De Bal et al., 2006; De Bal et al., 2008; Dholakia et al., 2022; Dierckx de Casterlé et al., 2006; Hewitt et al., 2021; Richardson, 2023; Wilson et al., 2019). There is limited evidence regarding how nurses manage conversations with patients related to assisted dying (De Bal et al., 2008; Elmore et al., 2018; Schwarz, 2003; Thorne et al., 2024; Wilson et al., 2020), and particularly when this act is illegal (De Bal et al., 2006; Knights et al., 2024; Schwarz, 2004). In areas where assisted dying is permitted, research commonly focuses upon the relationship between the patient and the physician who will provide the assisted death (Beahan, 2019; Norwood, 2007; Rutherford et al., 2021b; William, 2018). The practical management of these conversations has been highlighted in the literature, and the need for training to support discussing assisted dying where this is permitted is well discussed (Boström et al., 2025; Bustin et al., 2024; De Bal et al., 2008; Denier et al., 2010b; Lamba et al., 2024; Pesut et al., 2023; Sandham et al., 2022; White et al., 2021; Willmott et al., 2024). However, this is less well considered in areas where the patient is asking to discuss an illegal act.

The End of Life Learning Outcomes (Taylor, 2019) support nurses working in specialist palliative care in the UK in their development as experts in end-of-life care. These learning outcomes outline the foundations of training expected in palliative care and the requirements for nurses working at various levels, from assistive-level staff (non-regulated) to nurses working at consultant level. Within these learning outcomes, two aspects relevant to registrants address ethical considerations at the end of life, although how these translate into training and postgraduate education is up to individual institutions. These learning outcomes are:

- Analyse the overall approach of person-centred, value-based practice and how this relates to ethics, law and decision-making in palliative and end of life care.
- Use an understanding of the theoretical basis for applied ethics in clinical practice, demonstrate application of these in ethical reasoning and decision-making in palliative and end of life care, with ability to justify own ethical position in relation to palliative care practices.

Nurses working at clinical nurse specialist level are also expected to undertake advanced communication skills training, which is intended to prepare them for complex or challenging conversations with patients and those important to them. However, neither of these areas of training requires specific consideration of how to support patients expressing a desire to die or requesting to discuss assisted dying, nor a specific understanding of the associated legislation.

In areas where assisted dying is permissible, education programmes, including relevant communication skills, have been proposed as beneficial for healthcare professionals to develop the skills required to navigate the legal processes of assisted dying (Frolic et al., 2022; White et al., 2020; Young et al., 2021b). While knowledge of the law is recognised as necessary, even where the law supports an assisted death, nurses still report a lack of understanding of the legal requirements and its relationship to their professional responsibilities (Archer et al., 2025; Bustin et al., 2024; Byrnes et al., 2025; Hewitt et al., 2022; Hewitt et al., 2021; Lamba et al., 2024; Otte et al., 2017; Pesut et al., 2024; Schiller et al., 2019; Snelling et al., 2023). Despite it being recognised as important, specific training is not provided for physicians in responding to requests for assistance to die, which can lead to a lack of confidence in approaching these conversations (Byrnes et al., 2025; Clayton et al., 2019; Ho et al., 2021; Segerlantz et al., 2025). There is limited evidence on how this may apply to nurses; however, the lack of evidence could also imply that nurses' educational needs were also neglected.

2.5 Discussing assisted dying within the team: the influence of socio-cultural aspects

To this point, I have examined the impact of legal frameworks, professional regulations, and the role of services nurses work within that may influence the ability to address requests for assisted dying where it is not legal. Nevertheless, broader societal factors related to assisted dying can also shape discourse among team members and affect how nurses perceive their capacity to respond to requests for assistance to die. I will outline four influential, intersecting aspects that are considered to affect this discourse. These aspects are:

- The 'relationship' between palliative care and assisted dying
- The opinion of other team members
- Taboo of (assisted) dying
- The influence of the patient's desire to die

2.5.1 The relationship between palliative care and assisted dying.

With the rise of jurisdictions permitting assisted dying, palliative care services and the individuals working within them have had to examine how they may coexist. Despite a lack of evidence supporting the idea that permitting assisted dying harms the development of palliative care services (Chambaere & Bernheim, 2015; Colburn, 2025), it is frequently cited as a concern by healthcare professionals in palliative care (Hurst & Mauron, 2006; Rutherford et al., 2021a). Furthermore, it is commonly suggested that effective palliative care should negate the need for people to seek assisted dying (Hurst & Mauron, 2006; Lindblad et al., 2008; Variath et al., 2020; Wilson et al., 2021), with the principles and philosophy of these two forms of care often viewed as being in direct opposition (Colburn, 2019). Palliative care services can be involved in a number of ways, including delivering patient care leading up to the request for assisted death, care during the period between this request and death, and managing the death itself (Dierickx et al., 2018; O'Connor et al., 2021). A spectrum of models for how palliative care and assisted dying services can interact with each other, where this is legal, has been identified; these range from synergistic and cooperative to prohibitive and restricting access to services (Gerson et al., 2023; Gerson et al., 2020; Reed, 2025). Both service design and position statements of professional bodies contribute to the complex interplay between these services; often, this relationship is contentious. Nevertheless, as Downar and Preston (2025) suggest, addressing this matter serves the best interests of all involved parties, including patients and staff.

The relationship between palliative care services and assisted dying is further complicated by how palliative care distinguishes itself from assisted dying (Waran & William, 2020). Some healthcare professionals express moral uncertainty about the nature of interventions commonly undertaken within palliative care and their role in hastening death. These interventions may include the withdrawal of life-sustaining treatment and the use of sedation at the very end of life (Gerson et al., 2019). While often considered a natural form of dying (Stängle et al., 2021), some people with a desire to die may choose to voluntarily stop eating and drinking. Healthcare professionals may continue to have an active role in delivering care for patients who make this choice, but not intervene to halt the dying process (Lowers et al., 2021a; Lowers et al., 2021b). Nurses, in particular, describe uncertainty and unease about acts undertaken as part of palliative care that may hasten death (Beel et al., 2006; Bruce & Beuthin, 2020; De Vries & Plaskota, 2017; Halcomb et al., 2004; Hov et al., 2007; Sandham et al., 2022). Uncertainty across these acts of care primarily arises from whether death, in this context, is an intended or unintended consequence or side effect of the intervention or an omission to act for the healthcare professional (Auffray et al., 2024; Booker & Bruce, 2020; Cohen-Almagor & Ely, 2018; Gerson et al., 2019; Heino et al., 2021; Inghelbrecht et al., 2009; Inghelbrecht et al., 2011; Morita et al., 2004; Rys et al., 2015; Swart et al., 2010; Vissers et al., 2022). Although it is recognised within legal and ethical frameworks that these acts differ from assisted dying (Engström et al., 2006), the intentions of patients and healthcare professionals can be difficult to delineate within existing frameworks (Buiting et al., 2010; Faris et al., 2021; Lindblad et al., 2008). As Gerson et al. (2021) also suggests, there is no clear approach to guiding palliative care services on how to navigate the intersecting issues in the provision of assisted dying where this is legal.

2.5.2 The opinion of other team members

A culture of openness and effective communication within healthcare teams is vital for managing uncertainty and moral distress within ethically challenging situations (Booth & Robinson, 2025; Corradi-Perini et al., 2020; Whitehead et al., 2015). Open dialogue is suggested as an important tool to facilitate patients' access to palliative care services and optimise symptoms (Michael et al., 2024), and is also deemed essential when addressing assisted dying (Hewitt et al., 2022; O'Connor & Philips, 2020; Pesut et al., 2020b). A sense of belonging within teams and the ability to share experiences have also been suggested to support functioning assisted dying provision (Archer et al., 2025; Feijoo-Cid et al., 2025).

Consequently, nurses can feel isolated in managing requests for assistance to die as they navigate tensions between social expectations and personal beliefs (Archer et al., 2025; Hol et al., 2023; Pesut et al., 2020b; Wilson et al., 2021). Within the UK, doctors working in palliative care have described a fear of being ostracised within the speciality by discussing, specifically their support for, assisted dying (Ahmedzai & Fingas, 2024; Anonymous, 2019), and state they do not always feel represented by the 'palliative care position' due to this (Colburn, 2025). In jurisdictions that permit assisted dying, there is emerging evidence showing how other team members affect nurses' capacity to discuss assisted dying and the literature reflects nurses' fear of being ostracised due to personal moral beliefs (McDougall et al., 2020; Wright et al., 2021). Sandham et al. (2022) suggests that nurses feel required to maintain a neutral position with patients and their team in order to fulfil their professional role and feel able to act as an advocate for the patient, irrespective of their personal stance.

2.5.3 Taboo of (assisted) dying

Death denial and the subsequent taboo surrounding death in Western society are evidenced in both professional and public discourse (Abbey et al., 2020; McIlfatrick et al., 2021). It has been suggested that death denial and the associated taboo are sustained by a veil of silence surrounding death and dying, perpetuated by healthcare professionals (Llewellyn et al., 2016; Tradii & Robert, 2019). The medicalisation of care at end of life and the desire to cure or postpone death, have been noted as profoundly influencing healthcare professionals within this context (Carrieri et al., 2020; Robert & Tradii, 2019; Tradii & Robert, 2019). The act of dying is typically regarded as a taboo topic, with the pursuit of assisted death perceived as even more controversial and taboo. Yet, the specific origin of the taboo around assisted dying is poorly understood. It has been posited that the previous criminalisation of suicide and its perception as a symptom of mental illness may underpin this taboo (Wicks, 2020). It is also suggested that the complexity of language choice when discussing assisted dying also reinforces the continuation of the taboo (Kremeike et al., 2021; Llewellyn et al., 2016). Confusion over varying terminology, worries about misinterpreting people's views, socio-cultural contexts, and the challenges in tackling these issues have caused individuals to avoid confronting the topic, only to lead to further marginalisation.

McIlfatrick et al. (2021) suggests that societal awareness of a taboo around death and dying limits engagement in discussions about morality and poses significant challenges to articulating thoughts on the topic. However, this is paradoxical to the positioning of people who wish to actively engage in discussions about assisted dying, and especially those with death-positive attitudes who consider an assisted death (Jose et al., 2025; Menzfeld, 2017; Porta-Sales et al., 2019). Palliative care does not fundamentally deny that death occurs; indeed, one of its key aims is to encourage open discussions about death and dying in society to facilitate the provision of a ‘good death’. However, there can often be a disconnect between what patients and healthcare professionals view as a ‘good death’ (Cottrell & Duggleby, 2016; Kellehear, 2007; Kowaloff, 2024). Importantly, as Kastbom (2021) adds, in this context for patients, death refers not to the moment of dying, but to the process that unfolds over time in the prelude to death. This is often overlooked by healthcare professionals caring for the individual who focuses on maximising symptom management towards a peaceful, well-managed point of death (Kastbom, 2021; Kellehear, 2007). A 'good death', as suggested by Cottrell and Duggleby (2016), in this context, can in itself be a discourse created to shape and maintain social attitudes and behaviours surrounding death and dying. As I will explore, people working in palliative care appear reluctant to discuss assisted dying and are sometimes prohibited from doing so by their organisation. If, as Tradii and Robert (2019) suggested, the taboo arises from the perception of death as a failure to cure, then perhaps palliative care contributes to the development of assisted dying as a taboo due to the perceived inability to provide a 'cure' for a 'good' dying process for all.

2.5.4 The influence of the patient's desire to die

While the concept of a 'good death' can be problematic, the patient's desire to die and their interest in exploring assisted dying introduce an additional intersecting element, that some healthcare professionals may not perceive the reality of death as those facing it might (Robert & Tradii, 2019). For some people, having to experience the 'process of dying' may serve as a motivating factor to consider a hastened death. If healthcare professionals do not share this perspective, the request for assisted dying might not be deemed legitimate. Healthcare professionals express that refractory suffering at the end of life is rare (Gustad et al., 2021). There are examples in the literature that optimised symptom management, and exploring the patients' concerns and reasons behind their desire to die may resolve the wish to explore assisted dying (Kremeike et al., 2021; Michael et al., 2024; Ohnsorge et al., 2014). However, the desire to die, for those with life-limiting illnesses, is less commonly due to physical symptoms, which may improve with interventions, and is more closely linked to existential concerns of personhood, such as loss of autonomy and control, impact on dignity, and reduction in performance status, which are less likely to resolve (Adams et al., 2022; Dees et al., 2011; Downar et al., 2023; Downar & Preston, 2025; Fischer et al., 2008; Gerson et al., 2023; Güell et al., 2015; Guerrero-Torrelles et al., 2017; Hudson et al., 2006; Kligerman & Divi, 2020;

Knights et al., 2024; Michael et al., 2024; Ohnsorge et al., 2014; Rodríguez-Prat et al., 2017; Smith et al., 2015). In Chapter Three I will explore how nurses frequently experience a sense of inadequacy in their role, and the speciality of palliative care, when a patient's suffering cannot be alleviated, which can cause moral injury. Nurses often express the belief that a patient's enduring desire to die reflects poorly on the quality of the care they provide; a concern widely shared among professionals in palliative care (Bruce & Beuthin, 2020; O'Connor & Philips, 2020; Variath et al., 2020). Recognising that the desire to die will not abate has implications for nurses and their professional identity. As such, this may impact on their motivation when considering such requests.

2.6 Research aims and objectives

In areas where assisted dying is permitted, critical factors such as effectively communicating the law to patients, understanding the latent meaning behind patient requests, and ensuring consistent support and presence have all been cited as important to address. Considering the socio-cultural aspects that may influence how nurse can engage with discussions, we must confront whether individuals are genuinely allowed to explore the option of assisted dying. Yet little is known about how nurses conceptualise these decisions when the request for assistance to die is not legal.

The aim of the study is to explore how nurses, who work in specialist palliative care, respond to patients who wish to discuss hastening their death through assisted dying.

Three objectives were developed to achieve this aim. These are:

- To understand how nurses within specialist palliative care may respond to a patient when they wish to discuss seeking an assisted death.
- To understand the aspects that may influence and impact upon the nurses' reactions and responses to these discussions.
- To conceptualise nurses' process of ethical decision-making when a patient requests support in seeking an assisted death.

The methodology used to address the study objectives through the primary study will be outlined in Chapter Four. In the following chapter, I will present a qualitative evidence synthesis exploring nurses' experiences in acts that may be perceived as hastening death. Within the synthesis, I provide a broader examination of nurses' experiences to enhance understanding of the factors they might consider significant when responding to requests for assisted dying. This data is also examined through the lens of ethics of care. In the subsequent chapters, I will present the research findings from the study and discuss their implications for future practice.

Chapter 3: Qualitative evidence synthesis

3.0 Introduction

Within this chapter, I will present a thematic synthesis of the literature, which considers the experiences of nurses involved in acts that may be perceived as death hastening. Whilst assisted dying is undertaken with the intention to hasten death, other acts within healthcare have the potential to hasten death. However, these interventions are not used with this intention; examples of such care includes the use of sedation or the withdrawal of life-sustaining treatment (Gerson & Preston, 2021; Young et al., 2021a). To better understand aspects that may influence how nurses feel able to respond to requests to discuss assisted dying in the UK, a broader examination of the international literature relating to their experiences when involved in care that may hasten death was conducted. The findings of this synthesis were published in June 2025 (Ali et al., 2025).

3.1 Background

While some consider hastened death to be solely assisted dying (Marina et al., 2022), it is suggested that acts such as voluntarily stopping eating and drinking, withdrawal of life-sustaining treatment, and palliative sedation also constitute this (Gerson et al., 2020). On a clinical, conceptual, and philosophical level, what encompasses ‘hastened death’ remains poorly defined with no internationally agreed terminology (Mroz et al., 2021). Clinicians identify complex physical and moral issues that arise when attempting to define what constitutes an act with the potential to hasten death (see Table 1). However, there may also be a disconnect between doctors’ and nurses' perceptions of acts that hold the potential to hasten death (Abarshi et al., 2014; Anquinet et al., 2013; Leheup et al., 2015; Maiser et al., 2017; Rodrigues et al., 2020; Stängle & Fringer, 2022; Stängle et al., 2020a; Stängle et al., 2020b; Vieille et al., 2021), with nurses more likely to experience internal conflict and increased uncertainty about the nature of these interventions (Abarshi et al., 2014; Faris et al., 2021; Heino et al., 2021). This uncertainty is more marked in the use of sedation than in other interventions (Arantzamendi et al., 2021; Cohen-Almagor & Ely, 2018; Rys et al., 2015; Seale et al., 2015). Attempts are made within the literature to decrease the ambiguity that nurses feel about whether care may hasten death; however, it is also recognised that this originates primarily from physician-authored papers. The focus on 'educating' nurses to help them gain moral clarity may further marginalise their concerns about these acts (Wright et al., 2020).

Table 1: Definitions of acts that may hasten death

Term	Definition and intended aim	Intended purpose	Does this hasten death?
Assisted dying, including euthanasia	Intentionally ending the life of a patient by a health care practitioner by means of active administration of a drug by a health care practitioner at that patient's explicit request or by providing or prescribing drugs for a patient to use to end their own life (Mroz et al., 2021).	Healthcare – to support autonomous patient choice Patient - death.	Yes.
Sedation/ palliative sedation	The relief of suffering through monitored proportionate use of medication intended to reduce consciousness in patients with life-limiting illness (Arantzamendi et al., 2021; Cherny et al., 2009; Surges et al., 2024). An umbrella term referring to the management of refractory symptoms along a spectrum from	Healthcare – to support autonomous patient choice. Reduction of consciousness to relieve suffering (Surges et al., 2024). Promote comfort at end of	Uncertainty as to its status. Death as an unintended consequence of the intervention. Yes (Faris et

Term	Definition and intended aim	Intended purpose	Does this hasten death?
	continuous deep sedation though to 'light' sedation (Gurschick et al., 2015). The use of low doses of Midazolam or opioids for symptom management, where sedation is not the primary aim, is not considered palliative sedation within this context (Surges et al., 2024).	life (Gurschick et al., 2015). Patient – reduction of awareness or death (Serey et al., 2023; Voeuk et al., 2017)	al., 2021; Hahn, 2012) No (Beller et al., 2015; Gurschick et al., 2015; Maltoni et al., 2009; Park et al., 2021; Raho & Miccinesi, 2015; Surges et al., 2024; ten Have & Welie, 2014) Maybe (Heino et al., 2021; ten Have & Welie, 2014)
Withdrawal of life-sustaining treatment	Withholding or withdrawing medical treatment from a person due to medical futility or a person's voluntary and competent request (Radbruch et al., 2016) . These may also be referred to as decisions to limit treatment (Mehlis et al., 2018). A range of interventions, including but not limited to, withdrawal or weaning of mechanical ventilation (Efstathiou et al., 2020; Faull & Wenzel, 2022; Mazzu et	Healthcare professionals - Support patient choice in care and reduce treatment burden in the last days of life (Braganza et al., 2017) . Patient – reduce treatment burden	Dependent upon intervention and clinical condition. Timescale to death also be variable dependent upon intervention

Term	Definition and intended aim	Intended purpose	Does this hasten death?
	al., 2023; Munshi et al., 2015), oxygen (Bramati et al., 2023) or cardiac system support (Munshi et al., 2015) and discontinuing antibiotics (Munshi et al., 2015), parenteral nutrition and hydration (Mayers et al., 2019; Rady & Verheijde, 2017; Schwartz, 2015), blood transfusions (Graw et al., 2016), chemotherapy (Bluhm et al., 2015) or haemodialysis (Germain et al., 2007; Halvorsen et al., 2008; Hussain et al., 2015; Patel & Holley, 2008; Russ et al., 2007)	but may also be to avoid life prolongation.	
Voluntary stopping eating and drinking	Where a person actively choses to stop eating and/or drinking with the intention to hasten death(Lowers et al., 2021b). A self-initiated, active and ongoing effort, by a person with mental capacity, to accelerate dying in the contexts of suffering refractory to aggressive disease and symptom management, which can occur irrespective of care setting (Lowers et al., 2021b; Quill et al., 2018; Saladin et al., 2018; Wax et al., 2018; Wechkin et al., 2023). Voluntary stopping eating and drinking does not involve active intervention from healthcare professionals to withdraw treatment	Healthcare – to support patient autonomous choice Patient – to hasten death (Bolt et al., 2023; Quill et al., 2018; Quill et al., 1997)	Yes (Quill et al., 2018; Quill et al., 1997; Stängle et al., 2021; Stängle & Fringer, 2022)

3.1.1 The focus on experience

The term ‘experience’ can often be used without explanation as to what it may refer to (McIntosh & Wright, 2019). Experience can be considered as an active ‘intersubjective social and political’ process through which people enter in order to create meaning (Tirkkonen, 2019, p. 449). The relational understanding and expectations of the nurse-patient relationship define the nurse’s experience, yet their experiences are commonly amalgamated with those of other healthcare professionals, most specifically doctors. Despite it being recognised that the dynamics with the wider healthcare team is considered as potentially impacting how care delivery is experienced (Sekse et al., 2018; Vanderspank-Wright et al., 2018). Nurses identify their role as unique within the healthcare team. The frequency and intimacy of patient contact, seeing themselves as patient advocates, and coordinating care to support patients in navigating the healthcare system are all cited as specifically defining their role in palliative care (Sekse et al., 2018; Vanderspank-Wright et al., 2018). Both nurses and physicians believe that nurses are well-positioned to identify suffering and determine if symptoms are poorly managed or whether further treatment may be futile (Flannery et al., 2016; Heino et al., 2021). However, the level of involvement nurses have in decision-making is noted as an important factor that impacts the quality of their experience delivering care, often primarily influenced by the physician (Flannery et al., 2016). Nurses being required to undertake care they perceive not in the patient's best interest or where they feel they are witnessing unnecessary, and iatrogenic, suffering can result in moral injury (Čartolovni et al., 2021). While there appear to be some common issues for all healthcare professionals, synthesising research that specifically focuses on nurses will provide a deeper understanding of their nuanced experiences. This will inform the development of insights into the elements that might influence nurses’ responses to requests for assisted dying. Understanding where, or if, comparable experiences exist could help develop knowledge related to the practical, ethical and moral complexities nurses report when providing care at the end of life. Ultimately, this review seeks to further amplify the nursing voice in this complex and often divisive topic.

3.2 Review question

What can be learnt from synthesising qualitative research findings on the lived experiences of nurses when involved with acts that may be perceived as death hastening?

3.3 Methodology/ Methods

Experience is qualitative in nature (Bryman, 2016); as such, a focus on primary qualitative research is most effective in developing a deeper understanding of experience within the context of hastened death. A qualitative evidence synthesis was undertaken utilising thematic synthesis, as described by Thomas and Harden (2008). Thematic synthesis enables analysis ‘beyond’ the initial findings of the primary research, supporting the development of new meaning and concepts from data across various research methodologies (Aveyard et al., 2016; Booth et al., 2016). Thematic Synthesis is valuable when the research question aims to gain a deeper understanding of an unknown issue, rather than theory generation.

Thematic synthesis is also congruous with the underpinning epistemological considerations embedded within the primary study, which is explored in Chapter Four. The review exists within a social constructivist paradigm, where individuals' experiences of the world shape understanding and meaning-making (Crotty, 1998). This acknowledges the significant role of the social context of the research and the impact of my subjectivities on the analysis. These subjectivities influence the reflexive and iterative nature of the review question's development and the generation of themes, which are interrogated through and from my own situated knowledge. The macro and micro impacts of power on gendered work are also recognised and are fundamental to how the data is understood in this review, using ethics of care as an epistemological lens. This evidence synthesis is reported in line with the Enhanced Transparency in

Reporting the Synthesis of Qualitative Research (ENTREQ) checklist (Tong et al., 2012), which aids rigour and represents the iterative process of qualitative synthesis.

3.3.1 Search strategy

The search strategy and subsequent inclusion/exclusion criteria were developed using SPIDER (Cooke et al., 2012). SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was utilised to facilitate a search that considers experience across interventions. Table 2 outlines the terms generated through SPIDER to develop the search strategy.

Table 2: SPIDER

SPIDER	Term
Sample	Registered nurses
Phenomenon of Interest	Assisted dying, voluntary stopping eating a drinking, withdrawal of life-sustaining treatment, and palliative sedation,
Design	N/A
Evaluation	Experience
Research type	Qualitative

To increase the sensitivity of the search strategy, the research design was not specified within the search terms. Medical Subject Heading (MeSH) terms and database-specific linked terms were used within the search, the strategy was developed alongside a subject specialist librarian from Lancaster University, to support an effective search strategy (Tricco et al., 2011). Initial searches were run in December 2022 and updated in August 2024. The searches were conducted using the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and MEDLINE databases. The search strategy was tested against two known papers to ensure its quality. The search terms are identified in Table 3. Results were obtained by linking searches with the Boolean operator AND.

Table 3: Search terms

Database	Phenomenon of interest	Sample
CINAHL	TI ((MH "Suicide, Assisted") OR (MH "Euthanasia, Passive") OR (MH "Euthanasia+") OR ((stop* OR cease OR withdraw*) N5 (food OR drink* OR sustan* OR treat*)) OR (euthan*) OR (assisted-dying) OR (assisted-suicide) OR (suicide) OR (palli* N5 seda*) OR ((assist* OR haste*) N5 (death OR dying OR die))) OR AB ((MH "Suicide, Assisted") OR (MH "Euthanasia, Passive") OR (MH "Euthanasia+") OR ((stop* OR cease OR withdraw*) N5 (food OR drink* OR sustan* OR treat*)) OR (euthan*) OR (assisted-dying) OR (assisted-suicide) OR (suicide) OR (palli* N5 seda*) OR ((assist* OR haste*) N5 (death OR dying OR die))) Limiters 01/01/1997 Human	(MH "Nurses") OR Nurs*
PsychINFO	TI ((DE "Euthanasia") OR (DE "Assisted Suicide") OR ((stop* OR cease OR withdraw*) N5 (food OR drink* OR sustan* OR treat*)) OR (euthan*) OR (assisted-dying) OR (assisted-suicide) OR (suicide) OR (palli* N5 seda*) OR ((assist* OR haste*) N5 (death OR dying OR die))) OR AB ((DE "Euthanasia") OR (DE "Assisted Suicide") OR ((stop* OR cease OR	TI (DE "Nurses" OR DE "Nursing" OR Nurs*) OR AB (DE "Nurses" OR DE "Nursing" OR Nurs*)

Database	Phenomenon of interest	Sample
	withdraw*) N5 (food OR drink* OR sustan* OR treat*)) OR (euthan*) OR (assisted-dying) OR (assisted-suicide) OR (suicide) OR (palli* N5 seda*) OR ((assist* OR haste*) N5 (death OR dying OR die))) Limiters 01/01/1997 Human	
MEDLINE	AB ((MH "Euthanasia") OR (MH "Euthanasia, Active, Voluntary") OR (MH "Suicide, Assisted") OR (MH "Euthanasia, Active") OR (MH "Euthanasia, Passive") OR (MH "Right to Die") OR ((stop* OR cease OR withdraw*) N5 (food OR drink* OR sustan* OR treat*)) OR (euthan*) OR (assisted-dying) OR (assisted-suicide) OR (suicide) OR (palli* N5 seda*) OR ((assist* OR haste*) N5 (death OR dying OR die))) OR TI ((MH "Euthanasia") OR (MH "Euthanasia, Active, Voluntary") OR (MH "Suicide, Assisted") OR (MH "Euthanasia, Active") OR (MH "Euthanasia, Passive") OR (MH "Right to Die") OR ((stop* OR cease OR withdraw*) N5 (food OR drink* OR sustan* OR treat*)) OR (euthan*) OR (assisted-dying) OR (assisted-suicide) OR (suicide) OR (palli* N5 seda*) OR ((assist* OR haste*) N5 (death OR dying OR die))) Limiters 01/01/1997 Human	AB ((MH "Nurses") OR Nurs*) OR TI ((MH "Nurses") OR Nurs*

Thomas and Harden state that, within this form of synthesis, it may not be possible, or required, to locate all available evidence; instead, the strategy focuses on ensuring that no new research would alter the ‘conceptual synthesis’ (Thomas & Harden, 2008, p. 3). Reverse and forward citation checking, as well as reviewing recent national documents from the UK, were also included in the search strategy to ensure that no papers had been omitted that might alter the findings conceptually. This process was discussed regularly as part of the supervision process and stopped when it was agreed that the findings were conceptually rich.

3.3.2 Inclusion/Exclusion criteria

Pre-defined criteria were applied to establish the inclusion of papers in the review (see Table 4).

Table 4: Inclusion/exclusion criteria

	Inclusion	Exclusion
Population	Registered Nurses Patients over the age of 18	Registered nursing associates Studies with multiple healthcare professionals in the sample Patients or informal carers Volunteers
Intervention	Assisted dying/assisted suicide/euthanasia Withdrawal of life-sustaining treatment Voluntary stopping eating or drinking Sedation at end of life	Requests for assistance to die due to a mental health diagnosis Non-voluntary euthanasia *included in search terms for sensitivity but excluded in review Veterinarian studies
Outcome	Experience within the provision of care	Studies solely relating to the description of the medical

	Inclusion	Exclusion
		intervention and process of assisted dying Attitudes/opinions to assistance to die. Experience of the provision of care (considered solely in terms of level of involvement)
Language	Findings published or available in the English language	
Dates	Research undertaken after 1997, in line with first legalisation of assisted dying	Timeline (relating to legality of assisted dying) is not able to be established within the paper
Study design	Qualitative	Quantitative Mixed methodology Literature or systematic reviews. Grey literature including blogs Opinion pieces, editorials and commentaries Book/book chapters

The titles of the papers were initially assessed against the inclusion criteria; any papers that did not meet the criteria at this stage were discarded. Abstracts and full-text papers were reviewed if they appeared to meet the inclusion criteria after the title search was conducted. All included papers were then re-read to ensure their appropriate inclusion. A second reviewer, with subject expertise, blind-reviewed 10% of titles (360 out of 3600 papers) from the initial search against the inclusion criteria. The process was carried out using Rayann®, and the decisions were double blinded until both reviewers had completed their evaluation. Decision-making relating to the application of the inclusion criteria was discussed, and recommendations were made to provide rigour to the process. An example of this was how the concept of experience was understood by both reviewers, as this was central to the review process. There was consensus on which papers should be included.

3.3.3 Data extraction, appraisal and synthesis

Data were extracted using a tool developed from the work of Noyes (Noyes et al., 2018), which supports the extraction of large amounts of narrative data verbatim from the research (See Appendix 1 for an example). The tool was modified to include data relating to the review question, including the legality of assisted dying. The second reviewer undertook data extraction on 10% of the included papers (3 of 23) to clarity check the tool and protocol for appropriate data extraction. Uncertainty was resolved through initial discussion, and changes were made to the extraction tool to capture the necessary data. The studies were quality assessed alongside data extraction (Flemming & Noyes, 2021) using the Joanna Briggs Institute quality appraisal tool (Joanna Briggs Institute, 2017). No papers were excluded based upon this assessment, although data quality was considered reflexively during the synthesis, in keeping with the method (Thomas & Harden, 2008).

Analysis and synthesis were undertaken using the three-step approach (Thomas & Harden, 2008)

1. Coding text
2. Developing descriptive themes
3. Generating analytical themes.

Coding and theme development were undertaken inductively. A hybrid approach to coding was employed, utilising both NVivo® for descriptive themes and transitioning to pen and paper for the development of analytical themes (See Appendix 2). Line-by-line coding was initially undertaken, where initial codes were developed. Descriptive themes were developed through comparison of similarities from initial verbatim quotes and grouping into broader categories (see section 3.4.1). In line with the method, deep analysis occurred within stage three of the process. Reflexivity is fundamental in the development of a rigorous thematic synthesis. Therefore, regular discussions and reflections with the supervisory team were undertaken.

3.4 Findings

From 4384 papers assessed for eligibility, a total of 23 papers were identified regarding nurses' experiences of acts that may potentially hasten dying (see PRISMA Figure 1). Thirteen relate to assisted dying, including six from Canada, five from Belgium, and two from the USA. These papers originate from areas with permissive assisted dying legislation, except for De Bal et al. (2006), Dierckx de Casterlé et al. (2006), Schwarz (2003), and Volker (2001), which were undertaken in areas prior to a change in the law to allow assisted dying. Three papers, from Canada, the UK, and the Netherlands, discuss sedation, while seven consider withdrawal of life-sustaining treatment, all situated in jurisdictions without permissive assisted dying legislation at the time of the study. All papers concerning the withdrawal of life-sustaining treatment were based in intensive care settings. No papers exploring voluntary stopping of eating and drinking met the inclusion criteria. A summary of all included papers can be found in Appendix 3.

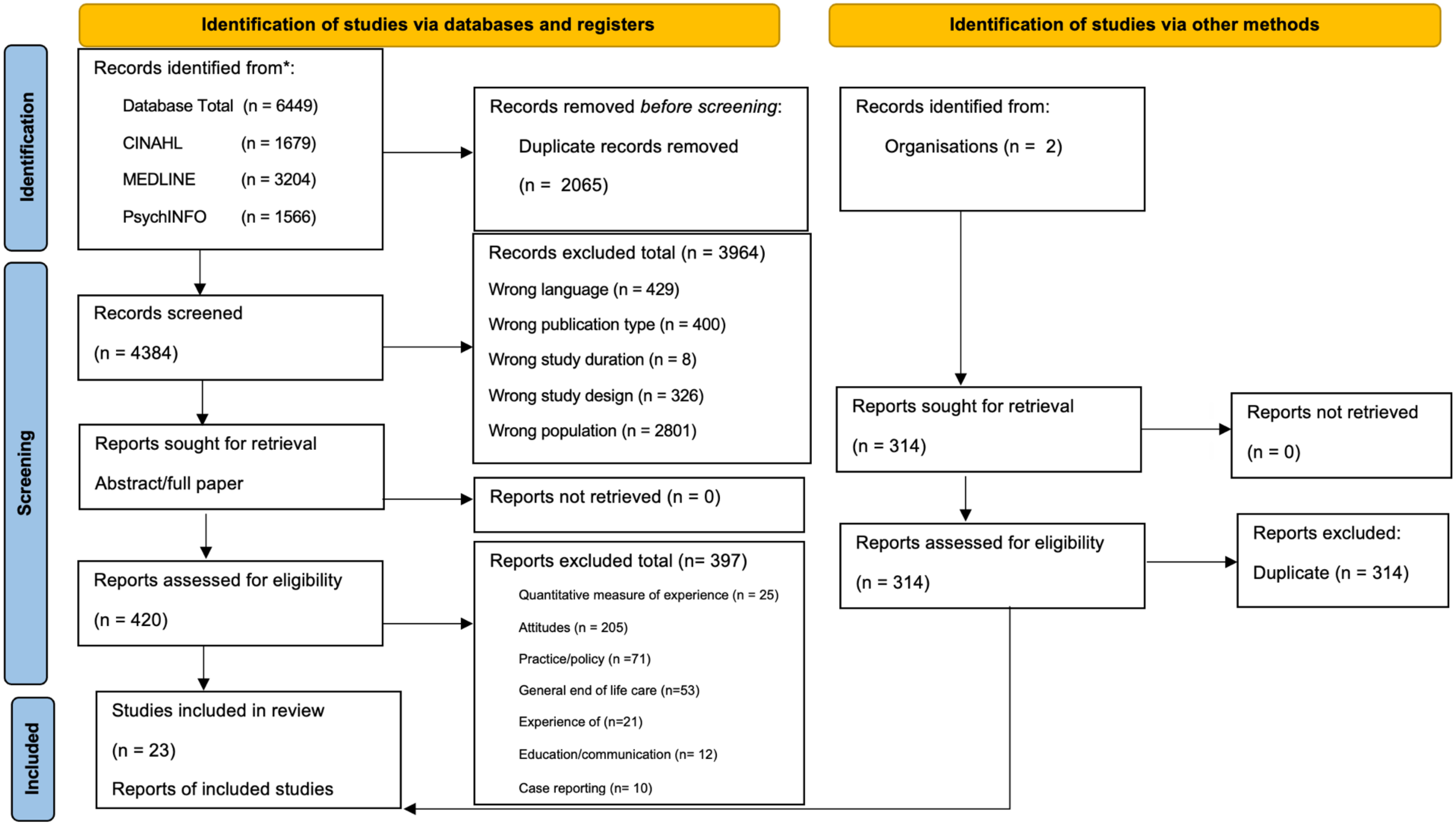
3.4.1 Initial theme development

Eleven initial descriptive themes were developed through early engagement with the data. These were

- Control
- Needing support
- Role of the nurse
- Palliative care as a proxy
- Emotional impact
- Implicit and explicit behaviour: turning a blind eye
- Enacting death

- Acting outside of existing moral frameworks
- Relieving suffering
- Impact of the family on experience
- Conflicts and tensions

These initial themes were developed by considering the interventions individually and were then reviewed through cross-analysis based on the interventions and a reconsideration of the review question. Through this iterative process, the themes were refined by examining overlapping concepts within the initial descriptive themes. For example, control, needing support, and acting outside existing moral frameworks became one cohesive theme, while the role of the nurses was subsequently incorporated into all four themes.



* Wrong publication type, including – opinion pieces ** Wrong study design, including systematic/literature review

Figure 1: PRISMA

3.4.2 Analytical themes

An overarching theme, *the emotional labour of care,* was developed with three subthemes that influence the experience of delivering care and the subsequent levels of emotional labour involved. The sub-themes are (1) experiencing personal and professional conflicts, (2) the provision of 'normal(ised)' care and (3) perceptions of palliative care as a proxy for hastening death. Table 5 identifies how the papers are represented within the themes.

Table 5: Themes

Theme	Assisted dying	Other acts that may hasten death
Overarching theme: The emotional labour of care	Showing and regulating emotions Bellens et al. (2020), Beuthin et al. (2018), De Bal et al. (2006), Denier et al. (2009), Denier et al. (2010), Dierckx de Casterlé et al. (2006), Herbert & Asri (2022), Pesut et al. (2020a), Pesut et al. (2020b), Pesut et al. (2021)	Showing and regulating emotions De Vries & Plaskota (2017), Efstathiou & Walker (2014), Halcomb et al. (2004), Hov et al. (2007), Johnson & Jack (2022), McMillen (2008), Taylor et al. (2020)
	Positive emotions Bellens et al. (2020), Beuthin et al. (2018), De Bal et al. (2006), Denier et al. (2010), Herbert & Asri (2022), Pesut et al. (2020a), Pesut et al. (2024)	Positive emotions Beel et al. (2006), Halcomb et al. (2004)
	Negative emotions Bellens et al. (2020), Beuthin et al. (2018), De Bal et al. (2006), Denier et al. (2010), Herbert & Asri (2022), Pesut et al.	Negative emotions Beel et al. (2006), Lokker et al. (2018), Halcomb et al. (2004), Hov et al. (2007), Johnson &

Theme	Assisted dying	Other acts that may hasten death
	(2020a), Pesut et al. (2020b), Pesut et al. (2024)	Jack (2022), McMillen (2008), Taylor et al. (2020)
	The impact of witnessing suffering Beel et al. (2006), Beuthin et al. (2018), Halcomb et al. (2004), Hébert & Asri (2022), Pesut et al. (2020a), Pesut et al. (2020b)	The impact of witnessing suffering Beel et al. (2006), Halcomb et al. (2004), Hov et al. (2007), Johnson & Jack (2022), Lokker et al. (2018)
Experiencing personal and professional conflicts	Moral tension Beuthin et al. (2018), De Bal et al. (2006), Dierckx de Casterlé et al. (2006), Denier et al. (2010), Pesut et al. (2024), Schwarz (2003)	Moral tension Halcomb et al. (2004), Taylor et al. (2020)
	The nurse's role in decision-making De Bal et al. (2006), Dierckx de Casterlé et al. (2006), Denier et al. (2010), Pesut et al. (2024)	The nurse's role in decision-making Beel et al. (2006), De Vries & Plaskota (2017), Halcomb et al. (2004), Hov et al. (2007), Lokker et al. (2018), Johnson & Jack (2022), McMillen (2008), Taylor et al. (2020), Vanderspank-Wright et al. (2011)
	Working within boundaries Bellens et al. (2020), De Bal et al. (2006), Denier et al. (2009), Dierckx de Casterlé et al. (2006), Hébert & Asri (2022), Pesut et al. (2020a), Pesut et al. (2020b), Pesut et al. (2024)	Working within boundaries Beel et al. (2006), De Vries & Plaskota (2017), Efstathiou & Walker (2014), Halcomb et al. (2004), Hov et al. (2007), Vanderspank-Wright et al. (2011)

Theme	Assisted dying	Other acts that may hasten death
The provision of 'normal(ised)' care	Controlling the point of death Bellens et al. (2020), Beuthin et al. (2018), Dierckx de Casterlé et al. (2006), Denier et al. (2010), Pesut et al. (2020a), Schwarz (2003)	Controlling the point of death Beel et al. (2006), De Vries & Plaskota (2017), Efstathiou & Walker (2014), Halcomb et al. (2004), Lokker et al. (2018), McMillen (2008), Taylor et al. (2020), Vanderspank-Wright et al. (2011)
	The nurse's perception of the dying process Bellens et al. (2020), Beuthin et al. (2018), Denier et al. (2010), Dierckx de Casterlé et al. (2006), Hébert & Asri (2022), Pesut et al. (2020a), Pesut et al. (2020b), Schwarz (2003), Volker (2001)	The nurse's perception of the dying process Beel et al. (2006), De Vries & Plaskota (2017), Halcomb et al. (2004), Johnson & Jack (2022), Lokker et al. (2018), McMillen (2008), Taylor et al. (2020), Vanderspank-Wright et al. (2011)
Perceptions of palliative care as a proxy for hastening death	Family perceptions De Bal et al. (2006), Denier et al (2010), Volker (2001)	Family perceptions De Vries & Plaskota (2017), Hov et al. (2007), Johnson & Jack (2022), Lokker et al. (2018)
	The nurse's uncertainty Beuthin et al. (2018), De Bal et al. (2006), Schwarz (2003), Volker (2001)	The nurse's uncertainty Beel et al. (2006), De Vries & Plaskota (2017), Hov et al. (2007), Johnson & Jack (2022),
	Navigating with and through language De Bal et al. (2006), Denier et al. (2010), Pesut et al. (2020b), Pesut et al. (2021) Pesut et al.	Navigating with and through language Beel et al. (2006), De Vries & Plaskota (2017), Johnson &

Theme	Assisted dying	Other acts that may hasten death
	(2024), Schwarz (2003), Volker (2001)	Jack (2022), Lokker et al. (2018), McMillen (2008),

Within this synthesis, the term ‘other acts that may hasten death’ serves as an overarching descriptor for the withdrawal of life-sustaining treatment and sedation. This is due to the comparative nature of the experiences and to facilitate comparison between acts regarded as part of established palliative care and assisted dying.

3.5 The emotional labour of care

The emotional labour associated with nurses’ involvement in care that may hasten death is an overarching theme within the studies. Emotional labour is defined as “the management of feeling to create a publicly observable facial and bodily display” (Hochschild, 2003, p. 7). It is an active process where behaviours develop in line with the social expectations of professional roles. Emotions can be suppressed, and outwardly expressed emotions and behaviours can be performative, depending on situational expectations (Hochschild, 2003), which is consistently observed in the studies. Overall, nurses identify a requirement to understand, navigate and conform to expected behaviours when involved with all acts that may hasten death, which requires emotional labour.

Opinions vary among nurses in the studies about what behaviours may be appropriate, including showing emotions during care delivery. When involved in the withdrawal of life-sustaining treatment, nurses feel that showing emotions publicly can be appropriate (Efstathiou & Walker, 2014), although they also described needing to hide these from the wider team (Halcomb et al., 2004; Hov et al., 2007). When caring for people having an assisted death, any outward physical or emotional response is generally removed from public view (De Bal et al., 2006; Denier et al., 2009; Denier et al., 2010a). Within palliative sedation, nurses frequently describe situations they find challenging, linked to witnessing suffering, though the expression of emotion is not considered.

Across interventions, nurses report that their involvement in care impacts them both positively and negatively. Experiences perceived as negative are reported as affecting nurses' personal lives, such as having difficulty disengaging from their experiences after work had ended. Throughout all acts in the review, nurses discuss emotional detachment as a useful strategy for managing emotional labour, although some do not consistently employ it in practice.

> *"As professionals nurses' sympathy extended to their patients, but a certain emotional distance was maintained. Many nurses underlined the importance of psychologically releasing the patient's request. Not all nurses succeeded in maintaining this emotional distance……Non-palliative care nurses in particular took their experiences home after their shift." (De Bal et al., 2006, p. 596)*

Instead, nurses often feel compelled to regulate their negative emotions while providing patient care in order to maintain their own well-being. Emotional labour is reported to diminish across all acts in the review as nurses gain experience in delivering care, both through desensitisation to witnessing death and the dying process, and through the development of clinical skills.

The intensity and level of emotional labour required is consistently regarded by nurses as linked to a desire to help when witnessing suffering. Nurses specifically report that iatrogenic suffering increases the emotional labour required to provide compassionate care and is also seen as motivation for involvement in assisted dying.

> *"That first experience troubled me. Not because of the experience itself, but because of all the previous events that could have ended much better if MAID had been available before. I have images of people I have accompanied in painful end-of-life situations (P17). We do MAID, it is not painful. There is pain, but there is much less pain and suffering compared to someone slowly dying for two or 3 days with pulmonary complications (P31)." (Hébert & Asri, 2022, p. 1638)*

Nurses who decline to be involved in assisted dying due to moral objections (conscientious objection) also report various aspects of care that generate emotional labour. The requirement to provide care for a patient knowing that they wish to have an assisted death, or to care for other patients while an assisted death is occurring, is reported as burdensome. The role of ‘conscientious objector’ also leaves them feeling vulnerable within their team, with support for their position reliant on the individual manager’s response rather than on organisational policy. The lack of managerial support leads nurses to feel they must self-regulate their emotional responses due to the uncertainty surrounding team members' reactions. Therefore, active involvement in assisting dying cannot be deemed the sole cause of emotional labour in these cases.

3.5.1 Experiencing personal and professional conflicts

This theme can be summarised as elements that create personal and professional conflict, affecting the levels of emotional labour required to provide patient care. Conflict arises when nurses, to meet professional expectations, are compelled to work beyond their perceived professional or moral boundaries. The sense of professional obligation nurses feel towards patients leads them to offer support, regardless of any moral tensions that may arise. This was consistently observed across all actions that may hasten death.

Conflicts experienced by nurses are, most commonly, linked to interprofessional tension and are a significant consideration in all studies. Most notably for nurses is the sense that their input is undervalued and their role in clinical decision-making is unrecognised within the healthcare system. Nurses describe themselves, within the healthcare team, as closest to patients and therefore best placed to accurately represent the patient’s wishes and clinical condition to others. There was consensus, within other acts that may hasten death, that nurses are often left alone in navigating the consequences of these decisions with patients and families. The quote from the Australian paper illustrates the consequent challenge for nurses to (re)present decisions that they may disagree with and deliver care they feel is not in the patient’s best interest, essentially becoming the representative of the plan of care on behalf of the healthcare system.

> *“When the doctors sought to withdraw/withhold treatment, the participants expressed that they were often dissatisfied with the management of the situation. The most clearly articulated complaint was that whilst the doctors excluded nurses from the decision making and formulation of the management plan, once a decision is made to forego medical treatment the nurse is left to manage the dying process. ‘‘The mind your business and I’ll make the decision, then they make their decision or have the family make the decision . . . and then leave you to deal with it... they do it all the time ….. ’’.” (Halcomb et al., 2004, p. 218)*

To reduce emotional labour, nurses need to feel supported by the clinical team, and a shared philosophy of care is deemed important. When mentioned, nurses perceive that policy, no matter what that may be, is supportive as it legitimises the nurses’ actions and is viewed as establishing safe professional boundaries. In situations involving other acts that may hasten death, policy is more likely to be replaced by clinical guidelines leading to ambiguity, with nurses describing tensions between guidelines and the perspectives of individual physicians. In the context of assisted dying, these tensions manifest at an organisational level, with nurses indicating a lack of input on structural and policy decisions.

> *“Nurses, however sometimes found themselves trying to assist in a MAiD procedure with no practice guidelines in their places of work. This created uncertainty in their practice, particularly when nurses remained the primary caregivers of patients contemplating or undergoing MAiD.” (Pesut et al., 2020b, p. 14)*

However, this was only observed when considering the enactment of legislative changes and may reflect the seniority of the nurses involved in this study. Overall, the requirement to provide care that contrasts with their professional or personal viewpoint can leave nurses feeling disempowered, which contributes to their emotional labour.

3.5.2 The provision of ‘normal(ised)’ care

This theme reflects the perception that the withdrawal of life-sustaining treatment and sedation are considered part of ‘normal' healthcare, whereas assisted dying is perceived as something ‘other’. The term ‘normal(ised)’ is used to represent nurses’ perceptions that other acts that may hasten death, whilst not part of a ‘natural’ dying process, are accepted as part of ‘normal’ dying. Assisted dying is regarded as a significant event and a non-standard, unnatural death, with nurses using terms such as ‘murder’ and ‘killing’ regardless of their moral position.

“A reflective process was described by Donna: *It was something really big for me when I saw the death certificate, it was this overwhelming feeling like, oh my gosh, I killed him [through MAiD]. Because I think I truly believed that knowing his situation, and his... sort of isolation, that* had I not *been open to the conversation,* had I not *helped him access the information, that he probably would have never been able to access the MAiD services…….”* (Beuthin et al., 2018, p. 516)

Being the cause of death was not a significant narrative within other acts that may hasten death. McMillen (2008) is the only example where nurses consider whether their actions, through withdrawing treatment, were the cause of the patient’s death.

> *“When asked if they played any part in the actual decision one participant replied*: ‘‘*No, and I don’t think I’d ever want to either because at the end of the day it’s somebody’s father, brother, mother whatever. No amount of money in the world could ever get me to make that decision I don’t think and I don’t know how they* [*the consultants*] *sleep at night sometimes*’’.”
> *(Nurse 3) (McMillen, 2008, p. 254)*

Within this theme, there is a shared narrative about controlling the point of death. For other acts that may hasten death, this concerns healthcare-led interventions that nurses report undertaking to deliver compassionate care, such as nurses attempting to de-medicalise the dying experience to optimise it for patients and those important to them. This connects to the concept of an aesthetic death (Taylor et al., 2020), with examples including controlling the bedside environment, ensuring relatives have time with the person, and titrating medication based upon the needs of those witnessing the dying process. Within assisted dying, this manifests as nurses advocating for their patients' choices and prioritising the patient within their caseloads. For an assisted death, the point of death is invariably driven and controlled by the patient. This 'othering' of death within assisted dying is, perhaps, linked to the control of the timing of death being situated outside of healthcare, a shift that disrupts the established or expected relationship between patients and healthcare professionals.

3.5.3 Perceptions of palliative care as a proxy for hastening death

Within this theme, the perception that palliative care provision can be seen as a proxy for hastening death is presented. In some cases, nurses perceive other acts that may hasten death as both physically and emotionally commensurate with an assisted death, expressing this through implicit and explicit communication. For example, Denier et al. (2010a) describe how some nurses consider sedation and assisted dying as part of a spectrum of interventions. Although not directly stated, this is suggested by nurses' concern about their own practices, such as ensuring sedation is used judiciously and feeling anxious if death is prolonged. Nurses also use phrases such as 'active dying' and 'very, very terminal agitation' to justify the use of sedation for intractable symptoms (De Vries & Plaskota, 2017, p. 152) and offer sedation as an alternative when assisted dying is requested (De Bal et al., 2006).

Nurses also feel required to navigate the concern that the public may perceive palliative care as a means to hasten death. In cases of sedation, nurses report that family members believe hospices and palliative care teams are involved with the direct intention of shortening life. Nurses express shock when confronted with requests to hasten death and feel a responsibility to address what they consider an ill-informed view. They articulate a desire to clarify that palliative care interventions will not hasten death. However, the uncertainty some nurses voice about the nature of these interventions means this response can be inconsistent with their personal views.

> *"All of the nurses expressed uncertainty that palliative sedation could or would lead to the death of the patient and they repeatably reflected on this possibility. They all reported experiencing anxiety at some time about such an outcome, but all maintained the position of wanting what was deemed "best for the patient" at that time." (De Vries & Plaskota, 2017, p. 152)*

These responses may constitute a performative action that nurses feel compelled to undertake as part of the 'nursing role'.

Nurses identify difficulty in establishing a moral line that links their external position with their internal stance, which involves considerable emotional labour. They express a reluctance to openly state the opinion that death may be hastened by the actions of healthcare professionals.

> *"There seems to be a discrepancy between the criterion on life expectancy in the guideline and nurses' views, where nurses appear to prefer a more limited life expectancy than the guideline. This may be related to nurses' concerns that sedation might hasten death." (Lokker et al., 2018, p. 160)*

As such, nurses may employ innuendo or metaphor to help them navigate a moral line they perceive as acceptable for themselves and those they communicate with, speaking to a shared implicit understanding of these interventions. In some instances, in countries where assisted dying was illegal, nurses utilised innuendo to provide covert advice concerning medication use when a desire to die had been expressed.

> *"While the term "overdose" was never used, it still was something that was understood as an "option" that the patient would have if they felt it was necessary." (Volker, 2001, p. 45)*

Open discussions regarding the intention to hasten death are primarily found in the assisted dying literature, and the legalisation of assisted dying is noted to reduce feelings of powerlessness among nurses. Overall, this theme highlights the complexity that nurses report navigating care that may hasten death, and how they feel compelled, despite uncertainty, to convey a narrative that interventions carried out as part of routine palliative care do not hasten death.

3.6 Discussion

The findings presented in this synthesis build upon earlier reviews, which have considered these interventions individually. These reviews describe the emotional impact on nurses, including the tensions of navigating family and doctor interactions (Vanderspank-Wright et al., 2018) and the need to regulate emotions to deliver care (Engström et al., 2006). This review also adds to the wide and often contradictory findings reported when healthcare professionals are overtly asked about attitudes towards, and experiences within, assisted dying (Blaschke et al., 2019; Hol et al., 2022; Willmott et al., 2021; Woods & Rook, 2022). Synthesis across acts of care that may, or intends to, hasten death has highlighted new parallels in experience for nurses. Emotional labour is intensified by the tensions created by nurses' uncertainty about their role in hastening death. Perhaps most significant is the recognition that supporting intentionally hastened death does not create unique challenges for nurses compared to acts typically provided within established palliative care. The synthesis appears to suggest the opposite. The normalisation of dying within other acts that may hasten death also normalises the high levels of emotional labour needed to provide care. This challenges a narrative that, for nurses, involvement in assisted dying may feel distinct from involvement in established palliative care practices.

To address the review question, the data is understood through the lens of ethics of care, which is explored in more detail in Chapter Four. Within the review, nurses' experiences are created through engagement with patients' lives, the embodied physical and emotional spaces in which nurses operate, and the individuals with whom they spend time during care delivery (Bergum, 2004; Elmore et al., 2018; Gallagher et al., 2015; Vanderspank-Wright et al., 2018). Within the assisted dying literature, the predominant relationship for nurses was between them and the patient, to optimise the experience for the person dying (Denier et al., 2010a; Pesut et al., 2021). Whereas for other acts that may hasten death, nurses consider those with the patient as most important, focussing on optimising the relatives' experience of dying (Efstathiou & Walker, 2014; Halcomb et al., 2004; Taylor et al., 2020). This difference may be influenced by the patient's ability to participate in care decisions. In other acts that may hasten death, patients are more likely to be semi-comatosed or in a medically induced coma; therefore, conversations will be focused on those at the bedside. The intention for the nurses is to support families in creating a positive lasting impression of dying (Kentish-Barnes & Meddick-Dyson, 2023; Neville et al., 2023) and linked to the provision of an ‘aesthetic’ death. However, this seemingly engenders the performative language and actions identified in the review, where the intention to communicate complex ethical decision-making is undertaken in ways to avoid misinterpretation.

The ‘spaciotemporal and bodily proximity’ of nurses to patients can make them uniquely placed to understand patients needs (Elmore et al., 2018; Sekse et al., 2018), which nurses also reported within the review. However, ‘institutional space’ is required to support their involvement in decision-making (Nortvedt et al., 2011). ‘Institutional space’, in this context, refers to a philosophical space that supports nurses in utilising their skills and acknowledges the unique roles different healthcare professionals play in providing holistic care. Within assisted dying, nurses appear to be afforded ‘institutional space’, perceiving themselves as taking a more proactive role in leading care (Elmore et al., 2018; Wilson et al., 2020). As such, feelings of disempowerment were not commonly reported. ‘Institutional space’ here provides a supportive culture that actively advocates for nurses to influence the structures in which they work, reflective of their clinical experience (Mills et al., 2020; Thacker, 2008). More commonly, nurses involved in acts that potentially hasten death, reference a lack of agency in care and a culture of ‘getting on with it’ (Halcomb et al., 2004), adding to the emotional labour required. It is also important to recognise that formal practical and emotional support for nurses reported as embedded within assisted dying services is not reflected across other interventions that may hasten death.

Nurses ‘proximity’ can also increase the emotional labour involved in providing care (Raus et al., 2014). Witnessing suffering is perceived as an expected aspect of the nurse’s role, which is required to be managed silently (Bruce & Beuthin, 2020). This links to a hegemonic and gendered expectation that nurses engage more in emotional labour compared to other healthcare professionals (Delgado et al., 2017). The parallels within emotional labour noted in the review occur as nurses routinely place more value on the well-being of others than their own. Whilst the expectation to regulate emotions can also explain a commonality of moral and emotional dissonance identified within the review, which appears distinct to nursing literature. Doctors, for example, have been shown to often lack social 'permission' to express emotions with colleagues when caring for critically ill patients due to the professional expectations of their role (Childers & Arnold, 2019) and tend to describe experiences centred on their own emotions rather than linked to patient experiences (Voorhees et al., 2014). As such, it is suggested that this form of emotional expression and subsequent emotional labour sits within a nursing space and the feminised expectations of the nursing role.

The concept of normal(ised) care identified within this synthesis has significance when considering the socio-political climate within palliative care, which may influence how nurses feel able to respond when patients wish to discuss assisted dying. Internationally, nurses do not currently see assisted dying as part of normal healthcare (Mathews et al., 2021). However, it is important to recognise that nurses view controlling the dying process, through the care they deliver, part of the routine care at the end of life. Yet, when patients seek to control the timing of their death, nurses struggle to see this as a standard part of care. The term normal(ised) acknowledges that care at the end of life is often highly medicalised and shaped by factors within healthcare control. As such, no death considered in this review is considered natural or normal dying; it must only be regarded as normal within institutional healthcare (Ashby, 2016). Nurses describe ownership to manipulate the care environment, undertaken in an attempt to (re)create a 'natural' or 'normal' death (Templeman, 2015), which is valued and seen as part of compassionate nursing care (Becker et al., 2017; Efstathiou & Ives, 2018; Gallagher et al., 2015). However, considering nurses' feelings of disempowerment in decision-making (Heradstveit et al., 2023), influencing the environment also offers nurses a means of control. The knowledge of providing this aesthetic death is seen as an opportunity to reduce the emotional labour required to provide care.

When acts that may be considered death hastening are subsumed into general nursing processes, the emotional labour involved in providing this care is not sufficiently acknowledged. Yet, this is inconsistent with the subsequent emotional impact reported by nurses and represents a significant tension highlighted in this review. As palliative care navigates local, national, and international paradigmatic shifts due to the increasing jurisdictions with assisted dying legislation, understanding the implications of delivering this care is essential. This review contributes a nursing perspective to this discussion, emphasising the significant parallels in the experiences of nurses across care that may hasten death, which may have previously been regarded as distinct.

3.7 Strengths and limitations of the review

This review is the first synthesis considering the experiences of nurses across acts that intentionally and potentially hasten death. As such, this review serves to amplify nurses' voices and, in some ways, attempts to address the subjugation of the value nurses bring to patient experience and outcomes, an aspect identified within the studies. The review takes a structured reflexive approach; therefore, offers one interpretation of the data. However, the use of a second reviewer throughout the iterative review process and the active engagement of the supervisory team add rigour to the review findings.

The review highlights the paucity of evidence relating to nurse experience, which may also limit its transferability. There is a lack of research relating to the withdrawal of life-sustaining treatment outside of the intensive care unit and sedation outside of the hospice setting. Despite the inclusion of voluntary stopping eating and drinking, there was no evidence considering nurses' experience in this area. A focus on these acts outside of 'traditional' settings would aid the development of a richer evidence base reflective of the places and people that deliver this care. This review must also be seen within its social context. The review can only present a Western-centric view of this topic, considering the geographical spread of the research, the diversity of participants, and the role of nurses in these locations. This is a significant area for future development.

3.8 Conclusion

Synthesising experience across acts that intentionally or potentially hasten death highlights parallels between experiences previously regarded as distinct. Nurses grapple with the complexities of understanding their roles and positions within the broader team when providing care that may intentionally or potentially hasten death. Uncertainty relating to whether interventions may hasten death is compounded by the expectation to challenge the narrative that palliative care does not hasten death. Overall, this lack of agency in care delivery increases the emotional labour involved in providing care. The review also highlights the impact of witnessing iatrogenic suffering and the realisation that neither physical nor emotional time is dedicated to supporting nurses within normal(ised) care. The potential implications for nurse wellbeing and whether this culture affects how they feel able to respond to patients wishing to discuss assisted dying should be considered. From a nurse’s perspective, there may be more commonalities in the experience of providing care in these contexts than previously recognised.

Chapter 4: Methodology

4.0 Introduction

In this chapter, I present the methodological considerations that underpin the empirical research undertaken. This study has been conducted to explore how nurses, who work in specialist palliative care in the UK, may respond to patients who wish to discuss assisted dying with them. Specifically, in this chapter, I outline how the research design has been developed to illuminate the underpinning ethical considerations that may influence nurses’ responses within these conversations. I will also outline the consideration that has been given to the ontological and epistemological underpinnings of this research, as well as the justification for the utilisation of a feminist approach to address the research objectives.

4.1 Aim of the study

The aim of the study is to explore how nurses, who work in specialist palliative care, respond to patients who wish to discuss hastening their death through assisted dying.

4.2 Objectives

The objectives of the study are:

- To understand how nurses within specialist palliative care may respond to a patient when they wish to discuss seeking an assisted death.
- To understand the aspects that may influence and impact upon the nurses’ reactions and responses to these discussions.
- To conceptualise nurses’ process of ethical decision-making when a patient requests support in seeking an assisted death.

4.3 Research philosophy

Methodologically congruent and coherent research findings must be supported by appropriate epistemological and ontological considerations (Bryman, 2016; Hesse-Biber, 2014). This research was motivated by my experience as a palliative care nurse; therefore, the methodology must also align with my own philosophical beliefs about the nature of reality, ontology, and knowledge creation, epistemology. The research objectives, which consider aspects that may influence how nurses can respond to requests to discuss assisted dying, suggest a reality that is not ‘fixed’, but rather one that is created through people’s active engagement and relationships with the world. The view that reality is not fixed, reflective of my worldview and ontological position, reflects a relativistic ontology. As such, the research exists within a social constructionist paradigm.

Social construction suggests that ‘reality’ is created and maintained through people’s interactions with the world. Knowledge and meaning-making are, in essence, social endeavours situated within individual interactions with, and understanding of, the social world within societal and cultural contexts (Crotty, 1998). Social construction also pays particular attention to the role of discourse between individuals in shaping understanding (Burr, 2015), drawing on the work of Wittgenstein, who considered that the use of language and shared meanings are governed by social practices. This also recognises that individuals will construct reality through their experiences, shaping and constraining discourse within social situations.

4.3.1 The feminist epistemology of standpoint theory

Epistemology examines the ways in which knowledge can be developed and how we can ‘know’ reality. Essentially, it questions whether there is a reality that is observable and measurable or one that is fluid and understood through an individual's interpretation of experience (Crotty, 1998). This study is based on feminist epistemology, which regards knowledge as created through engagement with individuals’ subjectivities. Knowledge, in this context, is also inherently political, with the acquisition and retention of knowledge by groups or individuals in power reinforcing and potentially intensifying their influence (Hesse-Biber, 2014). The study specifically adopts the feminist epistemology of standpoint theory, also referred to within the literature as standpoint epistemology. Standpoint theory claims that epistemic advantages are gained through the understanding of existing power structures and how this results in the subjugation of certain groups within capitalist and patriarchal societies (Haraway, 1988; Harding & Hintikka, 2003; Intemann, 2018; Risjord, 2010). Standpoint theory highlights how knowledge from specific groups is prioritised, while communities become marginalised due to the (dis)regard given to their knowledge, leading to their voices being further silenced (Hesse-Biber, 2014; Wylie, 2003). Moreover, and importantly in the context of the methodology, this recognises that individuals' situated knowledge allows them to understand oppressions that others, who are unaffected, may fail to recognise (Haraway, 1988). As a result, this awareness of oppression can provide epistemic privileges and promote a broader worldview (Hesse-Biber, 2014). Healthcare, and by extension nursing, remains deeply embedded in hierarchical and bureaucratic structures (Liaschenko & Peter, 2016) and individuals require an understanding of their own subjugation to be able to address it. Acknowledging these oppressions aims to elevate and amplify the voices of marginalised groups.

While standpoint theory has been critiqued for solely considering women's embodied knowledge, a gender essentialist view, I will be applying an understanding of standpoint theory based on 'second wave' theorists, including Donna Haraway (Haraway, 1988) and Sandra Harding (Harding, 1991, 2018). This recognises the intersecting influences that can affect experiences dependent on aspects such as gender, class, race, professional standing, and other identities that may be impacted by social power (Scully, 2016). For nurses, in this context, feminised perceptions of their role influence their position within the healthcare system and are subjugated by the dominant force of the historical perceptions of nursing as a female role and its existence within a medical hierarchy. These have persisted over time despite the inherent changes in the nature of the nurse/doctor relationship, the increased academic focus of nursing, and shifts in the demographic proportions of males and females in these positions (Ferguson & Anderson, 2021; Stein et al., 1990; Treinen et al., 2022). Within this thesis, specific focus will be given to the systemic structural causes of oppression that can establish the boundaries within which nurses consider that conversations about assisted dying should occur (when this is an illegal act).

4.3.2 Using Reflexive Thematic Analysis

The social constructionist paradigm of the research indicates that a qualitative approach is required to address the study's objectives of understanding and conceptualising the processes nurses undertake when engaging in complex ethical decision-making. The qualitative methodology of inductive Reflexive Thematic Analysis was used to enable this exploration (Braun & Clarke, 2006, 2019, 2021a, 2021b, 2023b). Braun and Clarke suggest that Reflexive Thematic Analysis serves as a methodology when transparent and congruous epistemological and ontological considerations, as well as theoretically informed findings, are rooted within the study (Braun & Clarke, 2020, 2021a, 2021b). Importantly, findings do not merely exist within the data to be 'discovered'. Instead, they are constructed through the researcher's meaningful and active engagement, adopting an 'artfully interpretative approach' that embraces the researcher's subjectivities and acknowledges their influence on the data (Braun & Clarke, 2020, 2021a, 2021b, 2023b, 2024b). In Reflexive Thematic Analysis, the analysis goes beyond the initial data and aims to weave a conceptually rich narrative within the findings. The inductive approach to analysis signifies that the data guides the development of findings, with no preconceptions about what may be developed (Braun & Clarke, 2013, 2014, 2020). Yet, this is only possible through active reflexive engagement by the researcher with their experience and subjectivities.

My identity as an intersectional feminist means that I hold a core belief in identifying the impact of different elements of identity, such as gender, class, and race, in shaping my lived experience. Fundamentally, this also means acknowledging where privileges exist within my identity and how they impact on my engagement with the world. Thus, the study's epistemological and ontological foundations align with my personal and professional worldview, providing methodological coherence to the research. The study is rooted in several of my core beliefs, chiefly that nurses are underrepresented in the existing empirical work conducted within this topic. Whilst other methodologies were considered, mainly Grounded Theory and Interpretative Phenomenological Analysis, these did not offer the ability to apply my situated knowledge within the research, based on the identified parallels stated.

Reporting guidelines for Reflexive Thematic Analysis are designed to ensure quality within the research process. However, an analysis of its application in palliative care shows that many practices labelled as Reflexive Thematic Analysis often fail to meet the required methodological standards (Braun & Clarke, 2023a, 2024a, 2024b). This gap arises mainly because previous reporting guidelines overlooked the philosophical and methodological aspects central to this methodology. The Reflexive Thematic Analysis Reporting Guidelines (RTARG) were created to rectify this issue and have been applied in the study design and reporting.

4.3.3 Theoretical lens and assumptions

The reflexive nature of the methodology means that the guiding assumptions within the research design, data, and analysis must be led by my worldview and congruous with the feminist epistemological lens. As such, alongside this feminist lens, data were analysed through the theoretical lens of ethics of care in order to develop a richer ethical understanding. Ethics of care is a feminist perspective that explores ethical issues by emphasising reasoning and decision-making centred on one's relationships with others, aiming to offer care and support. In this context, decision-making is viewed through an individual's interdependencies with others and their responsibility towards them based on their relationships (Nortvedt et al., 2011; Scully, 2016). As such, it is a relational ontology, which is fundamentally socially constructed. Using standpoint theory and ethics of care together relates both my ethical (ethics of care) and moral (standpoint theory) worldviews.

Ethical decision-making has been normatively regarded as rule-based (Scully, 2016). In contrast, ethics of care reflects that decision-making exists through relational engagement with other moral agents and pays attention to individuals' responsibilities to one another, along with the systems within which they operate (Tronto, 1998). This comprises four key elements: *attentiveness* to notice the needs of others, *responsibility* to provide care, *competence* to deliver the necessary care, and *responsiveness* to patients' needs (Tronto, 1993). An ethics of care is posited as closely related to nursing practice due to the interdependencies of care work that shape how nurses view their professional identity (Herring, 2019; Kittay, 2011), and is increasingly cited within both palliative care and the broader nursing literature (Bertaud et al., 2025; Butchart et al., 2023; De Panfilis et al., 2019; Haahr et al., 2020; Krajnc et al.; Woods, 2011; Yıldız, 2019). The relational aspect of ethics of care is also congruent with holistic assessment, which considers the physical, psychological, social and spiritual elements important to the patient, and is one of the fundamental principles within palliative care (Wright et al., 2021). Inductively viewing the data through the feminist lens of ethics of care, aims to facilitate a deeper understanding of the impact of the relational aspects that may influence ethical decision-making. Figure 2 outlines how the philosophical foundations of the study interrelate to create a methodologically sound approach to understanding ethical decision-making for nurses when patients wish to discuss assisted dying.

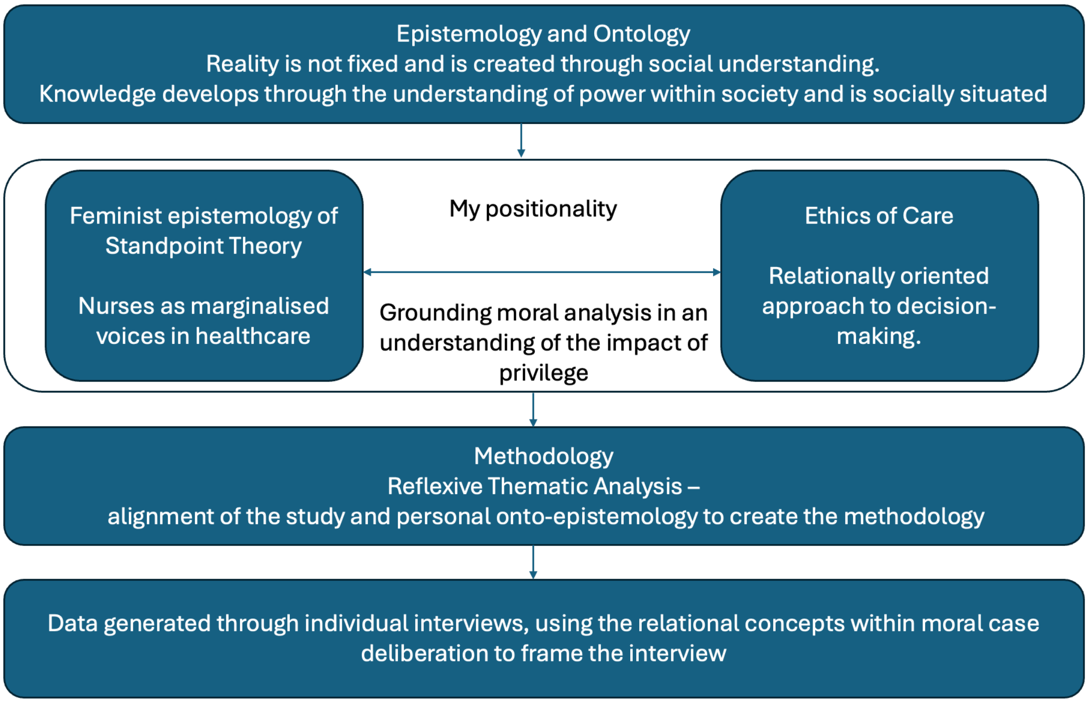


Figure 2: Methodological considerations

4.4 Recruitment and participants

The study focuses on registered nurses working within specialist palliative care in the UK when patients wish to discuss assisted dying. I initially felt that direct recruitment through the National Health Service and third-sector organisations might limit the response, due to my concerns that people may not wish to discuss assisted dying in the context of palliative care. I also wanted nurses to feel free to participate in the study without their organisation's involvement to reduce the potential of a 'corporate' response. Recruiting through social media has been suggested as a way to reach groups where recruitment challenges are anticipated (Topolovec-Vranic & Natarajan, 2016; Whitaker et al., 2017). Initially, participants were recruited through an account, @ADResearch22, on the social media platform X (formerly Twitter). Information on this account directed people to a study webpage (https://wp.lancs.ac.uk/assistancetodie), where they could express interest in participating via an email link. I then contacted potential participants directly through my Lancaster University email account, including a Participant Information Sheet (see Appendix 4) and a request to identify a suitable time for an interview. The initial recruitment strategy elicited only five responses. Due to limited engagement, I sought further ethical approval to alter the recruitment to directly approach professional contacts and those available through public-facing palliative care registries via email, which proved successful to complete recruitment.

4.4.1 Sampling and sample size

The sampling strategy employed a combination of purposive and snowball sampling. To gain an understanding of how nurses may respond to requests for assisted dying, I aimed to interview nurses working across the four nations of the UK. Participants were selected to represent a range of clinical roles across specialist palliative care settings, including community, hospital, and hospice. In addition, purposive sampling was employed to ensure the inclusion of participants with diverse perspectives on assisted dying. Given the ethical and moral nature of the topic, and the aim of conceptualising ethical decision-making, the deliberate inclusion of a range of views on assisted dying was fundamental to obtaining conceptually rich data. Participant eligibility was determined based on the inclusion and exclusion criteria outlined in Table 6. Establishing the sample size *a priori* is challenging due to the iterative nature of the methodology (Hennink et al., 2017). However, approval was sought to interview between 15 and 20 participants, informed by a review of studies with similar designs (Byrne, 2022; Clarke & Smith, 2015; Hanna et al., 2021; Hayfield et al., 2014). Thematic analysis has sometimes relied on the concept of saturation to determine sample size; however, this notion has been recently challenged in Reflexive Thematic Analysis (Braun & Clarke, 2021c). Braun and Clarke argue that data is generated through an interactive process between participants and researchers, suggesting that true data saturation is unattainable, as engagement will continuously yield new insights.

To address the research objectives, the sample size was determined during the data generation phase based on the concept of information power (Malterud et al., 2016). The potential ‘power’ of the information being primarily based on the methodological and philosophical approaches of the study, which indicate when sufficient conceptually dense data is generated in order to provide rich interpretation (Malterud et al., 2016; Nelson, 2017). The ‘power’ of the data to address the research objectives was considered, reflexively, throughout the data generation period. Data generation ceased when I felt the data were sufficiently rich, with no significant new insights from participants. This was facilitated by self-transcribing the interviews immediately after they were conducted, as well as by concurrent data collection and analysis, and regular reflexive discussion with the supervisory team.

Table 6: Participant inclusion and exclusion criteria

Inclusion	Exclusion
Registered Nurses	Registered Nursing Associates
Employed within a current role within a specialist palliative care organisation/team	Registered Nurses not currently working in a specialist palliative care organisation/team
Working within the United Kingdom	Not active on the NMC register
	Role does not involve patient contact

4.4.2 Consent process

Informed consent is a fundamental element of a safe and just research process. Participants should have sufficient, transparent information to make an informed decision about their involvement in the study, not feel under duress to consent, and have the capacity to consent and communicate the agreement (Iphofen, 2020). Capacity to consent and the ability for participants to communicate their agreement were presumed based upon the participants’ requiring active NMC registration to meet the recruitment criteria. Participants were sent a consent form with the Participant Information Sheet, which outlined the interview process and how participants could contact me with any questions about the topic before the interview (see Appendices 4 and 5).

The potential for duress was considered throughout the recruitment strategy. Interest from potential participants was followed up on one occasion if they had not responded within two weeks after the initial expression of interest. No further follow-up to arrange an interview was undertaken if they did not respond to this second contact. Participants were asked to return the consent form via email prior to the interview date. A reminder was sent the day before the interview if they had not sent the consent form back, and consent was reconfirmed verbally immediately prior to the interview. Consent forms were stored on the University's Microsoft OneDrive® in accordance with the ethical approval. Participants were able to withdraw their data up to 14 days after the interview; this information was contained in the consent form and reiterated prior to the interview.

4.5 Dataset generation processes

Data were generated through individual semi-structured interviews, which is recognised as an effective means of exploring topics where co-creating understanding is required (Bryman, 2016). Given the perceived relational influences of power and relationships, and the potentially sensitive nature of the topic, individual interviews were preferred over focus groups to enhance openness (Kaplowitz, 2000; Kruger et al., 2019). Interviews were conducted online via Microsoft Teams®, an increasingly popular platform for conducting face-to-face interviews. Videoconferencing was chosen to enhance participant accessibility and flexibility of involvement outside regular working hours, if needed, and is a familiar tool among healthcare professionals (Foley, 2021; Lo Iacono et al., 2016; Saarijärvi & Bratt, 2021). Field notes were taken during the interviews, and a reflective journal was completed after each interview, which was utilised to examine the findings throughout the analysis phase. The interviews were recorded on Microsoft Teams® and securely stored on Lancaster University OneDrive® to meet organisational security standards.

The initial interviews took place in a private pod at a local library, as I anticipated that the neutral setting would be advantageous. However, after reflecting on the first three interviews, I realised that, in this environment, I was treating each interview as an isolated task within the research process and felt disconnected from the wider research context. The following interviews were conducted in my home office, which led me to feel more submerged in the data and to take a more reflexive approach and, consequently, to generate richer field notes that integrated the interview data with insights from other discussions.

4.5.1 Development of a clinical vignette and interview guide

To facilitate discussion during the interview, I developed an interview guide based on a clinical vignette, which aimed to give clinical authenticity to the discussion. The vignette presents a hypothetical case of a patient who wishes to explore the possibility of an assisted death with the nurse (see Appendix 6). Braun and Clarke (2013) espouse the use of story completion methods to discuss and understand the social meanings that participants draw upon to construct their reality. However, they also highlight that these are not useful when participants are asked for their personal views on the situation, which is required to address the research objectives. Braun and Clarke (2013) suggest that, in these cases, vignettes can be successfully used to explore participants' considerations in these cases. Vignettes have also used in similar ways across both qualitative and quantitative studies relating to decision making and perceptions of assisted dying (Isaac et al., 2024; Philippkowski et al., 2021; Reader et al., 2021; Samuriwo et al., 2020; Singer et al., 2023). The authenticity of a vignette is key to participants' engagement; to support this the vignette was co-created with two clinical nurse specialists currently practising in specialist palliative care. I held a face-to-face meeting to discuss aspects highlighted in the literature as important for making the case realistic, including age, gender, disease status, and social situation (Colombo & Dalla-Zuanna, 2024; Gamondi et al., 2018; Lavoie et al., 2016; Roest et al., 2019). The vignette was developed based on their observations and then shared with the nurses for sense-checking and agreement before the pilot interviews. The nurses felt, in their clinical experience, that conversations exploring assisted dying were more common with male patients; however, it was agreed that a gender-neutral vignette would facilitate broader discussions regarding a range of factors that may influence nurses.

Public engagement events were organised to support the development of the vignette, recruitment materials, and interview guide. These took place before the pilot interviews. and involved five members of a patient and public involvement group within my employing organisation. Two events were arranged to enable all members to attend who had expressed an interest in being involved. Key elements of the discussion focused on their experiences of having challenging conversations with healthcare professionals and the aspects they considered necessary in this context. The groups also broadly discussed the topics of hastened death, assisted dying, and palliative care, which was valuable for understanding and providing feedback on the research aim and objectives, and recruitment materials.

An interview guide was developed to provide structure to the interviews, whilst also allowing flexibility in crafting lines of enquiry to support the iterative nature of the methodology. It has been suggested that nurses can present their emotional positioning regarding assisted dying before critically engaging in ethical reasoning surrounding the topic (Spronk et al., 2021; Thulesius et al., 2013). Therefore, to address the research objectives, the interview guide required an appropriate structure that could effectively elucidate moral and ethical concerns. Moral case deliberation has been utilised within healthcare settings in European countries, most notably the Netherlands, Norway, and Sweden, to explore care provision in morally challenging clinical cases, aiming to facilitate meaning-making through critical engagement (Abma et al., 2009; Dauwerse et al., 2014; Steinkamp & Gordijn, 2003; Weidema et al., 2013). Although moral case deliberation is frequently employed in clinical practice, its application as a research method remains limited. However, Pozsgai et al. (2025) have recently used moral case deliberation within an international study, including participants in the UK, that considered challenging communication with patients and relatives regarding palliative sedation. This study also identified how moral case deliberation facilitated a deeper understanding of the distinctions between moral and ethical decision-making within a research setting.

Moral case deliberation recognises that solutions to ethical problems cannot always be reached, which is often seen as the default approach among healthcare professionals (De Snoo-Trimp et al., 2020; Jellema et al., 2017; Weidema et al., 2013). Within the study, I applied the underlying principles and concepts of moral case deliberation to design the interview guide for individual interviews, specifically the Nijmegen method, as outlined by Steinkamp and Gordijn (2003). Five assumptions form the basis of this method:

1. Ethical questions are entwined within the interdisciplinary team
2. Moral problems are institutional
3. Consensus will be required for a functional team
4. A clear moral question needs to be posed at the start of the session
5. Facilitation is required

Using these principles to provide a structure for the interview guide helped me to draw out ethical considerations in the case (see Appendix 7). While this framework provides a structure for group discussions, the underpinning principles and assumptions within this model align with the study's feminist epistemological stance, considering the individual and organisational relational factors that may impact on decision-making in ethically challenging situations. To fully utilise the principles of moral case deliberation during individual interviews, a solid understanding of bioethics and the clinical case is necessary to facilitate the discussion and act as a ‘dissenting voice’ and challenge the participants, as outlined in point five of the Nijmegen method (Heidenreich et al., 2017; Jellema et al., 2017). I was able to utilise my knowledge of potential bioethical considerations, acquired through the completion of a master's degree in medical ethics and my clinical experience, in my role as an interviewer. Consequently, effective facilitation strategies must be considered when applying these principles to other researchers. Two pilot interviews were conducted to evaluate the interview guide and to refine my interview skills as a novice researcher. Although the interview guide remained unchanged following the pilot, I have reflected in section 4.8 on how this process contributed to the development of the interviews.

4.6 Data analysis

Analysis was undertaken using Braun and Clarke (2022) Reflexive Thematic Analysis six stages of analysis. These are:

1. Familiarising yourself with the data set
2. Coding

3. Generating initial themes
4. Developing and reviewing themes
5. Refining, defining and naming themes
6. Writing up

Initial data familiarisation occurred through the transcription of the interviews. Consequently, superficial analysis began on the first day of data gathering. Initial coding was conducted in NVivo® to generate codes based on the participants' verbatim quotes. Subsequently, to identify shared patterns and meanings within the data, deeper analysis was performed using a combination of handwritten notes and PowerPoint mind maps (see Appendix 8 for an example of this process). This approach helped explore the underlying, latent meanings within the data and visualise the story conveyed through the themes. Consistent with Braun and Clarke (2022), analysis was not a linear process but an ongoing, iterative engagement with the data. For instance, the names for the themes (stage five of Braun and Clarke's process) were only fully identified during the writing-up stage (stage 6), when a coherent narrative within the data was developed.

4.7 Research ethics

Ethically sound research must ensure that participants and researchers are safeguarded throughout the research process, with freedom of choice, minimisation of risk, and that there is value in the study to justify the participants' involvement. Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHMREC) approved the research protocol in December 2021 (FHMREC21043). An updated protocol was submitted to amend the recruitment strategy, which received approval in October 2022. An ethically sound approach has been considered and addressed throughout the design and delivery of the study (aspects of consent have been addressed within section 4.4.2).

To ensure the confidentiality of the participants, in adherence to the principles of the General Data Protection Regulation (GDPR), personal data must be protected. The level of data collected within the study is classed as 'special categories of personal data', as it concerns personal and philosophical beliefs relating to the end of life. Data should be reasonable and limited to what is required within the project; therefore, only data required to inform the study were obtained. For each participant, email correspondence, work-related information and consent forms were saved in a file, with each participant allocated a number. Pseudonyms and anonymised interview transcripts were saved in a separate file, each with its number. As such, both documents would need to be accessed to match the transcript to the individual. Interviews were recorded using Microsoft Teams® and were uploaded to my University OneDrive® as soon as practically possible following the interview. Access to the recording was limited to me and will be deleted following completion of the PhD. As I self-transcribed the interviews, sharing the transcripts outside the supervisory team was not required.

Data is anonymised in line with Information Commissioner's Office guidelines. True anonymity of the participant is not possible in this form of research, due to researcher involvement (Roth & Unger, 2018). However, within this study it means that participants should not be identifiable within the data and was achieved through the use of pseudonyms. Using pseudonyms, rather than numbers, means that the use of quotes, and the findings overall, feel closer to individuals involved. Participants were given the opportunity to choose their own pseudonym, as Allen and Wiles (2016) posits potential meaning within pseudonyms may lead to further understanding of the individuals and as such allowing the choice is congruent with the philosophical underpinning of the research.

The interview is based on a hypothetical case, although it was anticipated that nurses may reflect on their own experiences. As participants are nurses working within specialist palliative care, it was perceived that they would mostly feel comfortable discussing care at the end of life and any ensuing ethical challenges. However, it was conceivable that reflecting on these types of cases could be challenging. Participants were able to stop, or withdraw from, the interview at any point. The Participant Information Sheet signposted to support organisations and was reiterated following the interview if required, as outlined within the interview guide. Due to the nature of the topic, there was also potential for disclosure of illegal practice, although the likelihood of this was perceived to be low. The

Participant Information Sheet stated that if information was disclosed that raised regulatory concerns about the nurse’s practice, this would, in the first instance, be discussed with my supervisory team immediately after the interview and might necessitate onward referral. The potential for this disclosure is included within the consent form.

Finally, ethically considerate research should also extend to the researcher within the process. The research involves individual face-to-face interviews, and although these are online, the Lancaster University lone worker policy remains valid, as this is relevant for both psychological and physical safety. The nature and impact of the interview schedule meant that debriefing opportunities were embedded within the supervision process. As a part-time PhD student, and given my other commitments, I aimed to schedule one interview per week whenever possible. This approach allowed time to complete the transcription and reflect on the interview before undertaking the subsequent one.

4.8 Quality assurance

Several steps were undertaken to ensure the quality of the study design and its subsequent findings, in line with Braun and Clarke (2022, p. 269) 15-point checklist for ‘good reflexive TA’. Aspects within the checklist have been alluded to throughout the chapter through methodological coherence, such as the verbatim self-transcription of interviews and an iterative and reflexive theme development process, which includes revisiting the dataset during theme development. However, primary steps were also taken to facilitate the quality of the data set. The clinical vignette was co-designed with experienced clinical nurse specialists. An exploratory approach was adopted with the nurses to ensure that the vignette reflected situations the nurses might encounter in practice, as although I have clinical experience in palliative care, I was working in a non-clinical role at the time the vignette was developed. Through this process, the vignette underwent significant evolution. The subsequent public engagement event, with volunteers from the University of Huddersfield Public Partnership Group, provided a deeper understanding of relational aspects to consider within the vignette and consequently enhanced the interview guide.

To further support the quality of the study and to develop research skills, the interview guide was tested through a pilot process. The first interview was conducted with a nurse I knew through professional contacts. After reflecting on this initial pilot, I was uncertain whether our professional relationship influenced the conversation and the ability to ask and answer questions related to illegal practices. Given the sensitive nature of the topic, it was also essential to develop my ability to explore nurses' thoughts on legislation and how permissive laws might affect their responses. Therefore, a second pilot was carried out with a nurse who met the inclusion criteria but whom I did not know. The addition of a line of enquiry related to how the nurses may respond to the patient if assisted dying were legal was added through the pilot process. Finally, quality was maintained through the use of field notes and ongoing reflection throughout the research process. Ongoing discussion and review with my supervisory team were crucial for developing a coherent story within the dataset, ensuring a methodologically consistent approach.

4.9 Reflexivity

The researcher's positionality and their role within the data, methodology, findings, and analysis is crucial for maintaining methodological coherence in Reflexive Thematic Analysis. Therefore, I must acknowledge the subjectivities that influence my analysis, making reflection an essential part of my research process. I also recognise that I am situated within the research and would currently meet the inclusion criteria to participate in the study. However as suggested within standpoint theory, this also places me in a unique position to understand the forces that influence nurses' decision-making when faced with complex ethical choices.

My research question stems from my experience as a Clinical Nurse Specialist in palliative care, prior to commencing my PhD. In particular, the experience of caring for people with terminal agitation and having seen patients require high doses of sedatives to manage these symptoms. The clinical debrief typically centred on the uncertainties of the use and effect of sedative medications in practice, and conversations about care that could hasten death and assisted dying frequently emerged. It was evident that this topic caused debate and anxiety within the team. Consequently, I was drawn towards understanding the complexities of perceptions of hastened death and parallels with assisted dying.

When I began my PhD journey, I was in an academic (non-clinical) role. This position shielded me from certain questions I thought may surface regarding researching assisted dying while in clinical practice, particularly concerning the trust patients and staff place in me as a palliative care nurse. In 2023, I returned to clinical practice as the Lead Nurse for palliative care within an acute hospital NHS Trust. This occurred after the data-gathering phase and after undertaking some preliminary analysis. Allowing myself a period of intercalation to acclimatise to this new role offered me time to reflect on how my role may affect my approach to addressing the subject of assisted dying alongside my clinical responsibilities, have influenced my data analysis. Indeed, I felt the shift in roles deepened my connection to the research and reignited my drive to investigate questions related to hastening death and assisted dying. Working in an acute trust meant I was more frequently involved in withdrawal of treatment decisions and responsible for supporting team members to navigate these experiences. This helped with the ‘sense-making’ process during the iterative analysis phase. The experience of working in both community and acute care also illuminated a new understanding within the data, including the recognition of the importance of the care location on how nurses may respond. However, I sought to interrogate and verify this understanding by revisiting the data after the initial coding and development of provisional themes.

4.10 Conclusion

The research design adopts a feminist epistemology and a constructionist ontology. Using feminist epistemology specifically aids in understanding the relational factors that influence decision-making. This approach aligns with my worldview and supports a congruous, theoretically rooted Reflective Thematic Analysis methodology. Additionally, applying the ethics of care as an analytical lens to explore ethical decision-making complements the feminist philosophy guiding this study. In the following chapter, I present findings from the primary chapter, and in the subsequent chapter explore these findings within the current evidence base.

Chapter Five: Findings

5.0 Introduction

In this chapter, I present the empirical research findings aimed at understanding how nurses respond to patients' requests to discuss assisted dying. In the subsequent chapter, these findings are discussed in the context of the study's theoretical lens and existing research, and recommendations for practice are made.

5.1 Participant demographics

Within the study, 15 nurses who worked in specialist palliative care in the UK were interviewed. The nurses overall represented a senior workforce, with experience ranging from 5 to 40 years as registered nurses, with a mean average of 23 years, and a range of 1 to 19 years working in specialist palliative care. Interviewees were from England (n = 13) and Scotland (n = 2) and primarily worked, or had worked, in clinical nurse specialist roles. Two participants were male, and the rest were female. Participants were asked their stance on assisted dying, to inform the analysis, which was something some nurses found challenging to identify in binary terms, a challenge also identified in the literature (Rutherford et al., 2021a). Therefore, I felt it was important to allow a more nuanced understanding of the nurse's position, consistent with the methodology, and for these participants to use their own descriptors, if needed. The majority of nurses expressed that they held an overall supportive or neutral stance on legalised assisted dying, with two nurses opposing a change in the law.

Although the interview structure asked the nurses to consider their response to the patient in the vignette, all the nurses interviewed reflected on prior experiences when relatives wished to discuss the nurse's role in hastening death. The considerations for nurses when the request came from family differed from those when the request came from a patient. Nurses spoke about these scenarios empathetically and felt they understood the reasons behind the requests. While these were clearly frequent and important scenarios for the nurses interviewed, they fall outside the scope of the research objectives, which focuses on patient requests.

5.2 Theme development

The interviews were analysed inductively following the process identified by Braun and Clarke, as outlined in Chapter Four. Initial data orientation and code generation resulted in the development of 316 individual codes, which were subsequently merged into 37 broad themes. Through continued engagement and reorientation to the data, achieved through intensive relistening of the interviews, the data were disassembled and reassembled to gain a deeper understanding of the interactions between the themes (examples of the analysis process are contained in Appendix 8).

Three themes were developed around an overarching theme for nurses of *providing patients with solutions to remove the desire to die*. Although there are examples of nurses taking actions not focused on removing this desire, nurses viewed removing the desire to die as their primary consideration and integral to their role. This serves as an overarching theme for the nurses interviewed, as it is not a theme that operates in isolation but rather a thread that runs through all the considerations in this case. The three themes that influence how nurses engage with this unifying concept are:

1. *Using, (mis)interpreting, and (mis)representing the legal status of assisted dying to the patient.*
2. *The care setting influences how nurses can nurture relationships with patients and the wider team*
3. *Protecting the public's perceptions of palliative care.*

The themes serve as a structure that frames their responses within accepted boundaries.

5.3 Providing patients with solutions to remove the desire to die: ‘If we can alleviate that crisis in any way, you can really pick people up’

Nurses' reactions to a request to hasten death were largely shaped by a shared understanding that offering solutions to the patient to remove the patient’s desire to die is integral to the role of a nurse within palliative care. All nurses interviewed considered different ways of ‘fixing’ the patient’s desire to die. Nevertheless, the nature of these solutions varied based on what the nurse regarded as the most significant factor influencing the patient’s wish to die. To provide support to the patient, the nurses described an exploratory conversation with the intention of understanding the underlying reasons behind the patient’s request. Several nurses noted that the patient’s request for assistance to die was perceived primarily as a request to explore and optimise symptom management, even though this was not the direct question the patient in the vignette was asking.

> *“I see it very much as my role to try and make symptoms as manageable as possible, so straight away, I'm like….. I'm very much into, you know. ‘Ohh symptoms that's me, you know’.” (Monica, Community)*

Several nurses elaborated on this, suggesting that their role was to alleviate the patient's symptom burden and address the patient's desire to die.

> *“But sometimes people say those things because they're in crisis [due to symptom burden] and sometimes if we can alleviate that crisis in any way, which is what my current role can really do, you know, you can really pick people up and… and…. but they kind of change, you know.” (Cathy, Hospice)*
>
> *“Would he still feel the same if we managed, umm, those symptoms better? Because quite often that can happen, you know, that is the case and if you can manage the symptoms better people don't feel like that anymore.” (Deborah, Hospital)*

All nurses interviewed recognised that offering solutions may not eliminate the desire to die for every patient, particularly for those with uncertain prognoses, such as neurological diseases. However, the nurses could not view a patient’s desire to die as legitimate until they had explored the situation and offered what they considered could be solutions to the patient. Several nurses, who all supported assisted dying legislation, felt that a patient explicitly wishing to discuss assisted dying was a significant element of the conversation, which made the desire to die appear more legitimate.

> *"what they're asking for is, is euthanasia, isn't it, that's kind of….that's what makes it significant, it's not just a conversation around symptom control and things like that, it's, kind of, you know, it's actually somebody putting out there that they are considering euthanasia, which I think that's what makes it more real and more significant." (Helen, Community)*

Nurses who had objections towards assisted dying, expressed that requests for assistance to die were unlikely to persist as their interventions would resolve the desire to die.

> *"I've never had somebody who has actually remained, after exploring it, has remained with a 'I actually want an assisted death'." (Julia, Community)*

When nurses felt that, despite their interventions, the patient may still want to explore an assisted death, they described a shift in the focus of care: from symptom reduction to easing the burden of the patient's subsequent experience. Nurses do this by offering emotional or practical responses, whether the patient chooses to continue exploring assisted dying or not. Essentially, a different type of 'fixing' manifests across the nurses' care.

Finally, nurses reflected on aspects of hastened death that would not fall under the remit of assisted dying, which they may wish to discuss with the patient as a means to resolve the desire to die. Several nurses suggested that, while they could not support assisted dying in this scenario, they could endorse other (legal) care options that may either hasten a person's death or not prolong life, which could be offered within the remit of palliative care. This included advance decisions to refuse treatment and withdrawing interventions such as non-invasive ventilation.

> *"We were talking about his choices and to him that was a real revelation, and he said 'Oh yeah, but I would be panicky, I wouldn't be able to breathe' and I said 'well, that could be managed and these are choices that people have' [withdrawing non-invasive ventilation] and I said like, but something along the lines of 'In a situation where you have very few choices about*

> *what's going on to have that choice, umm, you may find that reassuring, you may find you may never choose to do that, but you may find that choice ultimately something that gives you a little bit of power back'." (Samuel, Hospice)*

Julia, who opposed assisted dying, also described a situation in which prolonging life by initiating interventions could be viewed positively as a means to allow the patient control at the end of life through withdrawing treatment at a time of their choosing.

> *"…and again, if they are doing the 'I would like to die' it's that little bit of 'well look, this is what end of life can look like and we can't help you die and we can't do that but what we can say is that we will do our utmost to make sure that your death is peaceful and dignified'. Um, and I have to say, this is interesting because the MND deaths I've been involved with have all been respiratory failure, which I hadn't realised until I started talking. So I am (pause) I can very confidently say that at the end of life for respiratory, this is what we do and these are the options, that we can bring you into the hospice, it can be planned, we can, you know, we can take off the non-invasive ventilation and ensure a peaceful death with sedation." (Julia, Community)*

The idea of eliminating the desire to die weaves through the various aspects that influence nurses' decision-making processes. The three themes presented below highlight the aspects that nurses then consider when responding to a patient seeking to discuss assisted dying.

5.4 Theme 1: Using, (mis)interpreting, and (mis)representing the legal status of assisted dying to the patient: "It's how much can you say or do without it being that you could be pulled up in front of court or something".

During the interviews, all nurses expressed that the legal status of assisted dying in the UK was the most important factor influencing, and often limiting, how they initially felt they should respond to the patient. Several nurses, regardless of their stance on assisted dying, stated that their first comments to the patient needed to clarify that the patient was asking for something outside the law. They reflected on their practice, recalling how they communicated the law to the patient and often conveyed this as a standard blanket statement.

> *“it's not something that's legal in the UK and I can't legally give you advice because it would be against my code of conduct and the law.” (Deborah, Hospital)*
>
> *“I think I'm wise enough and experienced enough for now to say ‘look I can’t assist you in any way in doing this (pause) if this is something you feel that strongly about doing and it's something that you will have to sort out, explore, find out about more’.” (Gemma, Hospital)*
>
> *“I hear myself saying it and what I do is I sort of, I start off with saying ‘well, we can't help you to die because it's not legal, it's not ethical’, and then once I've sort of …….in a nice way, obviously in a compassionate way.” (Monica, Community)*

A number of nurses reflected on why this felt important. They suggested that this makes their position transparent to the patient, allowing the patient to understand that any subsequent response would be bound within the law. The nurses reported this as a professional responsibility to meet their regulatory requirements. By stating ‘they would not break the law’, the nurse aimed to facilitate the sense that all subsequent actions could be viewed as patient-centered within that boundary. However, using the legal status of assisted dying as an initial response to the patient in the vignette also seems to provide the nurses with a form of protection.

> *“As a nurse, you are sort of trained because it is against the law in this country to be very resistant to this and I think your first reaction sometimes is ‘Oh my gosh, we can't talk about this because it's highly illegal’.” (Gemma, Hospital)*

As such this draws a metaphorical line under something that may make them feel professionally uncomfortable or, as I will discuss, something they do not entirely understand.

Following this, nurses used the legal status of assisted dying as a tool to direct the conversation to explore the reasons behind the patient’s request for assistance to die. However, moving the conversation quickly to symptom management had unforeseen consequences for the nurses. Several nurses discussed in the interviews how they felt they did not fully understand the legal status of assisted dying and the potential implications for practice, as they had not needed to explore this in-depth previously. The lack of engagement with the topic was surprising, given their assumed interest in the topic through their willingness to participate in the study. The nurses reflected that exploring the topic in the interview setting allowed them space to consider it in a way they had not had the opportunity to do previously.

> *"Well, I would certainly go and see what the law says about Dignitas and people travelling. I probably should have done it before now." (Tina, Community)*
>
> *"What you're discussing challenges me and in a way that I don't normally have to because of the legal position and the practicalities in this country." (Nicola, Hospital*)

As a consequence, several nurses discussed various examples of the assistance they would feel comfortable providing, including gathering information for the patient, offering direct advice, and supporting patients in planning travel to Dignitas. Some nurses stated that they could not assist with plans or be seen as encouraging the patient; however, there was a lack of clarity and conflicting views on what this might entail and where the limits may be.

> *"I don't know, do we have a legal obligation to report that [the patient may travel to Dignitas] or if somebody is classed as …someone sort of saying they're gonna kill themselves, you know. Is it, I don't know, I don't actually know. Is there a legal obligation for us to do anything about that?" (Cathy, Hospice)*

Other nurses confidently stated the law, but misinterpreted what would be permissible under the current legislation. This was despite the certainty they all presented to the patient about how they could support someone making this type of request. Notably, a number of nurses discussed actions they would feel comfortable undertaking that may fall outside the legal parameters in the United Kingdom, as summarised by Nicola.

> *"I know assisted dying is illegal, but I couldn't tell you 100% hands on heart that I know what assistance means. I mean I think if you were administering the medication, I think that's what it means, you know, you physically give them the medication, but actually taking somebody to the….. to the*

> *Eurostar I think it's probably OK. But giving them information I think is probably okay cause it's not. You know, I've wouldn't have a problem with that." (Nicola, Hospital)*

This is within the context of Nicola having experience caring for a patient who chose an assisted death.

> *"He had the facts, he knew more than we did about actually the ins and outs of getting over there." (Nicola, Hospital)*

This suggests a confusing legal picture leading to a lack of understanding of the law and also highlights a liminality between what the nurse may consider legal or moral actions.

The nurses interviewed suggested that, in addition to the law, they considered how they would navigate these conversations to ensure they worked within their professional frameworks. Consequently, they considered their actions carefully to ensure they were working within, and thus protected by, the Nursing and Midwifery Council (NMC) code (2018), their professional regulator.

> *"…..from a, you know, from a registration point of view from our professional guidance, we are not supposed to give, erm, an opinion (laughs) we're not….we're not supposed to express personal opinions to patients, so it would be…. it would be against our code of conduct to say to that patient, for example, 'yes, I agree, you should go to Dignitas and end your life'. You know that's not something that…… I wouldn't say that anyway, but it's not something we're allowed to say, that would be against our code of conduct." (Cathy, Hospice)*

Some nurses suggested that, as the patient wanted to discuss an illegal act, their response could risk their professional registration, commonly referred to as their 'PIN'. Working within the professional boundaries also appears to be a key driver for nurses to ensure the patient understood that what they were requesting was 'illegal' and may have direct implications for the nurse.

> *"It's how much can you say or do without it being that you could be pulled up in front of court or something." (Helen, Community)*

Daniel felt that this resulted in an unsatisfactory compromise between addressing the patient's needs and managing their own personal and professional risk.

> *"And I can only say 'at this point of time I don't wanna give you any advice regarding this because maybe there's options that we can explore here'. And that's not satisfactory at all because I think that's…where potentially the trust that you built with that person, it's gonna, umm, you know, disappear because they opened up for you…to you in a quite deep way and I feel like you can risk it and you know, lose your PIN." (Daniel, Hospital)*

At this point, nurses also considered whether they were in the best position to continue the conversation. Most nurses felt able to progress the discussion in some way, depending on their confidence and how they perceived the expectations within their role. Two nurses interviewed who worked in staff nurse roles suggested that they would ask more senior team members to take over the conversation at this juncture.

> *"I would have to refer to a member of the team who might have more expertise or more knowledge in it. You know, because I just wouldn't feel confident actually talking to them, saying, well, there's this, there's that X Y and Z, you know. So for me, I think it would be one of those conversations I would be saying to them 'I think you need to have, erm, I think I need to get a more senior member of my team to come'." (Jenny, Community)*

As such, decision-making in these cases would also transfer to a more senior nurse or doctor. Jenny also stated that she would seek the multidisciplinary team's advice before offering advice or support to the patient and would want a more senior member of staff to advance these conversations, discussing parallels with other end of life decisions.

> *"Obviously we've got our medical team as well, erm, who would be heavily involved and I think….I feel that in a situation where somebody was requesting assistance with suicide, this would actually ultimately go to consultants for, erm, guidance and input. So, it certainly would not be me leading on it (laughs). I think just because….. if we've got patients who've got advanced directives and things like that, it's always the consultants that deal with them so any of these particularly sensitive legal areas I think we would as a team say 'I think the medical team, the consultants from the Hospice need to really take the steer on this one…. take the guidance with this one'……I would, you know, at the end of the day also have a*

> *professional responsibility to maintaining my registration, which is why I'd always defer something like this to a more senior member of the team. I wouldn't deal with it on my own. Definitely wouldn't risk it, both for the patient and for myself."* (Jenny, *Community)*

Sandra, a hospice nurse with 40 years of nursing experience, also suggested that, despite her confidence in having these discussions, she would want to refer the discussion to the medical team.

> *"Erm, maybe because I've been around for a while and not (sigh)…....not.....I mean I would feel comfortable to sit and listen to anything anybody wants to say to me and discuss with me, you know what I mean. And like I said, I'm…..I might not have the answer to that question but then I would go and find somebody who did." (Sandra, Hospice)*

Delegating decision-making in this scenario to a more senior member of the team, whether a nurse or a doctor, reflects the nurses' belief that the response must be role-specific to ensure they operate within their scope of practice, rather than stemming from a lack of confidence in engaging in these discussions.

While nurses with more clinical experience in palliative care were generally more willing to discuss the topic with patients and offer them emotional and practical support, some nurses felt others may be less comfortable with this.

> *"I think I think with age and experience, you could believe there's less…..you're less judgmental (laughs). I think, like I think, yeah, yeah, definitely, I think I think you're more open to the bigger picture really and to…. as you've seen more and more experiences yourself in situations, umm, I think you're much more, I think I think when I was in my 20s, maybe I would have been horrified if somebody said that to me." (Cathy, Hospice)*

Monica and Julia, who described themselves as having an anti-assisted dying stance, suggested that discussing the request could be perceived as supportive of assisted dying. While Julia felt comfortable exploring the topic with the patient, Monica strongly believed that the extent of their role was to solely listen to the request.

> *"Erm, I would know not to advise them and say 'yes, I'd go and do that'. I think all we could do is listen." (Monica, Community)*

The Nursing and Midwifery Council (NMC) guidance states that nurses must adhere to the law; however, the stance of following the law appears moot when nurses do not fully understand the legal position regarding what constitutes assistance to die. Some nurses discussed an overall lack of guidance from the Nursing and Midwifery Council. Bea, in particular, expressed frustration at the level of support from the Nursing and Midwifery Council and believed that the regulator had a responsibility to provide more specific guidance for nurses.

> *"…..there is no real clear guidelines from the NMC. The NMC doesn't provide a stance on it, do they? They say that you should act in accordance with your professional code of conduct and act lawfully…..………I'm not saying they should say actually this is really wrong or this is really right, but actually, you know, as a… as a governing body you should have, I think you should have more of a stance on it and more direction for nurses, you know." (Bea, Hospital)*

Several nurses noted that this knowledge would enhance their flexibility and confidence during these discussions. Additionally, many nurses recommended that the Nursing and Midwifery Council provide specific guidance on this topic to support their practice. Despite the desire for guidance, none of the interviewed nurses were aware of the Royal College of Nursing's guidance for nurses regarding actions that may hasten death. Overall, they expressed that understanding the law could alleviate anxiety surrounding conversations with patients and their families.

A lack of understanding about the law led nurses to rely on what felt to them to be the 'right moral action'. They noted that planning to end one's life in the UK felt different from wishing to travel to Dignitas. If within the UK, nurses were more inclined to label this as suicide and more likely to discuss formal safeguarding procedures. Nurses referred to Dignitas as an assisted death, rather than suicide. Furthermore, they did not mention safeguarding concerns in the case of individuals planning to travel to Dignitas, and did not express concerns about the patient's capacity for decision-making in that context.

> *"Then that becomes a different issue [taking an overdose of medication provided by a healthcare professional in the UK] that's the safeguarding, that's a safeguarding for me and then I would go 'well actually, you know, I*

> *would need to manage that in a different way'…….. If they're talking about actually going to Switzerland for assisted dying then I could…I would be willing to explore that with them but if they're looking to, what I call commit suicide, with that medication I've prescribed, I think that raises different issues and then I'd be bringing in different people I'd be maybe referring to mental health team, maybe bringing in GP if they're at home. Certainly, at work I would be looking to maybe call the mental health team in to assess and support if I felt that that's what they needed." (Bea, Hospital)*

A number of nurses stated that travelling to Dignitas felt like a more legitimate option for patients, based on the consideration that assisted dying is legal in Switzerland. Some nurses, considering the potential implications for anyone who may need to assist in the travel process, reflected that family members may risk prosecution. However, overall, nurses viewed Dignitas as a more 'acceptable' option for patients and anyone who may assist them in this situation. A significant example of the nurse's misinterpretation or misunderstanding of the law.

> *"if someone, erm, someone helping them in Switzerland they're not gonna get, like, prosecuted, are they in Dignitas. But potentially someone could, you know, get sort of in trouble for helping in this country." (Monica, Community)*

Noting that the nurses' comfort in responding to patients was not solely based on their legal knowledge, rather influenced by a sense of what seemed morally and ethically permissible. Most nurses, however, blended the moral, ethical, and legal aspects of the case, often using legal frameworks to consider these three dimensions. Only one senior nurse addressed the potential to distinguish between ethical and legal matters. Nicola described how she had already engaged in some of the 'ethical gymnastics' due to her experience with a patient who underwent an assisted death at Dignitas, although it is important to note that she used ethical and moral interchangeable within the wider discussion.

> *"I think it is about that what I'm calling ethical gymnastics. I think you have to be able to work things out about where things sit and how you feel about it in order to……I do anyway, you know, I think about everything and need to feel comfortable with what I do and I'm……..I do think in nursing we need to become a bit better at that." (Nicola, Hospital)*

Nurses navigate a complex landscape in relation to discussing assisted dying, and feel bound by the legal status of assisted dying. This is both due to the requirements to adhere to the law and their adherence to their professional code. The consequence of the nurses' lack of understanding regarding the legal status of assisted dying however leads nurses to provide care that 'feels right' to them, which varies among the nurses interviewed. While nurses indicate that they cannot discuss assisted dying because of its legal status, they nevertheless feel comfortable exploring the patients' desire to die.

5.5 Theme 2: The care setting influences how nurses can nurture relationships with patients and the wider team: "*The power is with the person in the house, you know, because they're inviting you in"*

The services nurses work in can influence their ability to respond to patients wishing to discuss assisted dying. Nurses involved in the study operated across three main care settings within palliative care services in the UK: community, hospital, and hospice. The nurse's work environment, where the patient in the vignette received care, influenced how the nurse interpreted what they perceived as the essential aspects of these conversations. This observation is linked to two key factors: the type and longevity of the relationship nurses can build with the patient, which is dependent on how the service is structured, and the perceived acuity of the patient's symptoms.

> *"Hospital palliative care differs from community, nobody's….no one person is on my caseload. [In the hospital] I might go in and have a caseload one day and then that case load might be really different the second day and somebody else might be seeing the patients that I've seen the day before. So you know, it's not that Mr. Jones is on my caseload today so I'll see him again next week it doesn't work like that within hospital palliative care." (Bea, Hospital)*

Overall, nurses across various care settings and roles reflected that, regardless of their area of work, they believed they had more time and skills to engage in these types of conversations with patients than care teams providing generalist palliative care. Helen reflected on how she felt her role was unique in addressing this.

> *“I do think we're very privileged and that it is a very unique relationship, isn't it. So in terms of having conversations with patients….I’m not saying that doctors don't but, you know, because we do tend to have that ongoing input….. I think that…. I think we're just in a very good position to have those conversations with the patients.” (Helen, Community)*

All nurses working in the community described a sense of time to ‘sit with’ the conversation and an ability to easily revisit it if needed. The nurses' continued presence felt important for progressing and exploring the conversation with the patient.

> *“I think sometimes it's just still turning up and saying ‘hello, how's things?’ and listening and even if there's nothing that we can suggest to change or….. just to go, just to listen and be there and to know that someone's gonna stick around.” (Monica, Community)*

A number of nurses who worked in the community also described an almost corporeal process of ‘walking alongside patients’. They reflected that being invited into the patients' homes felt like an important aspect in their relationship, which facilitated trust and, in some way, levelled the perceived power dynamic within this relationship.

> *“I think in the home, you're kind of a guest in the home and, kind of, almost the power is with the person in the house, you know, because they're inviting you in and they maybe thought…. feel more free to be able to discuss things that they may not be able to discuss when they're in an inpatient unit.” (Samuel, Hospice)*

These nurses considered that if a patient wished to talk about assisted dying, their home felt like a ‘safe space’ for the patient, making the request seem well thought through and, therefore, more legitimate. Several nurses working in the community, reflecting on examples from their clinical practice, described how people commonly initiated these types of conversations as the nurse was leaving the house.

> *“So it was a doorstep conversation on my way out and I said, ‘listen, I'd like to come back and talk about this with the patient’.” (Samuel, Hospice [reflecting on his community experience])*
>
> *“if they mentioned it as I was about to walk out the door and I had to get to a next appointment then I might say ‘that's an interesting comment, would it be OK if we discuss this a bit more next time’ because I think that kind of thing needs the time and environment to talk about.” (Julia, Community)*

Nurses working in other settings did not discuss that patients might raise this topic with them in more covert ways. Patients gently introducing these conversations when the nurse is leaving may be a way to broach these subjects and gauge the nurse's reaction in a less ‘high stakes’ situation, assuming that the nurses would not immediately follow this up. This also provided the nurse with the opportunity to step away from the conversation and prepare for how to handle the situation.

Community nurses commented that knowing the patient for six months was pertinent to the case. Most of these nurses reflected on how their relationships with the patient and those important to them would have developed over time to build trust. Community nurses described a more enduring involvement with the patient throughout their disease process, which influenced how they felt able to respond.

> *“Because especially if the case we've known them six months and that's a really good, a really good basis for that discussion, because in this job, we don't know people six months, our length of time for patients two weeks, a month. In my previous job [community] I had known some palliative patients for years, so that is relevant to my previous experience……. if you've known someone a long time that you've… you've built up a relationship with them, a relationship of trust, you know. That they've made….they've maybe come to really trust you and really respect your opinion and vice versa. You know what sort of person they are….it's difficult sometimes to have those discussions with people when [the] relationship is very very transient.” (Cathy, Hospice)*

The need for time to build a relationship with the patient was not considered in the interviews with nurses working in the hospital setting. The nature of the service meant that they would see patients during an acute crisis and were less likely to have an established relationship with them.

> *"I work in a hospital setting, so I don't tend to see patients over a longer period of time, I tend to see them in short bursts, acute situations…or they're dying." (Nicola, Hospital)*

Nurses in the hospital setting reflected on the types of patients they might see as influencing their responses and recognised the challenges of quickly establishing a relationship with patients to provide effective support. The more acute nature of the presentation, alongside the potentially higher immediate symptom burden of the patients in the hospital and hospice, meant that nurses were more likely to question the legitimacy of the request. They suggested that the desire to die was more likely to be an acute response to their situation, their symptom burden, or caused by underlying mental ill health. The nurses also initially focused more on improving physical or psychological symptoms than those working in the community.

> *"If it's a quality of life issue is… are there things that we can do? What are your main symptoms at the moment? What are we doing for them? Is there anything we can do better? And I think the biggest question is if we manage them, would you still feel the same way? You know, I think that that's tends to be the question that I ask that makes a big difference." (Deborah, Hospital)*

While nurses working in the community wanted assurance that the request was not a reactive response to the situation, they mostly felt that discussions with the patient should focus on practical considerations relating to the patient's current and future plans.

Across all care settings, nurses felt that they should discuss the case at a formal multidisciplinary team meeting within their service. Most nurses interviewed were comfortable exploring the topic with the patient before discussing their assessment with the broader team. However, nurses described the input of the multidisciplinary team in these situations as having the potential to be both supportive and disempowering. Although the nurses' previous clinical experience and job role influenced engagement, the type of service they worked in primarily influenced what they considered to be the purpose of the multidisciplinary team discussion.

Nurses in hospital settings primarily discussed the multidisciplinary team helping identify other team members, such as clinical psychology, mental health teams, and chaplaincy, who might support the patient to manage psychological and spiritual distress. This aligns with the previous observation that hospital nurses were more likely to see the request as an acute response to the situation.

> *“if somebody's expressing suicidal ideology, then it's something that you have to act on and you would refer to…..for a* psych[iatrist] *assessment just for that team to assess the patient, to see if….. how much of a risk they are, if there's anything that can be done to help manage how they're feeling.” (Kelly, Hospital)*

Whereas nurses in community settings described their use of the multi-disciplinary team differently. Overall, they report greater autonomy in building relationships with patients in the community and utilised the wider team to seek (re)assurance that they had explored all aspects of care that could be provided.

> *“I think sometimes it is other viewpoints, so it's a wider discussion and it's making sure I haven't forgotten anything, it's making sure there isn't something that somebody sometimes people said ‘Well, have you thought about this?’ and you go ‘No, that never occurred to me’ so part of it is that making sure I've got all bases covered.” (Julia, Community)*

Nurses in the community were also less likely to be able to step away from the conversation and quickly revisit it, as hospital nurses would, by virtue of being in the same building as the patient. This was felt to be an important aspect in how nurses engaged with the wider team.

> *“if I'm concerned or I have worries, then actually I can just, I don't need to make a decision there and then I can, I can just say ‘actually I need to discuss this’ and I like that approach because actually what it means is that, actually I don't have all the answers.” (Bea, Hospital)*

The three nurses in the hospice setting all stated that conversations with patients were significantly less likely to occur in this environment, leading to their limited experience in understanding how the multidisciplinary team may support them. Contrary to the common belief that hospice services care for individuals with the most complex palliative care needs, it seems that healthcare professionals in this setting may not encounter these requests as frequently as in other care environments.

Finally, nurses' responses to the patient were influenced by their autonomy in developing relationships with patients and the opinions and positionality of other team members, including fellow nurses. Several nurses reported that their decision-making process could be affected by the need to navigate the views of other team members. However, many nurses felt it was essential not to share their thoughts on assisted dying with colleagues, regardless of what those thoughts may be, to ensure the team functioned effectively.

> *“Because you know, some people you don't know…….in work, you know, some people (pause) maybe don't want to say that they openly support something like assisted dying but it…. they might do personally, but I think it's because it's still so much to be explored that it's kind of, you know, you've gotta try and sometimes keep your thoughts a little bit…your cards a little bit close to your chest if that makes sense.” (Kelly, Hospital)*

Monica, an experienced community specialist nurse, described a conflicting relationship with her team. She felt that discussing the case with the team would provide her with reassurance but also raised concerns that she may be required to undertake actions she found disagreeable. Consequently, she was careful about how she presented the case.

> *“I mean, I think maybe you might start getting dictated [to] by managers, actually, in a way that you didn't want to do things. That would be.... that's a bit of a.....yeah, but I suppose then you've got to haven't you because we'd have to....you'd have to [then] put a case to say ‘well, actually I don't think that's the right thing’. That's the danger in sharing it isn't that you get sort of advice that you don't really want, but at the same time I think the instinct is to ‘oh got to share’……..I think this just sometimes….this, erm, this feeling of you've got to share anything a bit complicated for your own sort of protection. I mean it might be that I share things and then I'd get....I'd get opinions that I didn't like and then that would annoy me (laughs).” (Monica, Community)*

A number of nurses discussed how they felt that the medical team's perspective could overshadow the views of other professions within these discussions. In particular, clinical nurse specialists working in hospitals identified this as a practical outcome that was expected and accepted following the multidisciplinary meeting. Several nurses mentioned that they would consider the views of the multidisciplinary team, especially the doctors, during patient assessments, which would, in turn, influence their responses to the patient. When explored, these nurses appeared not to have questioned the expectation that they should represent the consultant or wider team’s opinion to the patient as their own. Gemma stated that the consultant may tell her how to respond, irrespective of the nurse’s opinion or clinical assessment.

> *“I think there is definitely, erm, yeah, a way you're expected to behave as a palliative care nurse and I think that is led by the* consultant*s, you know, is heavily influenced by the* consultant *you work under………I think amongst nurses and even within palliative care, you know it's, you know….you talk to my consultant, and she'll still give you a very strict, you know ‘Ohh, you've must say this, this and this’ ………..It becomes a bit like a family in palliative care and you do see them [the doctor] as a bit like a matriarchal figure, I suppose……I always think in any difficult situation I come across I think ‘what would my consultant think or do’ you know, and that and that's my way of thinking well, I'm doing it the right way (laughing) or not…. and it and it tends to work most of the time but it's….I suppose you could look at it as a bit of an interesting concept couldn’t you why we do that.” (Gemma, Hospital)*

Janet, who also had line management responsibilities, reflected that she sets expectations for the nurses in her team regarding how they might discuss this type of case. Janet set expectations with the intention of influencing the nurses' behaviour.

> *“I suppose as a manager, umm, I manage a number of teams and I would be really concerned if some of my staff were working out of the limits of their professional role. And I would be really concerned if they weren't involving the multidisciplinary team and the person’s GP and trying to speak with the family and patient openly.” (Janet, Community)*

However, being directed by, or directing, others within the conversation was not universal across the interviews. Helen, who had a clearer pro-assisted dying stance compared to some of the other interviewees, reflected that when considering the case study, she felt her role would be to protect the patient from the views of the multi-disciplinary team.

> *"I suppose in my mind it would be involving people so that….. to be an advocate for her and to then try and help in terms of bringing those discussions (pauses) even though she sounds like she's very capable woman and probably could do that herself. But I think it would be then to try and support her and taking it to the next level in terms of having those discussions with the…. with the medical side of things. Because I think she would probably would need them on board in terms of people then supporting her decision…. not necessarily to go to Dignitas because I don't think she'd ever get that with…. medically……….if this is what this woman was saying and wanting to do I would see that it would be a challenge and it would be, you know, I suppose putting it that there would be a battle ahead and I feel that that's where I'd say that for me it would be that I would see myself as being her advocate and pushing her…her view and her wishes for……actually I think the response…..you would anticipate there's gonna be a lot of push back on that. Whereas I'd say that's where I'd feel I'd have to find my voice to be able to push that through."* (Helen, Community)

Two nurses also provided examples from their own practice when they felt compelled to moderate their discussions with the medical team to meet the patient's needs. Nicola believed that her response was influenced by her experience with other members of the multi-disciplinary team reacting to a patient planning an assisted death in Dignitas. She expressed a sense of mistrust regarding the medical team's intentions, which affected the relationships among team members.

> *"I felt I had a duty at the time to give him all the information [about improving his symptom management to remove the desire to die] he needed. But the poor chap, everyone who came in day after day felt they had the same duty and responsibility and he probably heard it time and time again and it made-up his mind. I felt really sorry for him." (Nicola, Hospital)*

Due to this, although not directly voiced, there was a sense that nurses lacked the opportunity, outlet, and support to navigate these types of ethically or emotionally challenging situations within their roles. Helen also reflected on what she felt was an insufficient representation of nursing in the broader debate.

> *"I suppose people don't ask, do they, you know. Nobody's ever, apart from this here, and now nobody's ever asked us what our opinions are, we don't*

> *get invited to talk on the news when it comes up as a debate." (Helen, Community)*

During the interviews, four nurses discussed conversations with patients who had expressed a desire to die, recalling that they found the experience challenging and described how the research interview felt like an outlet for them. Their intonation and body language during the interview appeared to convey relief, with one of them asking for my opinion on their actions to seek reassurance. During the interviews, I felt that many nurses found it emotionally cathartic. The lack of an outlet for these discussions is a significant consequence of the way nurses feel they must navigate them within the multidisciplinary team. Overall, the service in which the nurse works can influence how they respond to patients wishing to discuss assisted dying. When responding to patients, nurses utilise the multidisciplinary team in various ways depending on the service they work in. Nurses in community settings appear to have increased autonomy in conversations with patients and the ability to build enduring relationships, which helps nurses understand whether the desire to die persists.

5.6 Theme 3: Protecting the professional and public perceptions of palliative care.

Palliative care traditionally has got a bit of a PR *issue anyway:*

The third theme examines how nurses consider the public's perceptions of palliative care when responding to a patient's wish to discuss assisted dying. Several aspects within this shape nurses' abilities to navigate conversations, including the taboo surrounding discussions of death and dying, the perceptions of palliative care having a role in hastening death, and that supporting assisted dying could negatively impact palliative care services. Nurses reflect that they feel required to respond to patients in a way that maintains trust in the intentions of palliative care and upholding the tenets of palliative care as not hastening death. Ultimately, nurses described how conversations about assisted dying can cause a public relations problem with a speciality already struggling with the public perceptions of their role at the end of life.

A common thread for nurses relates to how discussing assisted dying may impact perceptions of the role of palliative care.

> *"I think we've always been sort of on the back foot with that [perceptions that palliative care hastens death], trying to say 'no, no, no we're not hastening things, you know, this is all for symptom control'. So then to suddenly say, 'oh, yeah, it's OK, we're all pro speeding things up, and you can die quicker', kind of goes against the years of what we've been battling against with people's assumption of what palliative care is." (Gemma, Hospital)*

Nurses found it important to communicate to the patient that palliative care does not hasten death, thereby emphasising the need for clarity with the patient. Nurses who opposed or maintained a neutral stance on assisted dying were more likely to convey this message to the patient, using this stance to justify their opposition to the patient's request. Several nurses discussed how this also linked to their concerns about explaining their role as palliative care nurses when first meeting patients referred to their service.

> *"…….and often we will find that when people come in to see us for the very first time they're like rabbits in a headlight because of that connotation of palliative means I'm dying, we're the grim reaper team and we're anything but." (Jenny, Community)*

The need to explain the role of palliative care appears to stem from perceptions among patients and those close to them that palliative care can hasten death. This concern was further echoed by nurses discussing situations in their clinical practice where they have been asked to actively hasten death due to perceived suffering or a prolonged dying process. Although families were more likely to lead this, variations of the phrase heard in their practice, 'you wouldn't put a dog through this', were interpreted as both a request to hasten death and a means for patients to express distress regarding their situation.

> *"You always get the comparison to animals. I literally had that conversation yesterday with somebody. So, you know, 'my dog was sick last year, couldn't walk around anymore so we had her put down because that was the kindest thing to do but now I'm sat next to my mother who's not been eating and drinking for a week. And you're telling me you can't end her life when she's already gone'." (Deborah, Hospital)*

Nurses also discussed how family members perceived that other common interventions within palliative care, such as using injectable medication or a syringe driver, to deliver medication over 24 hours, were intended to hasten death. Deborah also mentioned how families could communicate this both implicitly and explicitly, describing a situation where a family member winked at her when she suggested using injectable medication. Despite the potential ambiguity of this non-verbal communication, the nurse felt she understood what was insinuated, laughing as she recounted this interaction with the patient.

> *“I was having a conversation about syringe pumps, starting a syringe pump, on somebody and they said, they started……they winked at me (laughs). I was like ‘ohh dear’ and you could tell that they thought that we were trying to expediate [sic] their death. And I had to really, kind of, say that is not [emphasis on word] what we're doing at all.” (Deborah, Hospital)*

Nevertheless, one participant suggested that nurses should be realistic about families’ perceptions of palliative care and the need to navigate this.

> *“….for some people you're still going into houses and people that can't swallow in the last days of life and trying to explain what a syringe driver is and why you're putting a syringe driver up. And they're still that ‘you're hastening death’ or ‘that will make my Mum die quicker’. So that view is out there whether we like or not.” (Janet, Community)*

Overall, nurses described varying degrees of shock and distress at overt requests to hasten death and the insinuation from patients and families that they might be involved in disingenuous or illegal practices. Monica and Julia, both of whom expressed their opposition to assisted dying, felt the most discomfort at these discussions, as this contradicted their clear position that palliative care practices do not hasten death. However, some nurses did express uncertainty about whether interventions within palliative care, such as the withdrawal of life-sustaining treatment, might hasten dying. Nurses who indicated they supported assisted dying legislation were more likely to convey this uncertainty.

> *“I think hopefully most nurses have sorted out in their head…. I've definitely sorted it out my head because I'm not changing anything, they're dying anyway. So actually I'm not really being 100% truthful when I'm saying what*

> *we……what we're doing is not accelerating anything cause actually, sometimes it does, you know." (Nicola, Hospital)*

At times, nurses report needing to communicate with certainty to the patient that palliative care does not hasten death, despite their own uncertainty. Gemma uses the phrase "toe the party line" to describe this form of interaction with patients and families, stating that there are few other occasions in her practice where she felt constrained in such a manner.

> *"Because you see, that's when I'd be a politician, you see and that's when I would (pause) I would swerve from a direct answer to that and that's where I would go back with 'what, what brought you to thinking like this? What has…what are you thinking and why have you asked me that question?' And that's why I'd go back and explore it." (Gemma, Hospital)*

She follows this up, again suggesting that there is an expectation within the role to behave in this way.

> *"I think there is definitely, erm, a way you're expected to behave as a palliative care nurse, and I think that is led by the consultants, you know…. is heavily influenced by the consultant you work under. As well as that, you see, myself and all nurses in my team have the Macmillan title, so again you've got that other title of 'oooh she's a Macmillan nurse', you know, you're holier than thou or supposed to be." (Gemma, Hospital)*

Nurses describe presenting either a position as agreed within the team, as considered in the previous theme, or not responding to preserve public trust in themselves, the broader nursing profession, and the principles of palliative care, despite the emotional cost to them.

> *"They do say that palliative care has a bit of a lifespan on it, that you can't do it for a long time because of the emotional impact of it. And I do wonder that, I mean, I love my job, but our turnover's pretty quick. We have lots of staff leaving, and I do wonder whether it's the emotional toil of that kind of constant decision-making and you being responsible." (Deborah, Hospital)*

During the interviews, the nurses also described a sense that a patient's desire to die could be perceived as a failure of palliative care services to 'manage dying', as illustrated by Gemma.

> *“I think you can see it as a failing, you know, you can even see it as a failing of palliative care if someone wants to die, because if…….there's an argument, isn't there that if there's good enough palliative care and you can symptom control someone and give them a good enough quality of life, then they shouldn't really be wanting to hasten it, should they.” (Gemma, Hospital)*

Consequently, it felt crucial for nurses to address unmet symptom management needs, intending to alleviate the desire to die, to demonstrate the benefits of engaging with palliative care services to patients and the broader community. Nurses expressed concern that failing to address these needs could adversely affect public confidence in palliative care. However, they also worried that this could also misrepresent what ‘normal’ dying is like. Nurses suggested that a narrative from palliative care professionals has contributed to the sanitisation of death by suggesting that ‘natural’ and peaceful dying can always be assured, which they felt may not reflect reality.

> *“Having been in palliative care for 12 years, I accept there are some arguments against assisted dying, which, ummm, are sort of to do with, well, if you've got great palliative care, then it shouldn't be needed, you know, you get great palliative care and everyone dies peacefully. But I know that that's not the case and I know that there's exceptions to that.” (Samuel, Hospice)*
>
> *“and I think there's a public misconception that people don't suffer at end of life and that we can….we can always alleviate suffering at end of life and it's just not true.” (Cathy, Hospice).*

Helen described a visceral “rage” from some palliative care professionals when discussing assisted dying and its ability to remove the desire to die and all forms of suffering at the end of life.

> *“there certainly isn't a drive within palliative care to have, you know, assisted dying in England. If anything within palliative care in England the rage against it comes from palliative care…….that's where they always get the consultants and the big wigs on the news and things, it all comes from palliative care saying it's…. about how we can make things alright and better when actually, you know, erm…...I'd say we, you know, we struggle to.” (Helen, Community)*

However, for nurses who oppose assisted dying legislation, there was a different narrative, which described the possibility of a peaceful death, and therefore living until this point should be encouraged.

> *"I think that as a society we've become very disassociated from there [dying]. We'll talk about birth, which can be completely horrific, but we won't talk about death, which can be beautiful and peaceful, and I think that's a cultural thing. But I think it is talking about it and pointing out the way that this is peaceful." (Julia, Community)*

Nurses linked the concept of the sanitisation of death and dying in society to a taboo around openly discussing assisted dying, which they reported as impacting how they felt they should or could respond to patients' requests. Nurses suggested that the patient in the vignette wanted to engage in open conversation with the nurse; they considered this extraordinary and a valuable means to initiate a dialogue. However, nurses still reflected that a taboo relating to discussing death and dying constrained their response, and although the nurses stated the patient wished to talk about assisted dying, it was ultimately the nurses who limited the conversation.

> *"There is still a massive taboo about it, isn't there, which doesn't help you having an honest conversation or feeling you can with somebody who is like this gentleman saying to you 'I've had enough, how do I end it?'." (Gemma, Hospital)*
>
> *"As the society we don't invest in it, we don't invest…. because we're very squeamish aren't we….we're a very squeamish society… we don't really like to talk about death, we don't like to talk about dying." (Cathy, Hospice)*

As such, this appears to relate to the nurse's wider societal perception that discussing death and dying is taboo. This, in turn, translates into conversations that disregard the patient's agenda and needs. However, one nurse, who had been working in specialist palliative care for six months, felt that some of the perspectives on dying were outdated and that newer nurses needed to challenge what he perceived as the status quo.

> *"And some, umm, more I would say, outdated views need to be flushed out, taken out from them… like you know this taboo of ending your life [through an assisted death] when there's nothing that you can do to…there's no*

> *curative treatment, there's still a taboo about, uh you know, people ending their lives. It's still seen as wrong, and I don't think it's only from the professional view it is a societal…ummm, a societal thing, right." (Daniel, Hospital)*

During the interviews, nurses were asked to consider the potential impact of passing permissive assisted dying legislation on existing palliative care services. Most nurses reflected on the notion that this could create fundamental problems for the services to navigate. They described the ability to explain how current practices differ from an assisted death would have the most significant impact on them and their relationship with the patient, as they are already finding navigating this perception challenging. Janet reflected that these concerns would create a 'public relations' issue for palliative care services, which, as Jenny's previous 'grim reaper' comment also illustrates, may already exist.

> *"I think that that's where the reluctance is and, we, palliative care traditionally has got a bit of a* PR *issue anyway and we're spending quite a lot of time trying to encourage people to access palliative care and to use it and we spend a lot of time saying we're not hastening death to then have to, umm, (pause) but I think, yeah,* pro*fessionals would feel then having to do a bit of a U-turn." (Janet, Community)*
>
> *"Because I know we've spent, many, many years in the* Hospice*, saying palliative care is about living until you die, it's not about assisted dying. And I think that would change the way people think about the* hospices *even more, cause it's taken us long enough to get people to realise that we use it for symptom control and then you can go home." (Tina, Community)*

The perceptions that palliative care may hasten death meant that most nurses interviewed felt that, if assisted dying were legalised in the UK, integrating assisted dying within palliative care services would be the most problematic way to operationalise this legislation. However, several nurses commented that palliative care professionals may be best positioned to manage these complex conversations, ensure that quality of life has been optimised, and navigate the ethical issues that arise during the process.

Overall, there was a sense among the nurses that this was a ‘square circle’ with no obvious solution. The awareness that legislation may have both foreseen and unintended consequences, irrespective of how it is enacted, was regarded as the most important point for the nurses involved in the study.

5.7 Conclusion

Managing and seeking to resolve the desire to die is a crucial aspect for nurses when responding to requests for assistance to die. However, nurses navigate complex and sometimes contradictory considerations regarding how and what they communicate with these patients. The three themes identify socio-political factors that influence or impact on how nurses feel able to engage with the patient, in order to understand the legitimacy of the request and whether the desire to die will resolve. In Chapter Six I will examine these findings within the context of the existing literature and critically assess them within the theoretical framework of feminist standpoint theory. I will argue how the patients’ request to discuss assisted dying ultimately acts as a disruptive force to palliative care, which influences nurses’ decision-making.

Chapter 6: Discussion

6.0 Introduction

In this chapter, I will explore how a relationally oriented approach to ethical decision-making offers a valuable framework for conceptualising decision-making processes that shape nurse-patient dialogues related to assisted dying. Considering the interpersonal dynamics inherent in clinical encounters allows an understanding of the importance of relationships and the power associated with them in influencing and guiding decision-making practices. Additionally, I will consider the findings within the context of research undertaken in jurisdictions with and without permissive assisted dying legislation. At the time of analysis and writing, the United Kingdom finds itself in a liminal space concerning legislation. Although neither the Terminally Ill Adults (End of Life) Bill nor the Assisted Dying for Terminally Ill Adults (Scotland) Bill had been proposed when the data was generated, nurses were reflecting on potential future changes in the law and identifying challenges operating within this liminal space. With the Terminally Ill Adults (End of Life) Bill having passed through the House of Commons, it now seems appropriate to interpret the data through the epistemological lens of possible future permissive assisted dying laws.

The nurses interviewed within the study considered aspects that would influence their ability to respond to a patient's request to discuss assisted dying. Through Reflective Thematic Analysis, three themes were developed, focused around an overarching theme of resolving the desire to die, to create a rich understanding of the interconnected socio-political and relational factors at play. Nurses offering solutions to the patient, in the vignette, with the intention of alleviating the desire to die. They viewed this as a fundamental aspect of their responsibility towards the patient, and only when it was established that the desire to die would persist, did the nurses consider the patient's feelings as legitimate. The three themes 1) *using, (mis)interpreting, and (mis)representing the legal status of assisted dying to the patient*, 2) *the care setting influences how nurses can nurture relationships with patients and the wider team*, and 3) *protecting the professional and public* *perceptions of palliative care* support the development of the conceptual model proposed within the chapter.

The quality and depth of the relationships that the nurses interviewed could build with patients also influenced how they may respond. Nurses working in the community reported greater freedom to explore requests with patients due to their ability to develop a relationship with them over time. This meant that they were more likely to view requests as valid, rather than, as nurses in hospitals often indicated, a response to an acute physical or psychological situation. The necessity to address assisted dying within the teams the nurses worked within could create tensions, as it encompasses a subject on which individuals may hold divergent viewpoints. Moreover, public perceptions of palliative care interventions undertaken with the intention of hastening death disrupt foundational beliefs held by those working in the speciality; that palliative care neither prolongs nor hastens death. In summary, the request to discuss assisted dying disrupts the expected and established norms among those with whom the nurses are interconnected and acts as a disruptive force to the relationships that nurses usually maintain.

To support the analysis of the primary study, a qualitative evidence synthesis was conducted, as discussed in Chapter 3. This synthesis enhances the understanding of nurses' experiences in acts that may be perceived as hastening death. The discussion of the primary data will specifically draw upon the relational tensions identified in the review. This includes tensions that arise when nurses feel required to endorse a position they disagree with, along with the emotional labour required to represent a viewpoint they do not necessarily support. Furthermore, the perception of palliative care as a proxy for hastened death, held by both the public and nurses, is a crucial factor highlighted in the review that affects and contributes to the primary findings.

6.1 Conceptualising decision-making

While the foundations of navigating care for people undertaking an assisted death have been proposed as fundamentally linked the relationships between the individuals involved (Norwood, 2007; Pesut & Thorne, 2023; Voorhees et al., 2014; Wright et al., 2021), there have not yet been attempts to conceptualise these relational aspects into a model that underscores the aspects influencing nurses' engagement with this form of discourse. Providing a conceptual model for decision-making becomes particularly important when considering such contentious and polarising issues such as assisted dying. This will be evident as I draw on research from similar topics such as the termination of pregnancy. The themes identified within the primary study and qualitative evidence synthesis translate into four distinct areas that impact how nurses feel able to respond to requests to discuss assisted dying with patients. These are:

1) The *permissibility* of assisted dying.
2) The *place* where patient care is delivered.
3) The *profession* of palliative care.
4) The nurse's *personal and professional* identity.

Applying critical feminist theory to interrogate the findings allowed for the exploration of dominant biopowers and epistemic forces that aim to sustain a cultural status quo in palliative care. How this translates to the desire to die acting as a disruptive influence on this status quo is explored in the following section. First, I will explore the factors that contribute to the status quo and then outline the proposed model. Within the conceptual model (Figure 3), I envision the current status of palliative care as a 'millpond' (importantly, millponds are intentionally created through the power exerted upon them), where the current philosophy of palliative care promotes a shared, calm, understanding of its aims. However, the patient's desire to die disrupts these waters, causing a relational ripple effect with far-reaching implications. Second, I will explain how this model can be utilised to understand the clinical implications and address potential issues.

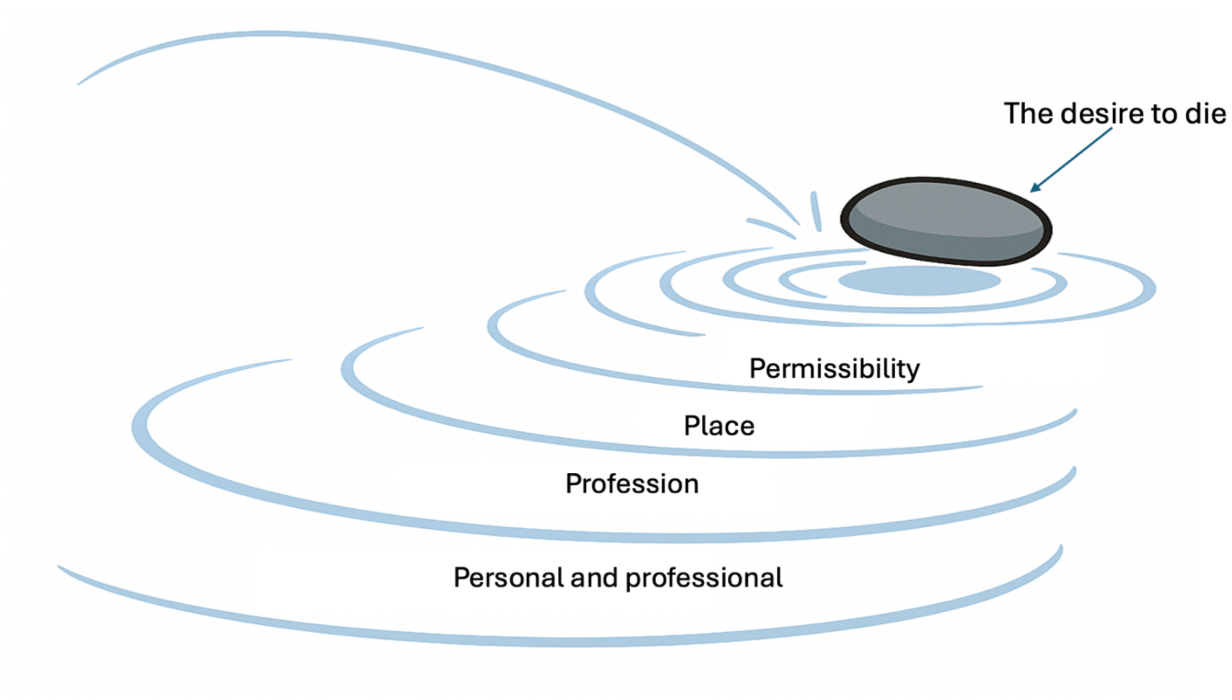


Figure 3: A relational conceptual model for ethical decision-making related to assisted dying.

6.2 The millpond of palliative care

To recognise how nurses respond to patients wishing to discuss assisted dying, we must first understand the socio-political context in which these conversations occur. The concept of *master narratives,* as discussed by Liaschenko and Peter (2016), represents a collective understanding and expectations of how to behave within a situation that ultimately becomes prescriptive for the group. Dominant groups create and perpetuate these master narratives to uphold and maintain their power, alongside narratives that advance their objectives (McCorkel & Myers, 2003). Ascribing to these master narratives can enable the maintenance of an appropriate cultural response when patients wish to discuss assisted dying and foster a unifying palliative care ethos within teams. Three palliative care *master narratives* pertinent to this discussion were considered within Chapter Two:

- that palliative care does not hasten death
- that adequate palliative care will remove the desire to die
- that discussing death and dying is considered taboo

In addition, recent assisted dying debates in the UK, including Select Committee evidence, have been primarily led by doctors arguing that it is inappropriate to discuss assisted dying until palliative care is adequately funded (Health and Social Care Commitee, 2024; Hospice UK, 2025). This may represent a new or emerging narrative within palliative care that has arisen from the debates on the proposed legislation. Although there is no scope within this discussion to explore in detail, it is worthy of noting as a potential interconnecting narrative.

These master narratives represent an underpinning philosophy of palliative care and create the current status quo of palliative care provision. I will now outline how the request to discuss assisted dying acts as a disruptive force to these narratives in palliative care. As a nurse working within the speciality, I have also been compelled to critically assess my (inter)actions within these dominant narratives, as advocated within standpoint theory, which also underlies the subsequent discussion.

6.3 The permissibility of assisted dying: Nurses care about the law, but does it care about them?

Nurses within the study believe that the law is the most important aspect governing their practice, creating an initial boundary for the conversation. The appeal to the legal status of assisted dying facilitates the nurses to steer the discussion towards solutions that aim to remove the patient's desire to die. The continued aim to remove the desire to die does not appear unique to the illegal status of assisted dying in the UK and is also reflected in jurisdictions where this is permitted (Blaschke et al., 2019; Elmore et al., 2018; Rutherford et al., 2021b; Variath et al., 2020). However, irrespective of the legal status of assisted dying, nurses need to feel confident that they are working within the law (O'Connor & Philips, 2020; Pesut et al., 2019; Zeilinger et al., 2025). Despite this the study identified that nurses working in specialist palliative care, who feel they commonly discuss assisted dying with patients, do not understand the legal implications of the patient's request. Despite the confidence most nurses expressed about how they would communicate the legal status of their request to patients, nurses consistently either misrepresented the law or acknowledged their misunderstandings of what constituted ‘assistance’, in line with findings of other studies undertaken where assisted dying is illegal (Hol et al., 2023; Knights et al., 2024). As I have previously outlined, there is limited, if any, preparation within UK curricula relating to supporting a nuanced understanding of the legality of assisted dying for nurses across any speciality. Nurses, however, describe wanting preparation for these discussions, again echoed in areas where assisted dying is legal (Bustin et al., 2024; Elmore et al., 2018; Gerson et al., 2023; Shapiro et al., 2024; Zeilinger et al., 2025). Research undertaken following the passage of permissive legislation suggests that nurses continue to feel underprepared when supporting patients and, fundamentally, continue to describe a lack of understanding regarding the law, which affects the ability to respond to patients appropriately (Blaschke et al., 2019; Hewitt et al., 2022; Lamba et al., 2024; Pesut et al., 2024; Thorne et al., 2024). Perhaps most importantly, nurses develop risk-averse strategies to avoid ‘stepping outside of the law’, a pertinent factor irrespective of legal status.

The lack of understanding of the legal status of assisted dying is the first example of epistemic injustice within the data, which is consistently observed throughout the interviews. The term epistemic injustice, first coined by Miranda Fricker in 2007, refers to the observation that systematic power imbalances in society may exclude groups from developing or communicating their knowledge (Fricker, 2007). An injustice occurs when a person is denied their actual or potential capacity as a possessor of knowledge *(qua knower*), ultimately influencing their existence as a moral agent. The consequence of limiting, or tabooing, conversations about assisted dying appears to act to deny nurses the autonomy to develop the language necessary to become ‘credible agents’ in the topic. Issues of testimonial injustice also occur throughout the data. Testimonial injustice refers to the phenomenon where challenging an expected narrative can lead individuals to doubt their understanding of the situation and erode their confidence in the credibility of their own knowledge (Della Croce, 2023). Where nurses are not provided with the means to build knowledge in this area or be recognised as credible sources, they will always need to defer to others who may have this opportunity. The lack of understanding about the law means that decision-making may be deferred to doctors within their team, with nurses assuming that they would understand the legal implications of the request. In some cases, this deferral is the expected output of the multidisciplinary discussion by both the nurse and doctor. While epistemic injustices have been identified in this context, nurses also seem to report feeling liberated by not having to assume ultimate responsibility, using the doctors as a shield against situations that make them uncomfortable. Whilst the nurses talked about exploring the request with the patient, no nurse discussed exploring the patient's knowledge about assisted dying, what it meant to them or how they understood its legal status. As such, nurses are conversely not recognising or considering patients *qua knower* (as a possessor of knowledge*),* assuming they have epistemic superiority over the patient. This lack of recognition raises the possibility that the nurse, and possibly other healthcare professionals, may be perceived as misleading the patient, either intentionally or unintentionally, due to their misunderstanding of the law. Therefore, it is reasonable to suggest that by nurses feeling required to be clear about the legal status of assisted dying as a moral good to foster trust in their relationship, the opposite effect may actually occur.

At the time of the interviews, the Terminally Ill Adults (End of Life) Bill had not yet been proposed; however, this data can now be viewed with the knowledge of what might be suggested if the Bill were to be passed. The lack of involvement, or consideration, of nurses in the development of legislation has been reported as problematic in other jurisdictions considering or permitting assisted dying (Bellon et al., 2022). Despite nurses viewing the law as their primary concern, the proposed Bill does not mention nurses, and they received limited consideration in subsequent parliamentary debates and Select Committee evidence. I would suggest that the epistemic injustice identified permeates more, or perhaps all, levels than just that between patient, nurse, and doctor.

6.4 The place where patient care is delivered: space as an active agent

Nurses and patients appear to require both physical and emotional space to engage in conversations relating to assisted dying. The embodied physical space in which nurses operate significantly influences relational engagement. The significance of embodied space was also demonstrated in the systematic review, which showed that nurses mainly focus on and prioritise the individuals with whom they spend the most time, the patient or relative, to enhance their experience. The connection formed between the patient and the nurse, within the study, was crucial when seeking to establish the perceived legitimacy of the request and whether the desire to die may persist if symptoms were optimised, which has also been observed across various healthcare professional roles (Gerson et al., 2023; Hol et al., 2023; Snijdewind et al., 2014). Within the hospital setting, the physical space has been suggested as holding the potential to generate physical or emotional segregation for nurses, both with patients and their teams (Hewitt et al., 2022). With aspects such as a lack of privacy and being cared for alongside strangers, limiting what can be shared (Larsen et al., 2014). As such, creating ‘space’ in this environment, which appears to be designed primarily to meet the needs of the healthcare professionals to provide care, is limited.

Nurses working in the community described a more explorative and open dialogue with patients, feeling less sure that the desire to die will cease in comparison to hospital nurses. Community nurses are required to build more enduring social bonds with patients and appear to have, and value, increased autonomy in managing this relationship independently to the multidisciplinary team (Howell et al., 2014; Walshe et al., 2008), which in turn facilitates the progression of these conversations (Norwood, 2007). Conceivably, the physical space provided by working more remotely from a team, in patients’ homes, also allows nurses emotional space from the master narratives of palliative care. This space allows the nurse a greater freedom to respond, develop a relationship, and understand the patient's request within its context before needing to discuss it with the broader team. Tina and Samuel both discussed the importance of being an ‘invited guest’ in the patient’s home, which is suggestive of a shift in the predominant power in these situations. Patients are more likely to recognise their home as a safe space that they can control (Kittay, 2011; Knights et al., 2024), and perhaps this creates a space where expressing existential distress with the nurse would feel safer.

Compared to the acute healthcare environment, being ‘in the patient's world’ facilitates a better understanding of the patient's desire to die within a complex, multifaceted, and interconnected context (Russo, 2021), which is also seen generally within community practice (Bowers & Redsell, 2017; Mills et al., 2025). Having more opportunities to revisit the discussion also enables the patient’s story to be understood beyond individual episodes, as a collection of complex stories over time (Russo, 2021; Variath et al., 2020). Overall, the community nurses possessed greater autonomy to engage in discussions and provide support to patients based on their evaluations, owing to the inherent structure of the service design. To consider this in the context of permissive legislation, Pesut et al. (2024) suggests that discussions about assisted dying should take place during periods of relative clinical stability, where the desire to die can be understood alongside the patient’s long-standing values. As such, the unstable or transitional phase of illnesses, common in the hospital, and in some cases the hospice, setting, appears less well placed to manage these conversations solely. If we accept that a request for assisted dying acts as a disruptor to the expected behaviour of patients within palliative care, considering that palliative care does not hasten death, patients may need ‘a safe space to express this disruptive thought’. Building on the analogy of palliative care master narratives as a millpond, it is conceivable that home provides patients with the tranquil waters they also need to facilitate progress in these conversations.

6.5 The professional influence of palliative care: a public relations problem for palliative care?

Nurses described a need to maintain the narrative that good palliative care can alleviate the desire to die and that palliative care interventions do not hasten death, thereby supporting the foundational principles of palliative care. It remains an imperative for palliative care professionals to address the desire to die and provide a ‘good death’ (Sallnow et al., 2022), despite the challenge of defining what a good death may entail (Cottrell & Duggleby, 2016; Krikorian et al., 2020). As Sallnow et al. (2022) also suggests, when discussing the work of Columba Quigley, this also helps to perpetuate narratives of ‘normal’ or ‘natural’ dying and solidifies the role that palliative care can play for people who are approaching the end of their life. The perception that palliative care interventions can eliminate the desire to die is commonly reported in the literature (Elmore et al., 2018; Kremeike et al., 2021; Lindblad et al., 2024; Rawlings et al., 2021; Willmott et al., 2020), with the alleviation of suffering to achieve this being viewed as an essential element of the palliative care nurse's role (De Bal et al., 2006; Dierckx de Casterlé et al., 2006; Streeck, 2020). As I have previously outlined, requests for assisted dying are rarely driven by unmet physical needs and often persist despite palliative care interventions. Yet, this does not stop, individuals working in healthcare from seeing a request for assisted dying as a failure to provide 'good palliative care' (De Bal et al., 2006). Considering that palliative care should encourage discussion about death and dying, it could be argued that people wishing to discuss assisted dying are not denying that death is approaching, but perhaps the tensions identified come from disrupting the narrative of 'what dying should look like'.

Wright et al. (2021) discussed that dominant voices can be used as a means of controlling the narrative within assisted dying, and whilst this is often prevalent in assisted dying research, it is not overtly recognised in the context of biopower. Several nurses reported feeling a lack of epistemic authority and that their knowledge was not regarded as sufficiently significant by others to influence the wider team in addressing these issues. They also felt that doctors often influenced the stance the team *should* take based on their personal opinions about the situation. Ultimately, nurses described how their concerns could be silenced, which influenced their further engagement with the multidisciplinary team, particularly the consultants with whom they worked. This silencing is seen to occur irrespective of the legal status of assisted dying narrative (Bustin et al., 2024; De Bal et al., 2006; Sandham et al., 2022; Wright et al., 2021), and is an observation that resonates across areas that face similar ethical challenges, such as the termination of pregnancy (Carson et al., 2023; McLemore et al., 2015). Although nurses reported that being required to manage the patient's care in ways they may disagree with could cause moral tensions, the nurses did not routinely challenge the narrative within the multidisciplinary team.

Overall, findings from the empirical study and review suggest the need to adopt a view that palliative care does not hasten death in order to feel supported by their team, often using ambiguous or euphemistic language to navigate this (Bruce & Beuthin, 2020; Schwarz, 2003). Nurses avoid taking or expressing a view that may threaten the position that palliative care does not hasten death, perhaps due to the fear that this may impact public trust in the speciality. This feeling is especially important when the public's perception of palliative care differs from how the speciality views itself. The need to navigate this through the use of euphemistic language is despite evidence indicating that a supportive environment is essential for open dialogue about assisted dying, regardless of its legal status (Dierckx de Casterlé et al., 2006; Hewitt et al., 2022; Hol et al., 2023; Pesut et al., 2020b; Sandham et al., 2022; Schwarz, 2004). What remains unclear is whether the nurses actively chose to defer decision-making or whether they were ‘silenced’. Managing dissent among other team members, especially when no solutions exist to address the desire to die, is viewed as particularly challenging, and perhaps, as Kremeike et al. (2021) states, avoidance through self-silencing can become a coping mechanism employed by nurses.

The nurses in the study identified that a persistent desire to die presents a challenge to the professional identity of palliative care. When patients express a desire to die through their exploration of assisted dying, and perceive palliative care as a substitute for that, it creates a ‘public relations’ issue that palliative care must manage. As a result, individuals involved in palliative care may feel compelled to reinforce the narrative, that palliative care does not hasten death, rather than confront their underlying concerns. The physical environment and cultural context that facilitate these conversations may also explain why nurses in hospice settings report that discussions about assisted dying are infrequent. Individuals and institutions turn to hospice leadership for guidance on what the ‘right’ stance from palliative care should be on this issue; even though the nurses in the study suggest that they are less frequently confronted by individuals who openly express a desire to die.

6.6 The nurse’s personal and professional identity: responding to the request

All nurses interviewed in the study indicated an expectation that discussing assisted dying would not be considered legitimate unless the desire to die was thoroughly explored and addressed. It is evident that a social script existed, to which the nurses in the study felt compelled to adhere. These social scripts define what may be seen as an appropriate boundary for the conversation (Feigenbaum, 2007). Adhering to interpersonal social scripts depends on cooperation between the actors in the conversation (Hesni, 2024), but importantly, they are maintained by those with the power to control the narrative. However, as I have suggested, a persistent desire to die through assisted death challenges the status quo of palliative care. Consequently, nurses characterised themselves as occupying a position wherein they must engage in cooperative disruption to facilitate the exploration of this topic within their respective teams. The concept of cooperative disruption, as discussed by Hesni (2024), suggests that instead of directly challenging social scripts and risking perceptions of disruption, individuals adopt a non-confrontational approach to navigate and question these scripts. This tendency was less prevalent among hospital-based nurses; however, community nurses frequently reflected on how they modify the narrative they share with their teams. Nevertheless, the expectations that nurses discuss the patient’s care plan with the multidisciplinary team offer a less socially risky way to explore the underlying narratives. The need for practical outcomes from these discussions to support patient care can also act as a boundary, allowing the team to move from philosophical to practical aspects if needed, limiting the conversation if participation becomes too challenging. The labour required to navigate these conversations was also observed in the systematic review, where nurses felt compelled to uphold a narrative with which they might disagree. These observations further evidence the lack of epistemic agency that nurses working within palliative care possess.

However, despite these external influences, the lack of agency can also enable acts of resistance to develop (Noggle, 2005). The nurses interviewed described small everyday acts they may undertake to support the patient in the vignette and also drew on examples from their clinical practice. In particular, nurses described feeling more empowered when they disagreed with aspects of the master narratives. I have used the term ‘disrupt’ throughout this chapter to describe the impact of a request to discuss assisted dying, although I do not believe that ‘disruptive’ is the most appropriate adjective to describe what the nurses are doing in this situation. This ‘disruption’ occurs when nurses attempt to protect patients against forces they perceive as adversely impacting them, undertaking such actions as part of their routine work. Considering this disruption from a ‘nurse-centric’ perspective, the way some participants described their approach to navigating the multidisciplinary team makes ‘disrupt’ seem like an actively damaging or destructive term, which does not align with the nurses’ intentions. Horton and Kraftl (2009) describe these forms of ‘disruption’ as ‘implicit activism’, which happens in modest and quiet ways often leaving no obvious trace that this has occurred. Despite the often invisible nature of this activism, this is also recognised to take considerable emotional labour (Florell, 2021), as also noted within the evidence synthesis in Chapter Three. In this context, I would describe these as everyday acts of activism, used to address injustices perceived by nurses, whether directed towards themselves or the patients they care for. While some may argue that activism is inherently disruptive, activism is only necessary where dominant powers prevail.

It has been suggested that nurses' initial reaction to ethical decision-making are primarily emotional (Spronk et al., 2021; Thulesius et al., 2013); however, the nurses interviewed did not demonstrate emotional responses. Instead, they considered responses that evaluated complex relational factors when deciding how best to support the patient within the structures in which they work. There is an emerging evidence base supporting the recognition of the complexity within nurses' ethical decision-making where assisted dying is legal (Pesut et al., 2020a; Pesut & Thorne, 2023; Wright et al., 2021). Therefore, perhaps the attraction to an emotional response also functions as a useful narrative to diminish the views and epistemic authority of nurses, who are recognised as more likely to express uncertainty about the nature of interventions in palliative care and to support assisted dying. An interesting parallel to consider is that an ‘emotional response’ has historically been used to deride female reactions and to portray them as irrational (Åhäll, 2018; Ahmed, 2015; Showalter, 1987), which appears relevant to the social perceptions of nursing as feminised work. Viewing the data through a feminist lens allows a critical perspective on the dynamics at play. As Sara Ahmed states, “if feminist critiques of sexism are knee-jerk, we might need to affirm the intelligence of feminist knees”(Ahmed, 2015, p. 7). For those holding power in the societal discussions about assisted dying and palliative care, a culture that does not allow critical exploration of its foundational beliefs, and a culture that makes nurses seem ‘irrational’, remains beneficial. It is also valuable to consider that medicine has corrected gender imbalance, unlike nursing, and is no longer a male-dominated profession, and within palliative care, medical staff are predominantly female. Perhaps this holds a key opportunity to challenge the predominant narratives. For now, nurses navigating these discussions is perhaps a feminist praxis that allows nurses to also care for themselves.

6.7 Providing patient-centred care for those requesting an assisted death

It may have been noted by this point that the patient is not included in the proposed conceptual model. While the needs of the patients and the relationship between the nurse and the patient weave throughout the findings, they are not reported by nurses as primarily shaping the decision-making process. Although many examples show nurses prioritising the patients’ needs in their plans, these did not seem to influence actual decision-making; aiming to remove the desire to die held greater importance. As an example, nurses reported that they felt that patients expected them to be clear at the start of the conversation that assisted dying was illegal. The nurses interviewed did not believe that this initial response would alter the development of the relationship with the patient. However, rather than questioning the patient and themselves about how this might impact the patient, it was not viewed from a patient-centred perspective.

The nurses in the study potentially assume an epistemological gap with patients and therefore wish to establish their epistemic authority over patients when they believe that their interventions will ultimately remove the desire to die. Since assisted dying is not legal in the UK, it is not possible to state how many people will continue to have the desire to die despite palliative care interventions. However, internationally, up to 4 percent of all deaths involve an assisted route (Mroz et al., 2021), with the majority of patients also accessing palliative care, and with similar service structures (Colburn, 2025; Gerson et al., 2020). As such, there is limited evidence to support that nurses are in a position of authority as to the potential to alter the patient's wishes for their future. While it is, of course, essential to ensure that patients' symptoms are addressed and that their requests are legitimate, exploring patients' concerns beyond simply removing the desire to die is important to consider. Adopting an approach of epistemic humility, where respect for the knowledge of others should be adopted, could be suggested as a way to address this (Ho & Unger, 2015). As such, the best course of action cannot be decided until all perspectives are understood and for healthcare professionals to move past the assumption that the desire to die can be removed may require varying degrees of humility.

Finally, and aiming to approach this issue from an epistemically humble perspective, if nurses see the removal of the patient's desire to die as the primary concern, are they genuinely considering the holistic care of the patient? The existential factors discussed in this thesis include aspects outside of the locus of control of healthcare, notably the influence of the patient's illness on their relational appreciation of the world. Indeed, the medicalisation of dying may have influenced this, as we remove people from their social worlds during times of illness (Pesut & Thorne, 2023), and it is perhaps why nurses in the community see this subject differently from those in the acute setting. This raises a final question about whether ethical decision-making regarding assisted dying, and consequently the care that follows, can be realistically deemed as patient-centred unless this is addressed. The core principles of palliative care promote a patient-centred approach. However, an enduring desire to die seems to challenge this. The idea that palliative care can facilitate a good death and eliminate the desire to die, or as some see it, serve as a panacea to suffering, conflicts with understanding the patients' needs in such cases. At times, the master narratives of palliative care may influence, overwhelm, and eventually subsume the patient-centred, holistic focus that palliative care aims to deliver.

6.8 Implications for practice and recommendations

Nurses expressed that the interviews were an opportunity to explore their thoughts on assisted dying, as they had not previously had the outlet to do so. They noted that the interview created a space to address uncertainties about the topic, and some participants sought clarity regarding the law and professional guidance during the conversations. I would argue that the ‘veil of silence’, discussed in Chapter Two, has left nurses with little opportunity to explore their concerns. The lack of space to explore uncertainty was also a key finding within the qualitative evidence synthesis. The provision of emotional and intellectual space for nurses to discuss their concerns about aspects of care relating to the desire to die, uncertainty about hastened death, and assisted dying is needed.

We find ourselves in a situation where nurses, as a collective, may not understand the law and are therefore less likely to have the agency to engage with the debate and legislative changes in the future, despite their significance. Nurses wish to be politically engaged (Schiller et al., 2019); however, they report being subjugated or oppressed in these conversations. This perpetuates inequality and reinforces the epistemic privileges of medical leadership. To enable significant engagement for nurses with the topic of assisted dying, a cultural shift is needed to actively support the development of knowledge for those most likely to face these conversations initially and who spend time ‘at the bedside’. Nurses need support to develop the hermeneutical tools necessary to understand and interpret the complexities of this subject. This may be through formal education programmes and include ethical considerations regarding hastened death and assisted dying with patients and the teams they work with. While it has been noted that UK legislation on assisted dying is unclear for nurses, there is also a duty to help individuals understand their legal responsibilities. Embedding considerations around hasten death into formal training can also support open conversations and work toward de-tabooing these discussions.

Nurses within the study state that their primary concern is working within the remit of the law, yet neither Bill proposed in the UK mentions nurses or reflect on their role within patient care. The lack of reference to nursing is despite them being the healthcare professionals most likely to be initially approached to discuss assisted dying (De Bal et al., 2006; De Bal et al., 2008; Dholakia et al., 2022; Dierckx de Casterlé et al., 2006; Hewitt et al., 2021; Richardson, 2023; Wilson et al., 2019). It is challenging to consider how nurses can move forward to gain epistemic authority when they find that they are not represented at this level. Preparing nurses to understand the legal implications relating to assisted dying has been highlighted as necessary in jurisdictions where assisted dying is legal (Bustin et al., 2024). However, there does not yet seem to be a model that can be replicated in its entirety to address this epistemic gap. Again, resources, whether physical or intellectual, need to be allocated to create space for nurses in the development of future legislation, services, and policies.

A key observation in the study was the fundamental difference in approach depending on the location of care. This must be considered when developing future services, especially if permissive legislation is enacted and has international relevance for other jurisdictions that may also be considering introducing assisted dying. It is possible that nurses, or other healthcare professionals, working in the hospital setting are not ideally positioned to lead this form of decision-making due to the nature of their relationship with the patient and the patient’s likelihood of being in an acute or unstable phase of illness. While patients can express their wishes in an acute setting, and preventing access for patients in these circumstances could be seen as an inequality, there must also be an opportunity for existing values and preferences to be taken into account. The ‘periods of reflection’ between stages of decision-making within the proposed Terminally Ill Adults (End of Life) Bill may support this; however, who is best suited to advance the request should also be carefully considered.

6.9 Areas for future development

Continuing to view data within the assisted dying discussions through a critical feminist lens is fundamental to ensure a deeper understanding of the structures that oppress underrepresented groups, such as nurses. Recognising and challenging the epistemic injustices that impact both the development of person-centred clinical practice and the research base to support care is also necessary. Excluding nurses' voices from the research base leads to their exclusion from key policy and services development, and ultimately from the practices that directly affect them, which can only serve to weaken practice.

The clinical vignette was designed to be gender-neutral to facilitate open discussions with participants. However, twelve participants subconsciously gendered the case study as male, one asked for clarification about their gender, and two identified the person as female. Those who gendered the patient as female shared stories of women they had encountered in similar situations and applied their learning from these experiences to the case. There was no scope within later interviews to explore the gendering that had emerged; however, it may be worthy of examining this separately from the scope of this study. Considering this observation through a feminist relational lens, however, may support future research in examining whether and how relational engagement with assisted dying differs depending on gender. This observation relates to the concept of the 'normative male', as discussed by Criado-Perez (2019). It could be suggested that, as the patient in the vignette had a supportive family, the person caring for them was presumed female, hinting at implicit and explicit biases about assisted dying (Sikka, 2021). Having identified aspects that influence ethical decision-making, it is noteworthy to consider whether these would have been fundamentally different if the patient had been overtly discussed as female or male. Therefore, undertaking the study with gendered case studies would be worthwhile.

To further explore the topic, replicating the study with doctors working in specialist palliative care would support a deeper understanding of the systemic issues that impact the discussion of assisted dying with patients. It would be expedient to compare the aspects doctors prioritise and how they view the engagement and involvement of the wider healthcare team within their decision-making process. The nurses interviewed were also mainly experienced nurses who worked, or had worked, as clinical nurse specialists and were therefore more likely to be confident or at ease in their work environments. Consequently, there is further potential to explore the topic among less experienced nurses and those working in generalist care settings to develop a more comprehensive understanding of its impact on patients. Finally, it remains unclear what influence the research design and interview structure has on the findings. To gain a deeper insight into the effects of epistemic injustices and whether nurses would adopt the same approach outside of individual interview settings, further investigation with group discussions around the case is warranted.

6.10 Study strengths and limitations

Methodological strengths and limitations of the primary study are detailed in Chapter Four; in this section, I will concentrate on the strengths and limitations within the findings of the overall study. This study, at the time of writing, represents the first opportunity for nurses in the UK to discuss how they may approach patient-led conversations related to assisted dying, when this is illegal. The study has a unique nursing voice within the assisted dying literature. The thesis presents a well-designed and constructed study that highlights the relational aspects of care through the application of feminist theory throughout the qualitative evidence synthesis and the primary study’s methodology. This is also the first attempt to develop a conceptual model for understanding ethical decision-making among nurses within the context of assisted dying, irrespective of its legal status.

The study provides an opportunity to explore and understand the aspects that might influence engagement with assisted dying discussions in anticipation of a possible change in the legal status of assisted dying in the UK. The findings, considered within the context of research undertaken in jurisdictions where assisted dying is also legal, illustrate important parallels; in particular, the way healthcare professionals understand the law and the impact of the lack of training to support this understanding. However, the study has also provided unique insights into the topic, which, to the best of my knowledge, have not previously been identified. The variation in nurses' approaches to patients when determining the appropriate response, contingent upon the care setting, constitutes a significant finding. These findings offer an important perspective to consider if assisted dying legislation is enacted in the UK. The relational focus of the study also evidences the importance of this lens when developing patient-centred services to ensure consideration of the support that the staff who work within them may need.

To enable nurses to share their opinions openly, recruitment was not carried out through organisations, but via social media and dissemination through professional networks, using purposive and snowball sampling. Consequently, the study involved a self-selecting sample of those who volunteered to discuss assisted dying. It can be assumed that the interviewees represent individuals with strong opinions on assisted dying. Considering aspects of epistemic injustice, it is also likely that those with ‘power’ or who feel empowered to discuss this topic in the research context are overrepresented. This might also explain the high number of nurses in senior roles and those with extensive nursing experience. The sample also primarily represented nurses working in clinical nurse specialist roles, and while this role represents a significant proportion of nurses working in specialist palliative care, the seniority of this role is not indicative of the entire workforce. A final limitation of the study is that, although recruitment aimed to include participants from all four nations of the UK, the sample only consisted of individuals from England and Scotland despite active recruitment. Palliative care service structures in Northern Ireland do not vary significantly from other regions of the UK; however, there are presently no proposed legislative amendments within this jurisdiction. It remains indeterminate whether alternative considerations for nurses in this region would have arisen had they been interviewed.

6.11 Dissemination of findings and learning

The dissemination of both learning and findings has occurred at various stages throughout the development of this thesis, serving both to share work and to strengthen the research through active peer discussion. The adaptation of the concepts underlying moral case deliberation was presented as an oral abstract at the Postgraduate Bioethics Conference, Bristol, in 2022. Early findings from the systematic review chapter were presented as part of a symposium panel at the 2022 Public Health in Palliative Care International Conference, Bruges. The final findings were then presented as an oral abstract at the 2024 European Association of Palliative Care World Research Congress, Barcelona. The review chapter has also subsequently been published in the journal Palliative Medicine in 2025 (Ali et al., 2025). Participants consented to the findings of the empirical study, including verbatim quotes, being used as part of the dissemination process; therefore, the next step is to develop the empirical study findings for publication.

Due to the contemporaneous nature of the research, I have been invited to speak at several events, which has afforded the opportunity to disseminate research findings and receive feedback, which has also helped clarify my thought processes. These include a roundtable event organised by my local MP before the first parliamentary vote on the Terminally Ill Adults (End of Life) Bill, as well as subsequent debates and roundtable events, including at the Royal Society of Medicine in February 2025. Following this, I have also been asked to present at a number of learning events for palliative care teams across the UK, who are keen to explore the impact of the Terminally Ill Adults (End of Life) Bill on their services and at wider events including the Global Palliative Nurse Network in October 2025.

6.12 Reflecting on the research process

It would be negligent of me to conclude this thesis without reflecting on my development as a researcher through pursuing a PhD and the importance of this experience to me as a nurse. Throughout my growth as a doctoral student, I have been led to consider how the relational aspects I am exploring connect to my own identity as a nurse. A deeper understanding of feminist theory, gained through the use of a reflexive methodology, has allowed me to recognise the range of identities I hold and how these shape my subjectivities, which I did not fully appreciate at first. I have spent a significant amount of time reflecting on this, particularly on how injustice is observed within the data. I realised that my sense of social justice, shaped by my identities, has guided my understanding of the data and the PhD process has equipped me with tools to articulate these insights more effectively. The irony that I initially lacked the words, and perhaps the confidence, to describe the epistemic injustices I have identified is not lost on me.

Most notably, returning to clinical practice as a nurse after commencing my PhD while still engaged in an academic environment was a particularly significant part of the journey. I initially thought that people would see the subject as unsuitable for someone with a clinical background to research. However, this was not the case; individuals not working in healthcare were generally interested and eager to hear my perspective, while healthcare professionals were more cautious but keen to understand how I was positioning myself. It is unclear whether this can be attributable to heightened interest in the Terminally Ill Adults (End of Life) Bill, as I work in England. Over time, though, I have observed that the responses of healthcare professionals have become more reticent, perhaps as I have been able to articulate my work more clearly. Furthermore, I recognise that, as a nurse, engaging in doctoral study is not common and, as such, I can feel disruptive of the cultural millponds within healthcare settings, some of which I have explored in this thesis, causing others to feel less certain about how to approach and discuss these topics with me. While doctors have a clear route to doctoral study and the expectation that they will continue a clinical role if they undertake an academic position, this is not an established or, indeed, encouraged route for nurses. Nurses do not possess the same cultural capital as doctors (McNamara, 2008), and as Chulach and Gagnon (2016) suggested, new nursing identities (such as those of a clinical nurse and researcher) are challenging existing perceptions of nurse identity. The central question I continue to consider, is whether, at the end of this journey, am I a nurse academic or an academic nurse, or perhaps, indeed, whether the title nurse needs a prefix or suffix at all.

When I first decided to undertake this research, assisted dying was a distant concern, but the topic has now become prescient. As a result, more people have asked me about my stance on this issue. I was, perhaps fortunately, in a position to examine this early in the research process, allowing me to understand it in a more nuanced way, now that questions about people’s ‘thoughts’ (meaning their position) on assisted dying are being asked more frequently. The process of PhD study has also given me the confidence to articulate that assumptions about people's positions cannot be made solely based on their interest in researching assisted dying, an aspect I have commonly encountered. I have suggested in the previous chapter that binary terms to describe people's stance is challenging; but this has led me to interrogate what a ‘neutral stance’ means to me. The confidence this has brought now affords me a greater understanding when people’s position on assisted dying is written in, metaphorical, invisible ink within their work.

6.13 Final statement

This study offers UK nurses the opportunity to discuss how they might engage in patient-led conversations regarding assisted dying. The interviews were undertaken during a time when discussions around assisted dying were prevalent in the media, with high-profile campaigns both for and against permissive legislation. The analysis of the data was undertaken during an additional significant shift in the public and professional discourse, with the first reading of the Terminally Ill Adults (End of Life) Bill. Nonetheless, these findings can be seen as supporting development of policy and practice, through these shifting sands, when a patient chooses an assisted death, regardless of whether the Bill becomes law.

Nurses report feeling confident in discussing the desire to die but are often excluded from conversations and considerations when developing legislation, local services, policies, and, as the nurses interviewed demonstrated, patient care. While I would argue that establishing universal recommendations based on these findings may not be feasible, it is vital to understand the relational influences of master narratives that shape palliative care. Such understanding is essential to fostering an environment conducive to open discussions regarding assisted dying within healthcare teams. Open conversations would not only support nurses in providing care for patients but may also promote patient-centred care for those wishing to explore assisted death. Recognising the impact of not talking openly on the delivery of holistic, patient-centred care is essential. Ultimately, understanding the systemic, structural, and epistemic injustices within the system is crucial for addressing the inequalities identified within this thesis.

Appendices

Appendix 1: Example of the data extraction tool within the qualitative evidence synthesis

Adapted from Noyes et al. (2018)

Title of review

What can be learnt from synthesising qualitative research findings on the lived experience of nurses when involved with acts that may be perceived as death hastening?

Publication details	Extractor name VA
Author(s) De Vries and Plaskota	Title of article Ethical dilemmas faced by hospice nurses when administering palliative sedation to patients with terminal cancer

Title of journal Palliative and supportive care	Year 2017	Volume 15	Issue	Pages 148-157

Study Information/Context
Country of study United Kingdom

Assisted dying legal at time of study? No	Assisted dying now legal ? No	Philosophy/Paradigm Interpretative approach

Study aims “Palliative sedation is a method of symptom management frequently used in hospices to treat uncontrolled symptoms at the end of	Study objectives/research question

<table>
<tr><td>life. There is a substantial body of literature on this subject; however, there has been little research into the experiences of hospice nurses when administering palliative sedation in an attempt to manage the terminal restlessness experienced by cancer patients”</td><td colspan="4"></td></tr>
<tr><td colspan="3">Study design
Phenomenology - Colaizzi</td><td colspan="2">Any further research questions addressed</td></tr>
<tr><td>Professional group
Nurses</td><td colspan="3">If Palliative care:
Specialist</td><td>Demographics
7 Hospice nurses who had cared for at least one patient who had undergone palliative sedation within the past year at a hospice-south of England.

All participants were female.
Their ages ranged from 24 to 62, with a median of 43 years. The length of time they had worked in pall care ranged from 7 months to 8 years</td></tr>
<tr><td colspan="5">Sampling and recruitment
Purposive</td></tr>
<tr><td colspan="2">Number of participants</td><td colspan="3">Drop out including reasons</td></tr>
</table>

7	20 were invited to take part and 7 agreed. Reasons for not wanting to take part were not documented.
Details of any theory/conceptual models used The concept of a good death	
Study date and duration Not stated	Research tools used Not stated
Methods of data collection Semi-structured interviews	Collected by and setting Did not state
If interview: questions asked asking participants to relate specific situations where they had been involved in palliative sedation of a patient at the hospice and how they had felt about this. We used prompts to probe about the types of medication used and for details on administrative practices	
Findings :	
Analysis Approach inc. justification Colaizzi stages of analysis – congruent with grounded theory “In our analysis, we believe we achieved a high level of rigor using the framework of de Witt and Ploeg (2006), where we: (1) established a balance between the voices of study participants and our own philosophical explanations for their experiences, which were underpinned by the concept of a good death; (2) followed an open and systematic process using Colaizzi’s framework; (3) determined that the study findings are useful to practice; and (4) found that they resonate with the experiences of other nurses in hospice	Reflexivity Not included

<table>
<tr><td>practice, as addressed above. Actualization of the findings and implications for future practice within hospice care are addressed later in this article</td><td></td></tr>
<tr><td>Strengths/limitations of the study (including diversity of sample): Researcher
This qualitative study included a small purposive sample of palliative care nurses practicing in one hospice unit. Nurses provide end-of-life care in multiple settings, and, as each setting has its unique characteristics, the results of our study do not reflect the experiences of all nurses caring for terminally patients and their families. Further, there were a number of challenges that were only touched on in the interviews and that require further exploration, eg the concerns expressed by one of the more senior nurses regarding not being able to discuss treatment options with patients who had terminal restlessness</td><td>Strengths/limitations of the study (including diversity of sample): Reviewer
Sample size and transferability
Well justified themes based on presented data</td></tr>
<tr><td colspan="2">Study findings including themes
Facilitating a “peaceful death” was interpreted as the primary purpose of administering palliative sedation to a dying person in the hospice. This interpretation was made based on the language used by the nurses, where they sought to enable and support patients to be “at peace,” “settled,” “comfortable,” “relaxed,” and “calm” as they approached death. Achieving this state was underpinned by a number of concerns, interpreted as ethical “dilemmas of care.” The dilemmas encountered included: medication decisions, “juggling the drugs,” concern that they (the nurses) had caused the death, sedating young people, requests for sedation from family and patients, and relatives conceptualizing hospice as a place where death is hastened. There was</td></tr>
</table>

a fundamental need for team support in decision making and emotionally managing the difficult and complex situations that were encountered by the nurses.

Key quotes inc. page numbers

“Facilitating a “peaceful death” was interpreted as the primary purpose of administering palliative sedation to a dying person in the hospice” Pg. 151

Facilitating a Peaceful Death

“All of the nurses were troubled at some stage by whether or not they had made the right decision in starting a particular medication” Pg. 151

“Three of the nurses had the experience of administering phenobarbitone to induce deep continuous sedation. When it was employed, it was the subject of long discussions and debate within the multidisciplinary team. It was also reflected on at length by the participants, “ Pg 151

“When using medications such as phenobarbitone, if the time was protracted before death occurred, the nurses started to doubt their original decision to begin palliative sedation” Pg. 151

“This was even more of a concern and dilemma when they became aware of family member discomfort about the length of time that the person remained heavily sedated” Pg. 151

Causing the death

“All of the nurses expressed uncertainty that palliative sedation could or would actually lead to the death of the patient, and they repeatedly reflected on this possibility. They all reported experiencing anxiety at some time about such an outcome, but all maintained the position of wanting what was deemed “best for the patient” at that time. The more experienced nurses expressed higher confidence in their decisions to administer palliative sedation, balancing this with the aim of the intervention” Pg. 152

“We had to give this gentleman quite a large dose of levomepromazine before we got him settled. And he did settle. He did die afterwards, I think within hours, which proves to me that it was very, very terminal agitation. It was a very large dose of levo that we had to give. And we did not give it all in once. Obviously, we went in, and when it didn’t work, we went in again. I feel that was appropriate. (N1:45 – 51)” Pg. 152 *quote illustrating justification of actions.

Sedating younger people

"The patient's age was a significant factor that led to dilemmas about using palliative sedation. Feelings and concerns regarding the impact of palliative sedation were more powerful if the dying person was younger." Pg. 152

"These rapid changes were frequently the reason why the patient had been admitted to the hospice. Family members regularly indicated their sense of helplessness and expressed a desire for the professionals to take control of the situation" Pg. 152

"This sense of helplessness was also experienced by the nurses, causing them to become cautious in their approaches to administering palliative sedation" Pg. 152

Requests for Sedation and Believing that Hospice Was a Place Where Death Is Hastened

"In many situations, when family members said that they just wanted their loved ones "to be comfortable," it was implicitly understood, and often explicitly expressed, that they wanted the patient sedated and did not want to be exposed to their restless and agitated behavior:" Pg 153

"These related to comments which intimated that family members believed that hospice nurses can, and do, intentionally hasten a patient's death at times. When they had to deal with overt requests from family members to accelerate a patient's death, they were often shocked that the implications were that they would be prepared to actually hasten the death" Pg. 153

"However, one of the more senior nurses admitted that she found not being able to discuss treatment options with the patient ethically challenging." Pg. 153

Being supported

"The importance of support when making decisions about administering palliative sedation was heavily emphasized. This included having opportunities to share the decision making with team members." Pg. 153

"One newly qualified nurse admitted to being very frustrated when she felt out of her depth and could not find anybody on the ward to talk to, from whom to seek advice" Pg. 153-154

“Being praised for “doing a good job” was also perceived by the nurses as a form of support. It reassured them that their actions were acknowledged and approved regardless of whether it came from the management or the relatives” Pg. 154

Discussion

“All of the patients discussed by the participants had cancer, confirming that this patient group is the most likely to receive palliative sedation” Pg. 154

“Our data also revealed a strong focus on experiences related to decision-making dilemmas specific to the type of medications that were used rather than perceptions about the experiences of family members” Pg. 154

“As also found in our study, in some instances the nurses found that the act of administering sedation for terminal restlessness was interpreted as “attempts to hasten death” “ Pg. 155

“The nurses in our study generally felt supported by the hospice team in decision making and in emotionally managing the difficult and complex situations that they encountered when administering palliative sedation. Furthermore, there was a recognition that high-level decision- making required experience, specialist skills, and consultation with team members, a finding upheld by other research” Pg. 155

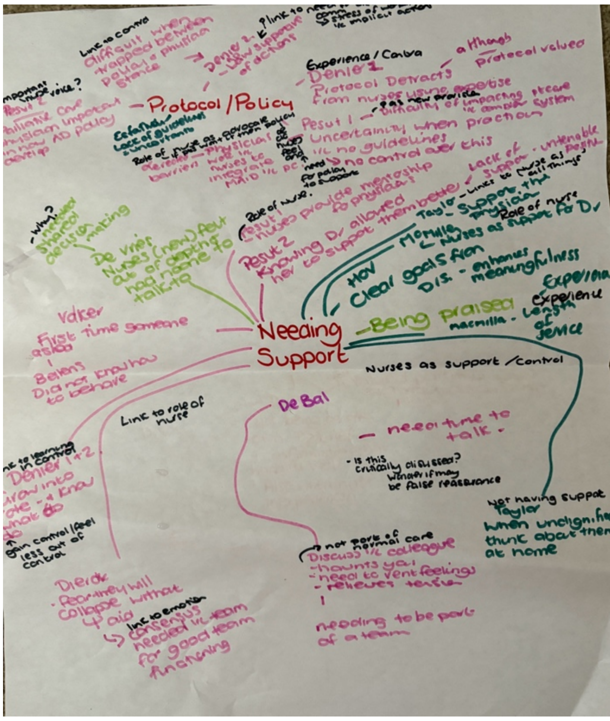
Study conclusions

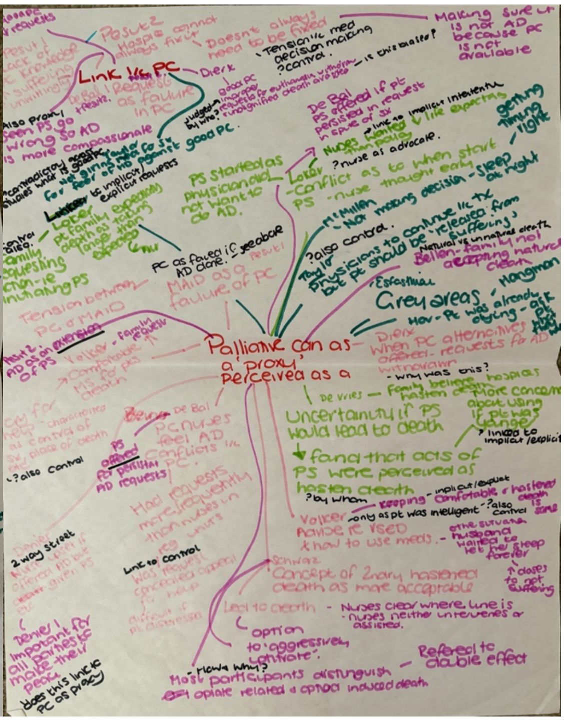
Hospice nurses frequently encountered ethical and emotional dilemmas when making decisions about and administering palliative sedation. In the United Kingdom, a hospice nurse is frequently the primary clinician who engages in discussions about symptom management with patients and families and is also the clinician who administers the palliative sedation medication. Our study demonstrates that hospice nurses are regularly faced with the responsibility of making decisions about complex symptom management and medication regimes when administering palliative sedation. Making such decisions requires confidence on the part of the nurses as well as good communication and sound supportive teamwork within the hospice

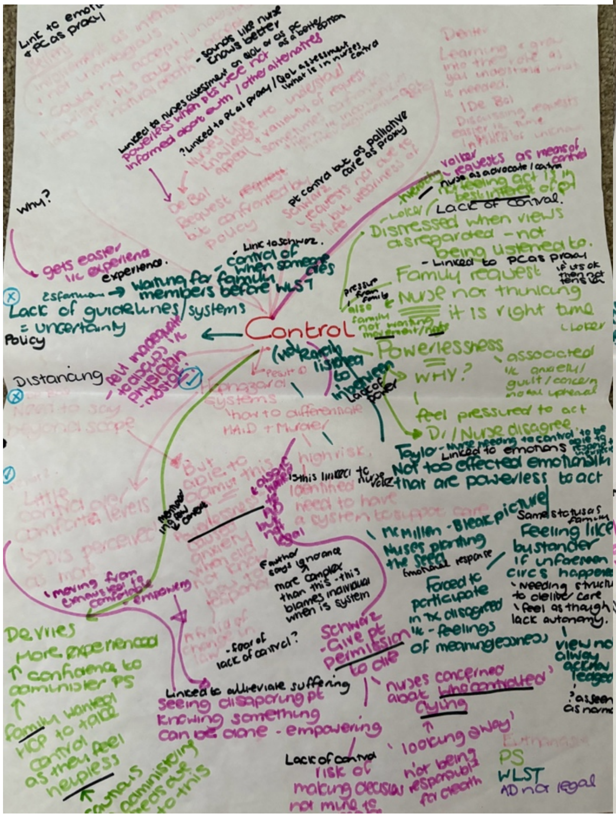
General reviewer comments

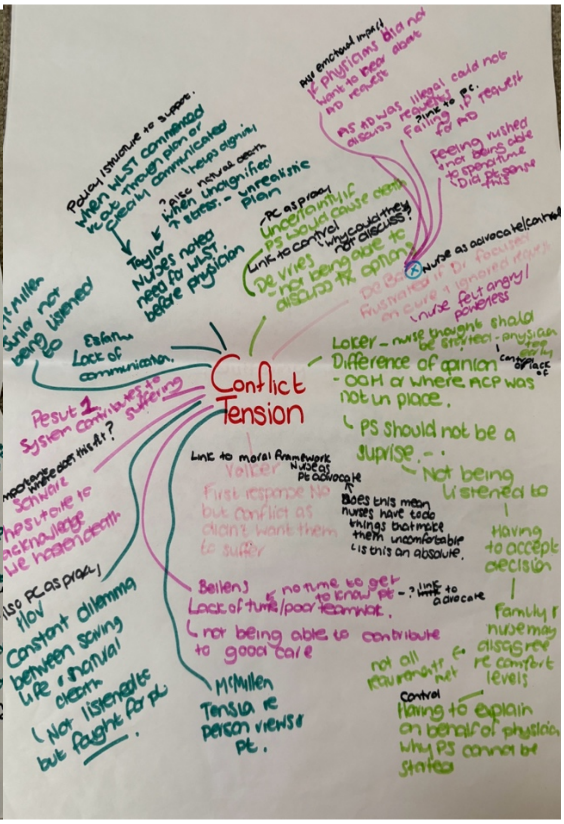
Aims not overtly stated however in the objective in the abstract it states it is looking at people with cancer although this appears to be just the sample that was gained through the recruitment

Appendix 2: Examples of coding and theme development process within the qualitative evidence synthesis









Appendix 3 : Summary of papers included in the qualitative evidence synthesis

Author and year	Country	Research question/s or aims	Sample	Data Collection	Methodology and analysis	Key findings
Palliative sedation						
Beel et al. (2006)	Canada: Manitoba Status of assisted dying: Not legal (prior to legislature)	Explore nurses' knowledge, attitudes and the meaning nurses attributed to the use of palliative sedation in dying adult patients in a palliative care unit.	Purposive sampling. 10 nurses within specialist palliative care unit, experience of palliative sedation.	Individual semi-structured face to face interviews	Qualitative study using symbolic interactionalism. Thematic content analysis.	Theme Working your way through the quagmire. Sub themes Definitional quagmire - Difficulty in the definition of palliative sedation. Indications for use quagmire - Uncertainty of when to use palliative sedation. The need to create comfort. The traumatic effect of not managing symptoms.

						Team and family readiness for administration.
De Vries and Plaskota (2017)	United Kingdom Status of assisted dying: Not legal	The experiences of hospice nurses when administering palliative sedation in an attempt to manage the terminal restlessness experienced by cancer patients.	Purposive sampling. 7 nurses within hospice, experience of palliative sedation within the past year.	Individual semi-structured interviews	Qualitative study using a Phenomenological approach.	<u>Theme</u> Facilitating a peaceful death <u>Sub-themes</u> Decision making and ethical and emotional conflict Causing the death Sedating young people Requests for sedation and believing that hospice was a place where death is hastened Being supported
Lokker et al. (2018)	Netherlands Status of assisted dying: Legal	Explore nurses' reports on the practice of palliative sedation focusing on their experiences with pressure, dilemmas and	Convenience sampling. 36 nurses across a range of clinical areas recruited through	Individual semi-structured interviews	No description of methodology Analysis undertaken using constant comparative method	<u>Themes</u> Experiencing constraints preventing action Experiencing pressure to act <u>Subthemes</u> Experiencing pressure to act before and during the palliative sedation process

		morally distressing situations	involvement in previous study			
Withdrawal of life-sustaining treatment						
Efstathiou and Walker (2014)	United Kingdom Status of assisted dying: Not legal	Explore the experiences of intensive care nurses who provided end-of-life care to adult patients and their families after a decision had been taken to withdraw treatment.	Purposive sampling. 13 nurses working in intensive care from 1 hospital	Individual semi-structured interviews	Descriptive exploratory qualitative approach. Data analysed using interpretative phenomenological analysis	Themes Caring for the dying patient and their family Providing and encouraging presence Reconnecting the patient and their family Dealing with emotions and ambiguity
Halcomb et al. (2004)	Australia	Investigate the experience of nurses caring for	Convenience sampling.	Individual conversational	Qualitative study using Phenomenological approach	Themes Comfort and care Tension and conflict

	Status of assisted dying: Not legal (prior to legislature)	clients in the ICU having treatment withdrawn or withheld.	10 nurses with experience of withdrawal of life-sustaining treatment.	interview.		Do no harm Nurse-family relationships Invisibility of grief and suffering
Hov et al. (2007)	Norway Status of assisted dying: Legal	Acquire a deeper understanding of what it is to be an intensive care nurse in situations related to questions of withholding or withdrawing curative treatment.	Purposive sampling. 14 (female) nurses working in intensive therapy unit.	Two focussed non-structured group interviews.	Qualitative study using interpretive phenomenology	Themes Loneliness in responsibility. Alternation between optimism and pessimism. Uncertainty – a constant shadow. Professional pride despite little formal influence.

Johnson and Jack (2022)	United Kingdom Status of assisted dying: Not legal	Explore experiences of high dependency unit (HDU) nurses caring for patients approaching withdrawal of life-sustaining treatment. Highlight any support or needs they may have.	Purposive sampling. 15 nurses with greater than 12 months experience working within an HDU	Individual semi-structured interviews	Qualitative descriptive methodology	Theme Supporting HDU nurses to provide and survive withdrawal of life-sustaining treatment Sub-themes Conflict in decision making Prolonging distress Moral distress The need to talk The need for further education
McMillen (2008)	United Kingdom Status of assisted dying: Not legal	Explore the perceptions, feelings and experiences of nurses relating to end of life decision making in one ICU in the United Kingdom	Purposive sampling.8 nurses working in the same ICU	Individual semi-structured interviews	Constructivist grounded theory. Analysis using framework analysis	Theme The nurses role Sub themes Experience counts Not really a nurses decision Planting the seed Supporting the family Being a patient advocate Theme

						Perceptions of the withdrawal of treatment <u>Sub themes</u> Getting the timing right Emotional labour
Taylor et al. (2020)	Norway Status of assisted dying: Not legal	Explore the experience of intensive care nurses when participating in the withdrawal of life-sustaining treatments from intensive care unit patients	Purposive sampling. 9 nurses with greater than two years' experience and experience of withdrawal of life-sustaining treatment	Individual semi-structured interviews	Qualitative descriptive and exploratory design	<u>Categories</u> ICU nurses' experiences of stress in the process of treatment withdrawal A requirement for interdisciplinary support and cooperation Elements to achieve a dignified treatment withdrawal process.
Verderspank-Wright	Canada	Explore the experiences of	Purposive sampling. 6	Individual semi-	Qualitative phenomenological study	Overarching concept: Trying to do the right thing.

et al. (2011)	Status of assisted dying: Not legal (prior to legislature)	critical care nurses caring for patients through withdrawal of life-sustaining treatment. Identify factors which nurses feel hinder or facilitate them caring for these patients.	nurses with over 6 months experience and cared for someone during withdrawal of life-sustaining treatment.	structured interviews		<u>Themes</u> A journey: creating comfort along the way Working in professional angst Providing memories
Assisted dying						
Bellens et al. (2020)	Belgium Status of assisted dying:	To explore how Flemish nurses working in hospitals and home care experience their involvement in the	Purposive and snowball sampling. 26 nurses working in hospital or	Individual semi-structured interviews	Qualitative study using grounded theory Analysis informed by Qualitative Analysis Guide of Leuven	<u>Themes</u> Intense and not unambiguous Professional fulfilment Frustration

	Legal	care of patients requesting euthanasia 15 years after the legalisation of euthanasia	home care with experience of euthanasia			
Beuthin et al. (2018)	Canada – British Columbia Status of assisted dying: Legal	Understand the range of nurses' experience in providing care for someone choosing MAiD, whether directly aiding, providing supportive care, or declining to participate	Purposive sampling. 17 nurses working across varied clinical setting.	Individual semi-structured interviews either face to face or via telephone.	Qualitative design using narrative enquiry. Data analysis using thematic analysis	Theme Profession of nursing Subthemes Holistic care without judgment Advocating choice Supporting a good death Theme Personal impact Subthemes Being pioneers Sensemaking: Taking a stand Experiencing emotional spectrum Theme Nursing practice.

De Bal et al. (2006)	Belgium-Flanders Status of assisted dying: Not legal (prior to legislature)	Explore nurses' involvement in the care for patients requesting euthanasia.	Purposive sampling. 15 nurses working in two acute hospitals in Flanders	Individual semi-structured interviews	Qualitative study using grounded theory. Constant comparison method, in line with grounded theory approach	<u>Themes</u> The nurses' conflicted feelings about (their involvement in) euthanasia Powerless: the central emotion experienced by participants The context of nursing care Nurses' key role in caring for patients with a euthanasia request: the process model.
Dierckx de Casterle et al. (2006)	Belgium-Flanders Status of assisted dying: Not legal (prior to legislature)	Palliative care nurses' views on their involvement in the care process surrounding euthanasia.	Purposive sampling. 12 nurses working in a palliative care setting.	Individual semi-structured interviews.	Qualitative study using grounded theory. Constant comparison method in line with grounded theory approach	<u>Themes</u> Hearing a request for euthanasia Participation in decision-making process Participation in the execution of euthanasia Supporting family members and colleagues

Denier et al. (2009)	Belgium - Flanders Status of assisted dying: Legal	What does participation in the euthanasia case process actually mean for the nurse involved?	Purposive and theoretical sampling. 18 nurses working in an acute hospital setting.	Individual semi-structured interviews - recalling a recent case of a euthanasia request.	Qualitative study using grounded theory approach Interview transcripts systematically examined to identify themes	Nurses had a procedural, action-focussed perspective or an existential-interpretative perspective which determined their view on the process. This manifests during the process, understanding of the purpose of involvement, extent of involvement and how it may evolve over time.
Denier et al. (2010)	Belgium - Flanders Status of assisted dying: Legal	To explore nurses' experiences in caring for patients requesting euthanasia.	Purposive and theoretical sampling. 18 nurses working in an acute	Individual semi-structured interviews, paper using the same dataset	Qualitative study using grounded theory approach Analysis method not described.	<u>Themes</u> Intense Experiences which changed and developed over time Various factors which positively or negatively influenced the nurses' experience of the euthanasia care process

			hospital setting.	as Denier et al. (2009)		
Hébert and Asri (2022)	Canada - Quebec Status of assisted dying: Legal	Explore how Quebec nurses personally and professionally face the new practice of MAiD and their role evolution. To describe the paradoxes experienced by nurses	Theoretical sampling. 37 Nurses within who had participated in MAiD. Nurses were French speaking no discussion about translation	Individual semi-structured interviews and focus groups	Qualitative study using grounded theory Constant comparison method in line with grounded theory approach	Nurses experienced a wide range of paradoxes during MAiD centred around 8 elements Confrontation about death Choice Time of death Emotional load New Bill Relationships with the person Communication skills Healthcare settings

Pesut, et al. (2020a)	Canada Status of assisted dying: Legal	Understand the implications of a legislated approach to assisted death for nurses' experiences and nursing practice.	Convenience, purposive and snowball sampling. 59 nurses who had been involved or conscientiously object to MAiD	Individual semi-structured interviews	Qualitative study, interpretative description. Constant comparison method	Themes The leadership taken by influential people within systems The presence and nature of a multi-disciplinary team The systems' complexity and capacity to support MAiD
Pesut et al. (2020b)	Canada Status of assisted dying: Legal	To describe nurses' moral experiences of MAiD in the Canadian context	Convenience, purposive and snowball sampling. 59 nurses who had	Individual semi-structured interviews. Uses the same	Qualitative study, interpretative description. Constant comparative method.	Theme Willingness to participate in MAiD: Morally relevant factors Sub themes Family and community influence\ Professional experiences Proximity to the act of MAiD Theme

			been involved or conscientiously object to MAiD	data set as Pesut et al. (2020a)		Experience of MAiD Sub themes Emotional experiences. Attributions Theme Moral waypoints Sub themes Patient choice, control and certainty It's not about me Nurses' role in alleviating suffering Moral consistency Reflections on the afterlife Peace and gratitude
Pesut et al. (2021)	Canada - British Columbia Status of assisted dying: Legal	Describe the experiences of nurses and nurse practitioners with the implementation and ongoing development of MAID from Bill C-14 to Bill C-7.	Purposive and snowball sampling. 50 nurses working across any setting	Individual semi-structured interviews via telephone.	Qualitative longitudinal descriptive study Constant comparative analysis	Theme Implementing Bill C-14: transitions and challenges Sub themes Normalised to a point From secrecy to visibility Greater accessibility Trusting the process

			within English-speaking provinces			Increase case, complexity and workload Remuneration challenges MAiD and palliative care: tensions and synergies Patient choice and inequities in access Benefits and challenges of programme integration <u>Theme</u> Eligibility and safeguards under C-14 <u>Sub themes</u> Evolving gestalt of eligibility Stress of telling someone they are ineligible Finding a wat to make someone eligible Waiting periods and final consent <u>Theme</u> Anticipating Bill C-7 <u>Sub themes</u>

						New population brings new complexities A cry for help not MAiD
Pesut et al (2024)	Canada Status of assisted dying: Legal	To explore the evolving practices related to MAID in Canada from the perspective of nurses.	Convenience, purposive and snowball sampling. 35 nurses with clinical experience of MAiD.	Individual semi-structured interviews	Interpretive descriptive study. Constant comparative analysis	Theme Introducing MAID as part of Advance Care Planning Living beyond capacity: waivers of consent Hastened death when death is not foreseeable: many shades of grey
Schwarz (2003)	United States of America Status of assisted dying: Not legal	What is the nature of the experience of being asked to help someone die	Voluntary response sample. 10 nurses who believed a competent person had asked them	Individual interviews	Van -Manen's phenomenology and thematic summary	Theme _Being open to hear and hearing Interpreting and responding to the meaning Sub themes Multiple meanings of hastening death Use of double-effect reasoning and the meaning of intentions

			for help dying.			<u>Theme</u> Responding to persistent requests for AID <u>Sub themes</u> Finding a moral line Conflicts and control over dying Providing direct AID
Volker (2001)	United States of America Inc. Oregon Status of assisted dying: Not legal	To explore oncology nurses' experience with receiving requests for assisted dying from terminally ill patients with cancer.	Purposive sampling. 40 Clinical Nurse Specialists in oncology	Submitted written stories, 48 included	Descriptive, naturalistic study. Thematic analysis interpretive interactionism.	<u>Theme</u> Control <u>Subthemes</u> Cry for help Hastening the process. What if….. Managing the morphine Countering with palliative care <u>Theme</u> Conflict <u>Subtheme</u> Collision of values. Distress <u>Theme</u> Covert communication

						Subtheme The dialogue around the request The silent knowing Theme The enduring influence Sub themes The unforgettable Lessons learnt

Appendix 4 : Participant information sheet

Participant Information Sheet

The responses of nurses working within specialist palliative care services in the United Kingdom when assistance to die is requested

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

My name is Victoria Ali and I am conducting this research as part of a PhD thesis within the Division of Health Research at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to gain an understanding of how nurses, working in specialist palliative care services in the United Kingdom, may respond to requests for assistance to die from patients. Through the use of individual interviews, the study aims to gain insight into how and why nurses may respond to these discussions and the factors that may influence this.

Why have I received this?

You have been sent this because the study requires information from nurses who work within specialist palliative care in the Kingdom and you have contacted me via the study webpage. Thank you for taking the time to respond and also your interest in being involved in this study.

Do I have to take part?

No. It’s completely up to you to decide whether or not you take part, thank you for your interest so far. You are able to withdraw your interest from the study prior to the interview at any point that you wish to do so.

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

If you decide you would like to take part, you would be invited to a single individual interview with me. The interviews will take up to 60 minutes and will be based around the discussion of a clinical scenario. The interviews will be held over Microsoft Teams and it is encouraged that you are in a quiet and private place for the interview. The interviews will be recorded and subsequently transcribed for analysis. You will be sent a consent form via email to review prior to the interview and the interview will be held after this is returned to the researcher. We can also arrange a pre interview call/s to clarify any aspects of the study if you wish.

Will my data be identifiable?

The information you provide is confidential within the research team and your contribution to this research will be anonymised. Your identity will be protected by using a pseudonym (you can choose your own) both within the transcript and within any outputs from the study. There will be limited data collected about your role and region of work, no further professional identifiable information will be collected. Data collected for this study will be stored securely and only the researchers conducting this study will have access to these data.

Specifically:

- Audio and video recordings will be deleted once the study has examined in fulfilment of the PhD requirements
- Transcriptions and recordings of your interview will be stored securely within the University online cloud storage, OneDrive.
- Transcripts will be kept for 10 years in line with the standard University guidance.
- The typed version of your interview will be made anonymous by removing any identifying information including your name, your pseudonym will be used.
- 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 your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is 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 results will be summarised and reported in a thesis as part of the PhD and may be submitted for publication in an academic or professional journal or presented at a conference.

Are there any risks?
There are no direct risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet. You can also stop in the interview at any point you wish.

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.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the main researcher:
Victoria Ali

Email: v.ali@lancaster.ac.uk
Project Supervisor details Professor Nancy Preston
Email: n.j.preston@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 Bruce Hollingsworth Director of Studies
Email: b.hollingsworth @lancaster.ac.uk Division of Health Research
Lancaster University Lancaster
LA1 4YW

If you wish to speak to someone outside of the PhD Doctorate Programme, you may also contact:
Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk Faculty of Health and Medicine
(Division of Biomedical and Life Sciences) Lancaster University
Lancaster LA1 4YG

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

Resources in the event of distress
If through the involvement in this study you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.
NHS confidential support line is available via 0300 131 7000
Please contact your GP for support and signposting to further NHS services
If you wish to talk to someone urgently please contact The Samaritans – call free 116 123

Appendix 5: Consent form

Consent Form

Study Title: The responses of nurses working within specialist palliative care services in the United Kingdom when assistance to die is requested: a qualitative study using reflexive thematic analysis

We are asking if you would like to take part in a research project that is looking at the responses of nurses working within specialist palliative care when patients wish to discuss assistance to die. The research is interested in your potential experience and responses to patients, this is specifically considering an assisted death but also may include other forms of hastened death such as de-escalation of interventions or voluntary stopping eating and drinking. The study will be using a vignette to frame the discussion on this topic.
Before you consent to participating in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. Then please sign and return the form via email.

If you have any questions or queries before signing the consent form please speak to the principal investigator, Victoria Ali. Your consent will also be confirmed verbally prior to the interview.

I confirm that I have read the information sheet and fully understand what is expected of me within this study	
I confirm that I have had the opportunity to ask any questions and to have them answered.	
I understand that my interview will be recorded via Microsoft Team and also audio recorded and will then be made into an anonymised written transcript.	
I understand that audio and video recordings will be kept until the research project has been examined.	
I understand that my participation is voluntary and that I am free to withdraw without giving any reason.	

I understand that once my data have been anonymised and incorporated into the analysis it might not be possible for it to be withdrawn, although every attempt will be made to do so. I understand that I have up to 14 days after the interview to withdraw my participation in the study.	
I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.	
I consent to information and quotations from my interview being used in reports, conferences and training events.	
I understand that the researcher will discuss data with their supervisor as needed.	
I understand that 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 principal investigator may need to share this information with their research supervisor	
I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.	
I understand that my stored data may be used by other researchers during this period for secondary data analysis	

I consent to take part in this study

Name of Participant___________________ Signature_____________________

Date ___________

Name of Researcher __________________Signature ____________________

Date ___________

By proceeding with the interview you confirm that:

- You have read the participant information sheet and understand what is expected of you within this study

- You understand that any responses/information you give will remain anonymous
- Your participation is voluntary
- You consent for the information you provide to be discussed with my supervisor at Lancaster University
- You consent that the data will be pooled and published and that quotes could be published
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished

Appendix 6: Vignette

Today you are seeing a patient who you have known for the past six months. They are 62 years old and were diagnosed with Motor Neurone Disease 3 years ago. They are married and have two children, both in their twenties, both living around an hour's drive from their parents.

The symptoms your patient has been experiencing have increased in recent months, and they have always talked openly with you about this. You are seeing the patient today as part of a routine assessment. They are finding the symptoms they are experiencing, as they say, "much more difficult to manage and accept". In particular they tell you that it is the deterioration in speech and swallowing that are most upsetting and they feel that their family are also finding this difficult to see happen. Your patient offers today that they have spoken to their family about the fact that their disease is palliative and know that they will eventually die from this and feel that they want this to be soon and something that they can be in control of. They tell you they have spoken to their partner about helping them to die, either in the UK, but have also been researching whether they could travel to Dignitas in Switzerland, and their family may be willing to help. They wonder what you think they should do?

Appendix 7: Interview guide

Interview schedule/topic guide

Introduction

Introduce self and brief outline of the aims of the study.

Expected to be an hour – how long do they have?

Reiterate that the interview will be recorded.

Reiterate that the person can stop at any point if needed.

Check that the participant has read the participant information sheet and clarify consent.

Demographics

Clinical Vignette

Show on screen and read out

Explain the terms that are used

Question guide

Does this feel familiar to you?

1. *Talk me through your assessment with this patient?*

Trigger questions

- How may you respond to her request?
- Any alternative for care – ceilings of treatment etc?
- What do you find to be the most morally justifiable choice?
- Can you tell me more about the reasons behind your response?
- Do you think other nurses may react the way you will, and why? - include
- Why do you feel about having this conversation?
- Can you discuss the possible consequences of their decision and summarise your action plan.

2. *What so you think the key moral aspects and/or ethical dilemmas in this case?*

Trigger questions

- What is the nurse’s responsibility key obligations towards this patient?
- What do you understand by obligations?
- What are the medical aspects that may impact on the decision making?
- How may the team you work within respond to your actions and does this influence your response?
- What patient or social aspects may impact or that you take into account? Why is this?

3. *What do you think the expectations are of you in this case?*

Trigger questions

- What does respect for autonomy mean in this situation?
- What are your obligations to the patient and family?
- What are your obligations towards the team?

Talk me through the action plan again

Other aspects

If this was legal how may this influence your response?

Where are the limits in the conversation?

What do they understand by the law?

Interview participants debrief outline and distress protocol

Immediately following the interview

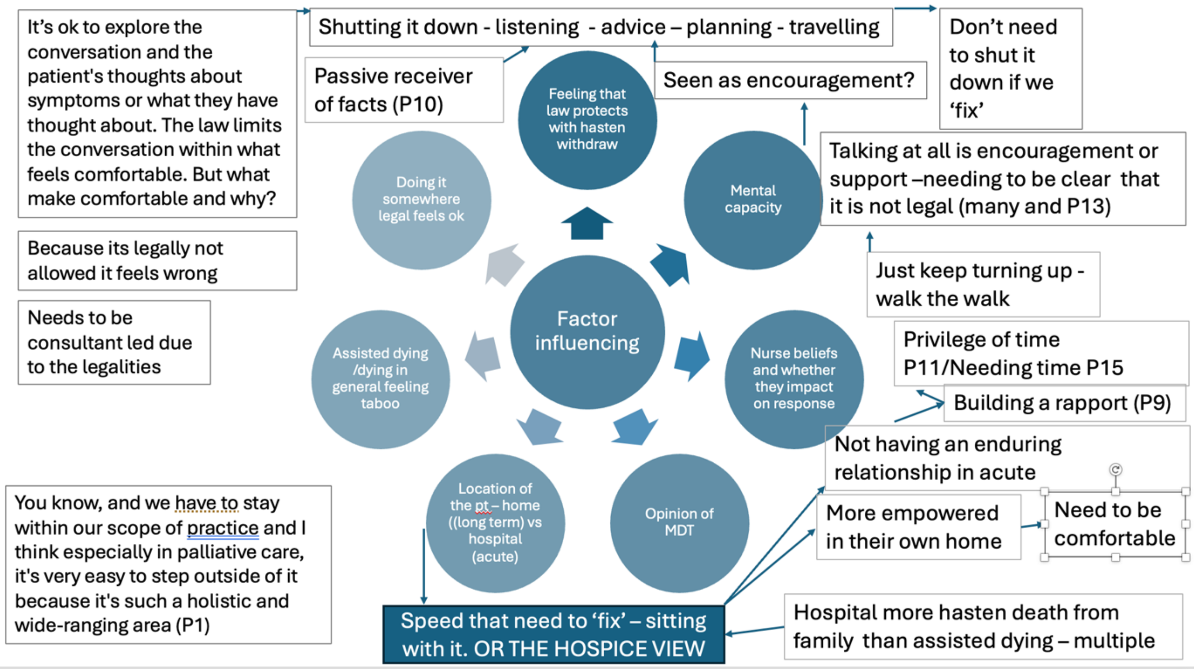
How do you feel?

How did you find the interview?

Sources of support and signposting to organisations as needed

Clarification of follow up contacts if any questions or concerns arise as a result of participating in the project. The participant will be signposted to contact the researcher at any point if they wish. This information is also contained in the patient information leaflet but to be specifically given post interview

Appendix 8: Examples of the analysis process within the empirical study



It's ok to explore the conversation and the patient's thoughts about symptoms or what they have thought about. The law limits the conversation within what feels comfortable. But what make comfortable and why?

Shutting it down - listening - advice – planning - travelling

Don't need to shut it down if we 'fix'

Passive receiver of facts (P10)

Seen as encouragement?

Feeling that law protects with hasten withdraw

Doing it somewhere legal feels ok

Mental capacity

Talking at all is encouragement or support –needing to be clear that it is not legal (many and P13)

Because its legally not allowed it feels wrong

Factor influencing

Just keep turning up - walk the walk

Needs to be consultant led due to the legalities

Assisted dying /dying in general feeling taboo

Nurse beliefs and whether they impact on response

Privilege of time P11/Needing time P15

Building a rapport (P9)

Not having an enduring relationship in acute

You know, and we have to stay within our scope of practice and I think especially in palliative care, it's very easy to step outside of it because it's such a holistic and wide-ranging area (P1)

Location of the pt – home ((long term) vs hospital (acute)

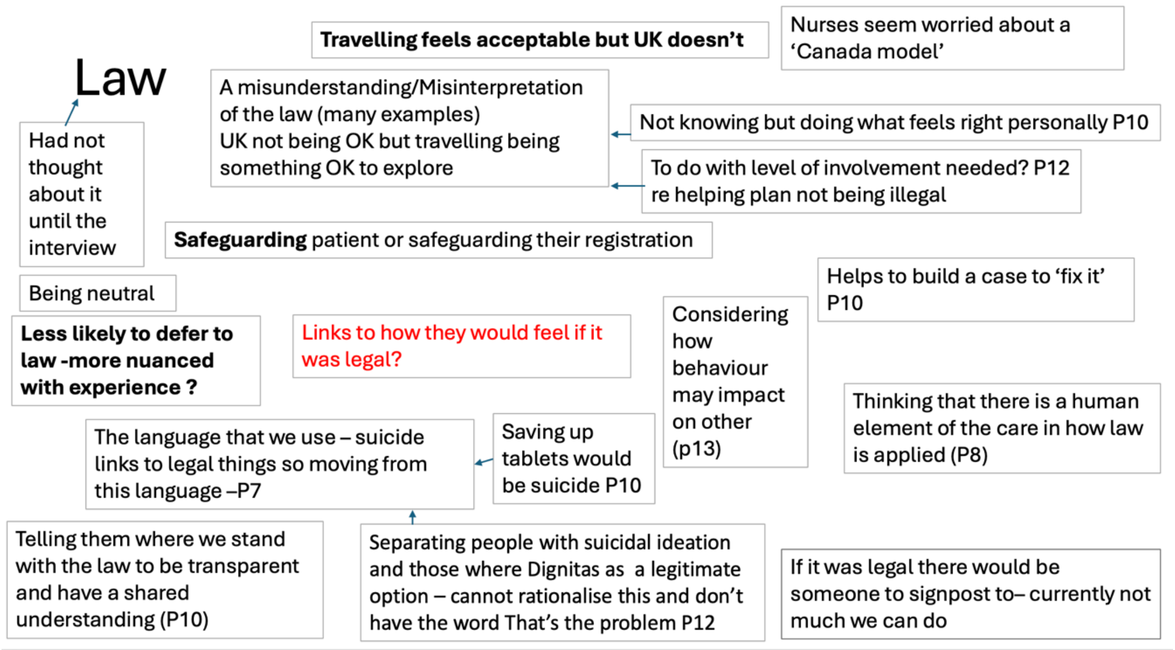
Opinion of MDT

More empowered in their own home

Need to be comfortable

Speed that need to 'fix' – sitting with it. OR THE HOSPICE VIEW

Hospital more hasten death from family than assisted dying – multiple



Travelling feels acceptable but UK doesn't

Nurses seem worried about a 'Canada model'

Law

A misunderstanding/Misinterpretation of the law (many examples)
UK not being OK but travelling being something OK to explore

Not knowing but doing what feels right personally P10

Had not thought about it until the interview

To do with level of involvement needed? P12 re helping plan not being illegal

Safeguarding patient or safeguarding their registration

Being neutral

Helps to build a case to 'fix it' P10

Less likely to defer to law -more nuanced with experience ?

Links to how they would feel if it was legal?

Considering how behaviour may impact on other (p13)

Thinking that there is a human element of the care in how law is applied (P8)

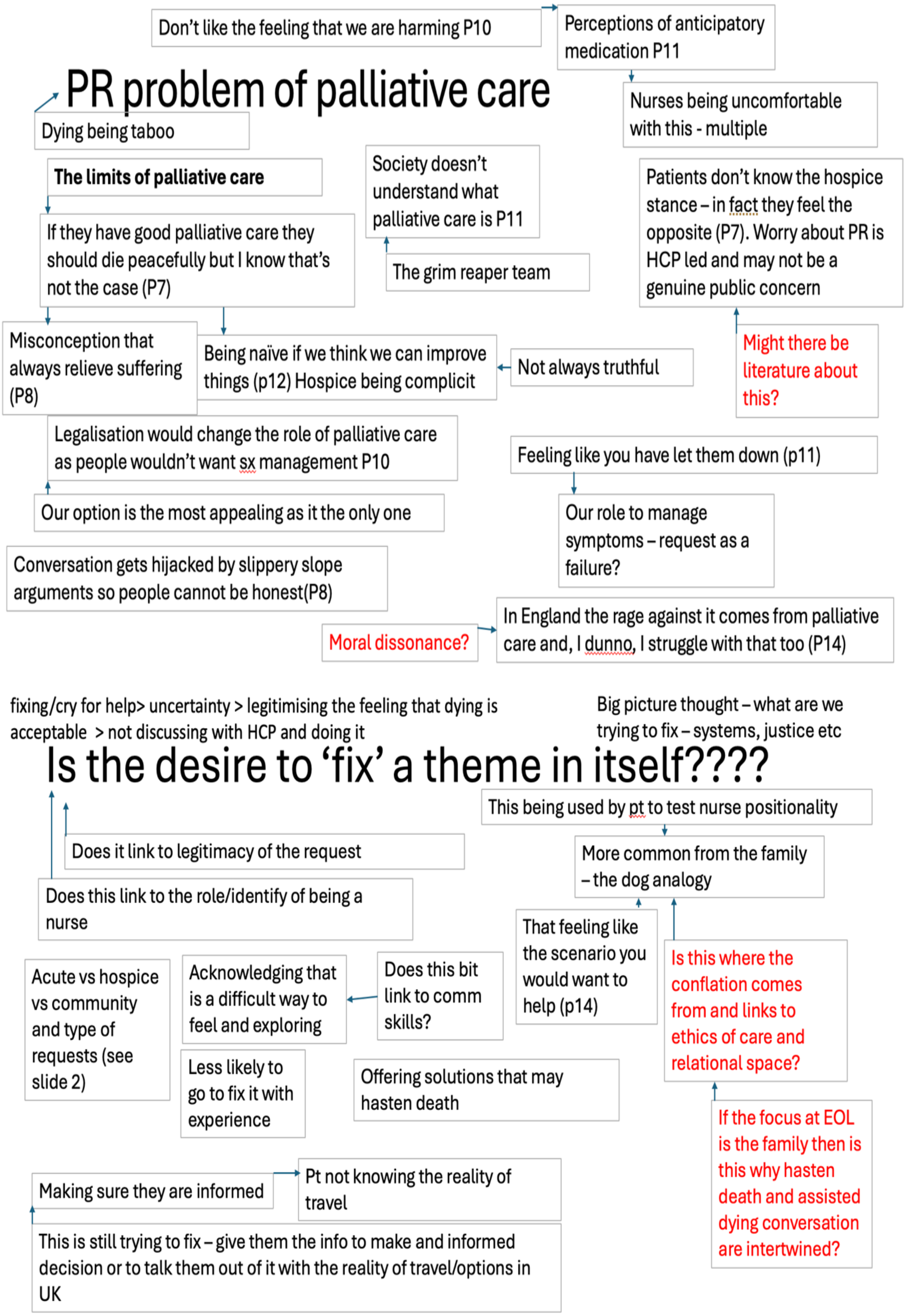
The language that we use – suicide links to legal things so moving from this language –P7

Saving up tablets would be suicide P10

Telling them where we stand with the law to be transparent and have a shared understanding (P10)

Separating people with suicidal ideation and those where Dignitas as a legitimate option – cannot rationalise this and don't have the word That's the problem P12

If it was legal there would be someone to signpost to– currently not much we can do



Don't like the feeling that we are harming P10

Perceptions of anticipatory medication P11

PR problem of palliative care

Nurses being uncomfortable with this - multiple

Dying being taboo

The limits of palliative care

Society doesn't understand what palliative care is P11

Patients don't know the hospice stance – in fact they feel the opposite (P7). Worry about PR is HCP led and may not be a genuine public concern

If they have good palliative care they should die peacefully but I know that's not the case (P7)

The grim reaper team

Misconception that always relieve suffering (P8)

Being naïve if we think we can improve things (p12) Hospice being complicit

Not always truthful

Might there be literature about this?

Legalisation would change the role of palliative care as people wouldn't want sx management P10

Feeling like you have let them down (p11)

Our option is the most appealing as it the only one

Our role to manage symptoms – request as a failure?

Conversation gets hijacked by slippery slope arguments so people cannot be honest(P8)

Moral dissonance?

In England the rage against it comes from palliative care and, I dunno, I struggle with that too (P14)

fixing/cry for help> uncertainty > legitimising the feeling that dying is acceptable > not discussing with HCP and doing it

Big picture thought – what are we trying to fix – systems, justice etc

Is the desire to 'fix' a theme in itself????

This being used by pt to test nurse positionality

Does it link to legitimacy of the request

More common from the family – the dog analogy

Does this link to the role/identify of being a nurse

That feeling like the scenario you would want to help (p14)

Is this where the conflation comes from and links to ethics of care and relational space?

Acute vs hospice vs community and type of requests (see slide 2)

Acknowledging that is a difficult way to feel and exploring

Does this bit link to comm skills?

Less likely to go to fix it with experience

Offering solutions that may hasten death

If the focus at EOL is the family then is this why hasten death and assisted dying conversation are intertwined?

Making sure they are informed

Pt not knowing the reality of travel

This is still trying to fix – give them the info to make and informed decision or to talk them out of it with the reality of travel/options in UK

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