

**Navigating End-of-Life Conversations in an Oncology setting: A Qualitative
Study of Physician and Patient Perspectives**

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Dedication

“There is a land of the living and a land of the dead and the bridge is love, the only survival, the only meaning”— Thornton Wilder

This thesis is dedicated to my mother, my inspiration.

1954-2016

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Contents

Dedication.....	2
Acknowledgements.....	3
Contents.....	4
Abstract.....	5
Chapter 1: Introduction.....	6
Chapter 2: Background.....	14
Chapter 3: Literature Review.....	34
Chapter 4: Methodology.....	64
Chapter 5: Findings	93
Chapter 6: Discussion.....	138
Chapter 7: Conclusion.....	155
References.....	170
Appendices.....	199

Abstract

Clear communication at the end of life is recognised as essential in oncology, but research highlights persistent challenges in addressing the multiple dimensions of these conversations, including clinical priorities and patients' emotional needs. This study explores how physicians and patients navigate conversations at the end of life within the context of terminal cancer. Semi structured interviews were conducted with four patients diagnosed with terminal cancer and four oncology physicians, at a busy oncology clinic, in a major UK city. Data was analysed using reflexive thematic analysis.

Findings suggest that conversations at the end of life are influenced by the conflicting demands of biomedical priorities and patients' psychosocial needs. Physicians tended to prioritise clinical issues and often avoided existential topics, while patients placed greater emphasis on emotional and spiritual aspects of their experience. Factors such as perceived patient denial, differing attitudes towards family involvement and cultural or religious influences, contributed to these differences. A further dynamic was identified in relation to empathy. Most patients described physicians as empathetic and attentive, whereas physicians reported the emotional strain of repeated exposure to illness and dying and described experiences of 'empathy fatigue'. The varying accounts of empathy do not necessarily indicate opposing perspectives, rather they seem to reflect the positions occupied by patients and physicians. Patients evaluated empathy in the context of their individual encounters, while physicians described working in pressurised environments while managing an ongoing emotional load.

These findings highlight the need for better education and training to enhance physician awareness and an emphasis on a more holistic approach to end of life care, to include sensitivity to cultural and religious beliefs and familial factors.

Chapter 1

Introduction

The aim of this study is to explore how patients and physicians navigate the complexities of end-of-life conversations within the context of terminal cancer, with attention to relational, contextual, and meaning-making processes. The term 'navigation' is used in this thesis to describe the on-going relational process through which physicians and patients engage in EoL conversations. It acknowledges that what occurs within these conversations is influenced by what each person brings to the encounter and by what develops through their interactions. As conversations unfold, they are influenced not only by interactions between participants but also by the broader organisational context in which they take place.

In writing this thesis, I speak from the position of a researcher, bereaved daughter and family therapist. My interest in this topic is deeply personal. It is rooted in my experiences of witnessing my mother's illness and death from cancer (Bhambra, 2019). During this time, I felt the impact of illness both as a relative and as someone who at times felt like a 'second patient', a concept identified in previous research on family experiences of serious illness (Laryionava et al., 2018). These experiences sensitised me to the relational aspects of illness and to the significance of the relationship between physicians, patients and family, during periods of profound uncertainty. An important part of this process was the relationship that we shared with the consultant oncologist (CO), who oversaw her care. While being with my mother in medical consultations and navigating the realities of her prognosis, I found myself

grappling with a feeling of disconnection, with our CO. My mother and I were living through one the most significant existential challenges and our CO seemed distant and impersonal.

As a family therapist, I am attuned to the importance of effective communication, empathy and the need for emotional connection at points of crisis in people's lives. My personal and professional experiences motivated me to explore how such conversations take place in oncology settings, and how these experiences might be improved to enhance the experiences of patients and families. This research takes a systemic approach, seeing communication as relational and context dependent, rather than individual. Conversations are seen as interactive processes shaped by emotional, cultural, professional and institutional factors (Hoffman, 1981). Adopting a systemic lens enables exploration of how meanings about illness, dying and care are negotiated between patients, physicians and families, within clinical encounters.

Context

Communicating about end of life (EoL) is a key task for health professionals who care for patients with advanced cancer and represent a fundamental aspect of quality care (Collins et al., 2018). In the EoL context, physicians and patients' interactions often encompass topics such as prognosis, dying, care preferences and emotional concerns. Research suggests that many patients prefer conversations about prognosis and EoL issues to occur early in the illness trajectory to enable them to participate more actively in planning and decision making (Brighton and Bristowe, 2016). There are several advantages associated with early communication including

patient satisfaction, improved quality of life for patients and less aggressive medical treatment towards the EoL (Harnischfeger et al., 2023). However, both clinicians and patients may find these discussions difficult since they occur during times of uncertainty, emotional stress and tough choices. Gaining insight into how people experience these conversations is vital for enhancing patient care and clinical practice (Cherlin et al., 2005).

Despite the benefits and recommendations for early integration of such discussions into EoL care, studies report that conversations are often initiated too late in the patient's illness trajectory (Mack et al., 2012). This may be explained by the fact that discussing EoL issues is frequently described as one most stressful aspects of working in oncology practice (Granek et al., 2013; Baille et al., 2002). Oncologists tend to avoid initiating and addressing issues in a timely way often because of personal discomfort, death anxiety, lack of confidence and fear of creating distress or destroying hope for patients (Harnishfeger et al., 2023). Patients may also display avoidance or ambivalence in their preferences for information (Collins et al., 2018). These differences may lead to delays in starting EoL discussions. Although communication about EoL issues is a central aspect of oncologists' work, studies have highlighted that oncology clinicians would benefit from more guidance and training in managing such conversations (Harnishfeger et al., 2023), as sub optimal communication affects patient satisfaction and clinical outcomes for patients (Eid et al., 2009).

While previous studies have often examined the perspectives of either physicians or patients (Collins et al., 2018; Rodenbach et al., 2016) relatively few studies have

explored both perspectives together. Yet, patients and physicians may construct different interpretations of their experiences, shaped by their roles, expectations and positions (Moniz et al., 2021). Therefore, examining both perspectives may generate a nuanced understanding of how EoL conversations unfold and highlight barriers and challenges that arise during interactions, including differences in beliefs about death, communication preferences cultural norms, denial, personal discomfort and time constraints (Granek et al., 2013; Harnishfeger, 2023). Understanding these differences is essential for informing communication practices and improving quality of EoL care.

I open this thesis with two brief extracts from interviews conducted as part of the present study, to highlight the complexity that can arise during EoL conversations. The first is from a physician detailing a challenging consultation with a patient, while the second is from a patient reflecting on their experience of a physician, during a serious illness discussion. Although these extracts relate to different encounters, their juxtaposition highlights the range of experiences that might characterise EoL communication. Presenting these examples at the onset helps to situate the research within EoL contexts. These extracts are revisited and examined in greater analytical depth in the findings chapter.

Physician

'she kept interrupting because she was in so much distress that she was just crying and then we had to keep starting again. I wasn't sure how much she'd taken in. Um, she was just in a lot of outward distress to the point that you couldn't really get any of the points that you wanted to make across and do a full consultation without it taking

absolutely ages. And I think, in a way because it took so long and it was so stressful, my empathy for that patient was kind of waning towards the end and I just kind of wanted to have a breather myself. Like it was just a really, really difficult patient’.

Patient

‘His approach, his demeanour, everything about him was just, he was spot on... (name of doctor) never took his eyes off me ... he just took his time and explained it in layman’s terms, and he didn’t baffle me. I felt really comfortable with him, and I felt like I could ask him absolutely anything. He was amazing’.

The present study addresses the following research question:

How do patients and physicians navigate the complexities of conversations at the end of life, in the context of terminal cancer?

Sub Questions

How do beliefs and attitudes about death shape how these conversations unfold?

What barriers or tensions complicate meaningful communication between patients and physicians?

How is family involvement navigated?

Key Terms

In the United Kingdom, EoL care refers to the support and medical attention given to individuals anticipated to be in the final stage of their life. According to guidance from the National Institute for Health and Care Excellence (2011), EoL care applies to adults

who are likely to die within the next 12 months, including those with advanced, progressive or incurable conditions, general frailty and life-threatening acute conditions caused by sudden catastrophic events. Within the National Health Service (NHS) EoL care aims to support individuals to live as long as possible until death, ensuring dignity, comfort and respect, while addressing physical, psychological, social and spiritual needs. It also encompasses advanced care planning, shared decision making, symptom control and support for families and carers (NHS, 2023).

Palliative care (PC) is defined as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It aims to prevent and relieve suffering through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual'. (World Health Organization, 2020). UK guidance from NICE also frames PC as holistic, person-centred care, that can be delivered alongside active treatment and is not restricted to the final phase of life (National Institute for Health and Care Excellence, 2011).

Oncology is a medical speciality concerned with diagnosing, treating and managing cancer through approaches such as chemotherapy, radiotherapy and immunotherapy. In the UK, oncologists typically care for patients at all stages of illness, including when the disease progresses and cannot be cured. Consequently, oncologists are often responsible for communicating information about prognosis, treatment options and care planning (Kassa et al., 2018). While both oncology and PC aim to enhance quality of life for those facing serious illness, they are distinct fields with separate training

requirements (Joint Royal Colleges of Physicians Training Board, 2022; Royal College of Radiologists, 2023). Oncology primarily focuses on treatment directed at tumours whereas specialist PC focuses on symptom relief and holistic support for patients and families (NICE, 2011, updated 2019). NHS policy increasingly supports integrating PC alongside oncology while still recognising the unique expertise of each field (NHS England, 2022). The present study involved patients under the care of oncology teams rather than PC specialists. Therefore, the conversations examined all took place during oncology consultations and not within PC.

The literature review draws on research from both oncology and PC, acknowledging the contribution that each discipline has made to the understanding of communication regarding serious illness and EoL issues, however, it is important to emphasise the oncology context for the present study, as timing, expectations and professional roles may vary across clinical settings (Storey et al., 2011). However, while these UK based definitions provide a framework for this study, international research indicates that key terms such as palliative care and end of life care, are frequently applied inconsistently across healthcare systems and within oncology and PC literature (Hui et al., 2011). Recognising and accounting for this variability is important when referencing international literature, as differences in terminology can impact on the timing of interventions and interpretations of communication processes.

Structure of thesis

This thesis is divided into 7 chapters. Chapter 2 presents a reflexive narrative detailing my personal story of loss. Subsequently, an overview of the relevant medical context, in which the research is grounded, is provided. Chapter 3 examines some of the

relevant theory and research from systemic psychotherapy, oncology care and PC literature. Chapter 4 describes the research design including recruitment, data collection, ethics and my epistemological position, which underpins the research enquiry. Chapter 5 presents the findings, with illustrative quotes from participants. Chapter 6 discusses the findings in relation to the existing literature and chapter 7 concludes with a summary of findings, strengths and limitations, self-reflection and implications for practice and areas for future research.

Contribution to knowledge

The thesis contributes to knowledge by providing a detailed examination of how physicians and patients navigate EoL conversations, within an oncology setting. By bringing together both physician and patient perspectives, it deepens an understanding of how these conversations are influenced by factors including individual beliefs and experiences, clinical uncertainty, emotional labour and family involvement. In doing so, the thesis provides a systemic view of communication as a relational and contextually negotiated process with implications for communication education, clinical practice and professional support for physicians engaged in these conversations.

Chapter 2

Background

This chapter situates the present study within the broader cultural, social and institutional contexts surrounding death and dying, in contemporary healthcare. As this research explores how patients and physicians navigate the complexities of conversations at the EoL, in the context of terminal cancer, it adopts a systemic psychotherapy perspective that understands such conversations as arising within several contexts which intersect. These include family relationships, professional and institutional cultures, as well as social expectations and talk about death, (Fredman, 1997).

In line with a systemic practitioner – researcher perspective, this chapter opens with an account about my own experiences of witnessing my mother's illness and her subsequent death. I then reflect on my volunteer work in a hospice and my professional roles as family therapist and a trainer in the 'Conversations Inviting Change' model, where I have taught communication skills to healthcare professionals. These experiences have shaped my interest in EoL communication and inform the basis from which this research is conducted. This will be followed by an overview of the wider contexts in which EoL communication occurs. I examine evolving societal attitudes towards death and dying, the medicalisation of death and I make some comments on the development of the hospice and palliative care (PC) movement.

From relative to researcher

In 2016, I was training in systemic psychotherapy, when I lost my mother to cancer. In February of that year, she was diagnosed with a low-level treatable cancer. Initially, the prognosis she was given was 'good', well, 'good' as far as cancer diagnosis go, and we were hopeful that she would make a full recovery. But within a few months of her diagnosis, she became increasingly unwell, and a CT scan revealed metastasis, with stage 4 cancer. In a final consultation with our consultant oncologist in July, he delivered the devastating news that 'the treatment hadn't worked' and that my mother had 'weeks to live'. She died in August 2016. When attending hospital appointments, we depended on our consultant's 'expertise' and believed he could 'fix' things. But during the final consultation, our hopefulness became hopelessness, when he broke the news that there was no further treatment available, and that death was imminent. I was struck by how brief that final consultation was. He spoke about the 'non resuscitation order' (NRO) which my mother signed, and he provided details about palliative care support in the community. After we left the consultation room, I remained preoccupied with why the consultant's focus was on the NRO and my sense of his detachment, from his dying patient.

Following my mother's death and as a way of processing my grief, I wrote to our consultant with my thoughts and questions related to my experience of our doctor-patient-family relationship. This punctuated the start of more reflective conversations between us. I saw his communication, through the medium of writing, as his willingness to engage in dialogue, from which something new could perhaps emerge.

I recently re-read the emails which we had exchanged in 2016, and I have reflected on how my thoughts and expectations as a relative have since changed. I now recognise that the experience which I described in my earlier correspondence to the consultant, is only one perspective and was dependent on the context which we were in, at that time. Having conversations with patients and physicians as part of my present research study, has offered me many different perspectives for consideration. To enable me to understand the nuances of their stories, I have had to reflect on and challenge my own biases and fixed ideas, about the physician-patient relationship.

As part of my systemic psychotherapy training which I completed in 2017, I was required to write a dissertation. I used that as an opportunity to explore the following question, 'Sharing bad news with terminally ill cancer patients: What does it mean for a physician to deliver news in a sensitive way?' Based on the outcome of the dissertation and the gaps which were identified in communication skills for doctors, I wanted to utilise my skills as a family therapist and to somehow bridge the gap between the systemic and medical models. It is in this spirit I embarked on the doctoral programme with the intention to research how physicians and patients experience conversations about the EoL. Prior to starting the doctoral programme, I wrote about my experience of loss, my hopes for research and the transition I made from 'relative to researcher' in an article published in Context Magazine (Bhambra, 2019).

In another article published in Context Magazine, I shared details of the struggles which I faced after my mother's death (Bhambra, 2022). My mother was a Hindu and as part of traditional Hindu rituals, to prepare the deceased for the funeral, the body is

washed and dressed by a family member. I completed this ritual for my mother. When I reflect on the experience of watching my mother dying and holding her lifeless body, as I completed the rituals, I realise it was during that time that I first became aware of my own mortality (Bhambra, 2022, p. 18). I had embodied the trauma and suffering that I had witnessed, and this later manifested into a health anxiety, which led me to believe that any small changes in my body were symptoms of an undiagnosed, terminal illness. Each time I experienced a new symptom, I found myself in my doctor's consultation room, seeking reassurance (Bhambra, 2022). I was fortunate to have a doctor who understood my concerns in the context of my grief and my fear of illness, and we were able to work through my anxiety.

I share these personal stories with the intention of highlighting that carrying out research about death has not been straightforward. At different points over the last several years, I have found myself in the grips of a health anxiety, I have relived aspects of my mother's illness and death, as well as confronting other significant life events. I have tried to capture the impact of some of this in my writing i.e., how my experiences have influenced my thinking and the development of my research. I have also found myself reflecting on existential questions, triggered by the stories I heard from the participants, whom I interviewed. They have each taught me something about what it means to 'get close to death' and that death is what gives life purpose. It has been a deeply moving experience and a great privilege to have met my research participants and to have heard their stories.

Volunteer work in a hospice

Prior to starting my research, I volunteered at a hospice in London, in 2022. This was with the intention to join a community who were to become the subject of my research interest. I wanted to get 'experience near', to gain insight into practices related to death and dying. I signed up to do the 'breakfast shift' which involved serving food to patients and having chats with them. By immersing myself in this way, I was able to gain insight into life at the hospice and hear from patients, about their experiences. To my surprise, my attempts to engage health care staff in conversations about their views on death and dying and their experiences of working in a hospice, were not successful. I sensed their reluctance to speak openly about these matters.

I was struck by certain practices which I observed. For example, I recall there was a white board in the kitchen with names of inpatients and information about their dietary requirements and room number. When a patient died, their name would be wiped off the board and replaced with 'died'. I did not hear staff members speak about a patient's death, instead, death was announced through the ritual of 'wiping clean' the board. Observing this process left me feeling uneasy and somewhat confused about why, within a hospice setting, professionals were reluctant to speak about death, openly. This raised the question about the 'denial of death' in PC and the extent to which it impedes conversations with dying patients. Zimmerman (2007, p.297) suggests that 'as a society and as individuals, we have come to recognise ourselves as 'death denying', a self-characterisation particularly prominent in palliative care discourse and practice'. She highlights that 'denial' is an impediment to open discussions about dying and advanced care planning. Further, Zimmerman (2007, p. 297) suggests that 'the

personal struggle with mortality has become an important instrument in the public problem of managing the dying process’.

Narrative medicine and systemic understandings of clinical conversations

Narrative medicine brings together a diverse body of work drawing on medicine, anthropology and sociology (Charon, 2006; Frank, 1995; Kleinman, 1988). In the United States, its development has been closely associated with the work of Rita Charon who defined narrative medicine as an essential part of clinical competence, grounded in close attention to patients’ stories of illness and suffering. In this sense, narrative competence refers to the clinician’s capacity to recognise, interpret and respond to narratives, during medical consultations. Clinical interactions are seen not just as opportunities for exchanging information but spaces where ideas about illness, prognosis and personhood are formed. Charon’s contribution provides an important foundation for examining how narratives play a role in EoL consultations. From a systemic perspective, narrative competence can be understood not only as an individual skill but as a process that unfolds during interactions involving patients, family members and clinicians. Within these encounters, stories about illness may be taken up, challenged or reimagined in ways, often reflecting professional, institutional and cultural discourses. Therefore, narrative medicine offers a way to examine how EoL conversations are influenced and shaped by wider systems of beliefs.

Narrative based primary care emerged in the UK during the 1990s, through the convergence of narrative medicine with family systems medicine (Launer, 2006). This approach positions illness narratives within relational and systemic frameworks,

showing that stories are shaped by ongoing interactions with family members and clinicians over time. From this perspective, narratives do not simply reflect experience but help to structure how responsibility, hope and decision making are negotiated within clinical encounters.

Anthropological perspectives further highlight the cultural and social embeddedness of illness narratives. Kleinman's (1988) distinction between illness as a 'lived experience' and disease defined as an 'alteration in biological structure', draws attention to the way patients draw on available cultural frameworks, to make sense of suffering. Similarly, Frank (1995) suggests that people use storytelling as a way to come to terms with illness, arguing that serious illness disrupts our sense of identity, time and personal orientation and storytelling helps to restore a sense of meaning. Narrative approaches are important in the context of EoL care because conversations often extend beyond diagnosis and treatment to encompass issues related to loss, identity and mortality. Multiple and sometimes competing narratives may coexist within the same consultation i.e., clinicians may orient towards professional narratives of responsibility and emphasise on prognostic discussions and institutional protocols, while patients and families may draw on personal, cultural or spiritual beliefs that sustain hope or resist finality (Hira et al., 2025; Kvale et al., 2022). These differences can shape what is considered appropriate to discuss in consultations and what may contribute to avoidance and tensions in EoL conversations.

Systemic and narrative theorists have highlighted how dominant professional narratives can marginalise alternative meanings and stories, in contexts characterised

by power differences (White and Epston, 1990; Anderson, 1997). This is relevant to triadic encounters involving physicians, patients and families where beliefs and attitudes about death are negotiated. For instance, family members may adopt protective narratives that prioritise hope or provide emotional shielding for the patient, whereas physicians may be compelled to initiate discussions about EoL care planning. Attending to how these narratives interact is important as it allows for a more nuanced understanding of how power differences, silence, tensions and misunderstandings can arise in consultations (Charon 2006; Greenhalgh et al., 2016). Narratives in this sense function as a resource that both enables and constrains what can be spoken about in EoL discussions.

While narrative approaches in an EoL context may be valuable they have also been subject to criticism. A critical perspective is offered by Dutta (2025) who argues that stories do not necessarily provide access to patients lived experience because the story is an interpretation, shaped by language, memory and context, rather than the experience itself. This concern becomes more noticeable in EoL care where physical and cognitive decline or emotional distress, may lead patients to respond with silence or fragmented communication rather than coherent story telling. From this perspective, an overemphasis on narrative competence risks framing such expressions as deficits rather than as common responses to suffering and mortality.

Conversations Inviting Change

Within the UK context, Conversations Inviting Change (CIC) represents a specific application of narrative and systemic ideas, within healthcare education and

supervision (Launer, 2018). Pioneered by Caroline Lindsay and Dr John Launer, CIC is an approach to teaching and practising interactional skills, grounded in narrative concepts and family systems theory. The approach is based on the idea that ‘everyone in health and social care – whether as a patient, service user, or practitioner – tells stories about their experiences and can benefit from being skilfully questioned about them’ (Launer, 2018, p. xii). CIC adapts questioning practices developed in family therapy, particularly drawing on Tomm’s (1988) framework of reflective and strategic questioning and some of the conversational practices of Michael White and David Epston’s (1990) narrative therapy. Within a health care setting, this involves clinicians moving away from seeing themselves as ‘fixers’ of a problem and instead to take the position of a ‘witness and questioner’ in relation to the patients they meet, and to invite the patient to consider their problems from a new perspective (Launer, 2018). While CIC is not specifically designed for EoL care, its emphasis on curiosity, reflexivity and positioning offers a useful framework for attending to how conversations about serious illness unfold.

I have received training in CIC and am part of a team of educators who have delivered training to doctors and other health professionals both in the UK and internationally. My background combined with my training as a family therapist informs my interest in communication practices and my understanding about what constitutes ‘good communication’. I focus on fostering collaboration and practising reflexivity. My background influences me to see communication as a relational process rather than solely an exchange of information and I recognise curiosity and feedback (Watzlawick et al., 1967) as essential components of effective communication. I acknowledge that my way of thinking brings certain expectations to the research process and I am careful

not to assess clinical encounters solely through therapeutic ideals but to analyse them in relation to the context in which they occur.

Death and dying in contemporary society

During the 1950s and 1960s, death was widely regarded as a taboo subject within dominant Euro-American cultural discourses (Newman, 2004; Zimmerman et al., 2004). This period was characterised as the ‘never say die’ ethos in which physicians, sick people and their families, avoided talking about death. Medical practice during this time was also marked by an authoritarian model of care in which physicians were seen as the experts and principal decision makers. Within this framework, the most valued physicians were those who could identify further treatments to forestall death, while patient’s values and preferences were afforded little weight (Byock, 2014, p. xi). It was against this backdrop that Elisabeth Kubler – Ross’s work on ‘*On Death and Dying*’ represented a significant challenge to prevailing norms of medical authority (Byock, 2014). Central to Kubler-Ross’s research which focused on interviews with dying patients, was the belief that open communication about death between physicians and patients could enable a good death (Newman, 2004), thereby reframing death as a process that warranted dialogue and care. More recently there has been renewed emphasis on promoting open conversations about death through public campaigns and initiatives (Launer, 2018; Dying Matters, 2016). However, the emergence of such initiatives suggests that some discomfort and silence around death persists, requiring ongoing efforts to legitimise death talk. To understand why discomfort with death and difficulties in EoL conversations persist, it is useful to

consider how medicine itself came to be organised around particular ways of knowing and speaking about illness and death (Seale, 1998).

Where death was once a communal event, often occurring in the home and witnessed by family members, it has become largely institutionalised and privatised, predominantly occurring in hospitals and other healthcare settings and distanced from daily life. As a result, many people reach adulthood with little direct experience of seeing death and dead bodies (Boas, 2024). Historically, physicians rarely attended the bedside of the dying, instead priests usually offered spiritual care. This dynamic has shifted over time, with the emergence of a new relationship between medicine and death, characterised by the notion 'medicine was now to do battle against death' (Seale, 1998, p. 77). Within this framework, medicine not only delivers medical treatment but also produces a set of protocols, norms and narratives that influences how people perceive illness and dying. Seale (1998) argued that death is not simply a biological occurrence, but a phenomenon shaped by professional ideologies, organisation pressures and institutional protocols. For example, in medical settings death maybe framed as a technical problem or failure, which affects how physicians communicate prognosis, hope and uncertainty.

To examine how institutional factors influence communication, Foucault (2003) offers a framework for understanding how power and knowledge operate within medical encounters. In his analysis in *The Birth of the Clinic*, Foucault described the concept of the 'clinical gaze' as a crucial element in the development of modern medicine (Foucault, 2003). The concept refers to the specific way that the body and illness are

observed and discussed. The patient becomes the object of observation, and the focus shifts to the pathological processes of the body, rather than the personal identity and experience of the patient (Foucault, 2003, p.8). This reorganisation of perception positions physicians as authoritative knowers; by claiming expertise and knowledge in this way, they gain power and patients' subjective accounts risk being marginalised. Foucault argued that power operates through everyday practices, language and institutional norms, making medical knowledge closely linked to power and influencing what can be spoken about within clinical settings. When this theory is applied to EoL conversations, it highlights how medical discourses may determine what is spoken about and what remains unsaid. For example, physicians' discussions about dying often focus on biomedical priorities, while patient perspectives may tend to centre on other concerns. From this viewpoint, Foucault's ideas can help us to understand tensions in EoL communication as outcomes of deeper historically situated structures and beliefs that shape communication.

The advancement in scientific medicine has orientated clinical practice towards the prolongation of life (Heath, 2008). This trend of 'denying death' may carry the implication that physicians experience a sense of failure or defeat, when they cannot keep patients alive or 'prevent death' (Back et al., 2009; Quill, 2000), which may in turn impact on their approach to EoL conversations. Although clinical studies and guidance recommend that conversations about EoL occur early in the cancer trajectory (Harnischfeger et al., 2023; Bailey and Cogle, 2018), such guidance operates within a medical culture historically structured to resist the acknowledgment of death. For example, the Royal College of Physicians report *Talking about dying: how to begin honest conversations about what lies ahead* (Bailey and Cogle, 2018;

updated in 2021) identifies a widespread culture of avoidance and an expectation that modern medicine would cure all ailments. The report acknowledges the difficulties associated with talking about mortality and suggests there is a need for more open conversations. These perspectives are drawn upon to position EoL conversations within wider institutional and socio - historical frameworks. Collectively they highlight how professional expertise, medical authority and organisational structures influence the context in which conversations about death take place. Such theoretical perspectives complement systemic and narrative approaches to communication by bringing attention to how power and responsibility are negotiated within clinical encounters.

In the 1970s, anthropologist Ernest Becker proposed that humans are distinctive in their capacity for 'symbolic self-awareness', which makes them acutely conscious of their own mortality. He argued that this awareness generates in all humans a deep seated, largely unconscious death anxiety, that individuals must manage in order to function in everyday life (Becker, as cited in Yunt, 2024, p. 9). He explained how, to cope with this anxiety, individuals and societies construct shared 'symbolic systems of meaning' including beliefs, religion and moral frameworks which both sustain a sense of purpose and function as a defence mechanism, against death anxiety (Yunt, 2024, p. 11). Although Becker's argument was developed at the level of broad cultural world views, it has implications for understanding professional cultures, including medicine. In this sense, medicine can be understood as a constellation of shared norms, expectations and practices that shape how physicians interpret, approach and communicate about death. Viewed from this standpoint, health care professionals themselves may be vulnerable to death anxiety which can subtly influence how they

communicate with dying patients (Scott, 1981). Becker's theory further emphasises that these challenges are not simply individual but situated within broader cultural and existential contexts that shape the potential for meaningful conversations about death and dying.

Emergence of palliative care

In the 1960s, palliative care (PC) as part of the UK hospice movement, emerged. Arguably, this marked a shift from the perceived cultural 'denial of death' and an attempt to engage with dying patients. In 1967, Dame Cicely Saunders founded St Christopher's Hospice, which was the first hospice in the world to combine pain and symptom management with clinical research, teaching and compassionate care. This approach posed a philosophical and practical challenge to the dominant medical culture of the time, which was primarily focused on curing diseases, rather than supporting patients through the dying process (Launer, 2016). Saunders emphasised that pain is not only physical but also psychological and spiritual. Her work laid the foundation for palliative medicine as a medical speciality (Walsh et al., 2011). PC represented both a medical and cultural innovation as it acknowledged death as an inevitable part of life and sought to humanise the dying process by incorporating social and emotional dimensions into care.

In the UK, hospices are considered specialist PC inpatient units (Pini et al., 2020) that also provide community-based PC services. Previous studies have found that patients who are referred early to PC services may benefit from improved quality of life, fewer hospital admissions and greater autonomy over their EoL care (Zimmerman et al.,

2014). However, patients are often referred late in the illness trajectory, limiting their opportunities to discuss EoL issues (Pini et al., 2020). In the UK, there is variation in hospice use, influenced by area-based deprivation (Chukwusu et al., 2020). Despite the success of hospice care in some areas, terminally ill patients in hospitals often experience care that is hampered by staff shortages and resources, limited recognition of impending death and poor communication with patients and relatives (Launer, 2016).

While the hospice movement and palliative medicine have informed current practices in EoL care, research indicates that these approaches may not always correspond with patient's actual experiences. Julia Lawton's ethnographic study of hospice patients in the UK demonstrates that the principles underpinning hospice philosophy, particularly the facilitation of 'a good death' in which patients are supported to live with autonomy, comfort and dignity until death, may conflict with the realities of bodily deterioration and dying (Lawton, 2000). I am particularly drawn to Lawton's work because of its relevance to a systemic exploration of EoL communication. Drawing on data collected from participant observation; Lawton developed the concept of the 'unbounded body' which refers to the deterioration of the physical body and the breakdown of bodily boundaries such as visible decay and loss of control. This concept highlights how physical decline is not solely a biological process but a socially mediated one as it leads to a reorganisation of roles and communication patterns. For example, if a patient loses speech or cognition, physicians may redirect their conversations towards family members and family members may start speaking on behalf of the patient, rather than with the patient. Lawton's analysis demonstrates that hospice practices correspond to prevailing cultural norms which seek to distance death and the process of dying from daily social life (Lawton, 2000, p. 143) through the

management of patients' physical changes and the discomfort these changes may cause in others. Her findings indicate that difficulties in EoL communication arise not primarily from individual avoidance or insufficient professional skills, but from broader societal constructs surrounding death.

Lawton's analysis of hospice practices also highlights a wider structural issue in EoL care related to the fragmentation between services that attend primarily to dying and those orientated towards cure. This is pertinent in oncology settings where there is a recognised mismatch in the 'culture' of oncology compared to PC services. Walsh et al. (2011, p. 52) make the point that cancer treatment in oncology has been considered problematic in this regard due to the perceived reluctance of some physicians to engage in open discussions about prognosis, in part because of the dominance of the cure orientated model. For example, it is common for people with advanced cancer and a poor performance status to still get chemotherapy, within days of death, reflecting the assumption that a cure or significant palliation is possible for every patient at every stage of disease, without any factual basis to support this approach (Walsh et al, 2011, p. 54). Integrating PC teams with oncology has been proposed to improve cancer care and patient outcomes (Walsh et al., 2011; Bradley et al., 2025). An integration of PC teams with standard oncology care may be an effective way of supporting oncologists in communicating about the EoL, in an open and honest way (Granek et al., 2013, p. 132). Considering these points together with the tensions highlighted by Lawton (2000), it illustrates that EoL communication is shaped by a complex interplay of institutional norms, societal discourses and patients lived experience. This context provides a lens for examining how patients, physicians and families navigate difficult conversations.

Conceptualising end of life communication as a systemic process

EoL communication in terminal cancer has often been viewed as a linear process, positioning the physician as the primary agent and focus on transmission of information from physician to patient (Baille et al., 2000). The present study adopts a systemic perspective, not simply because it offers an alternative perspective but because it enables different questions to be asked about how communication is organised and negotiated within different contexts. Illness and dying are inherently relational experiences, understood as events that reverberate through patterns of relationships, communication and meaning within families (Burnham, 1986). Rather than viewing experiences of illness as located within individuals, a systemic perspective examines how families adapt to illness and handle the stress and uncertainty that illness evokes (Minuchin, 1974; Bowen, 1978). This way of thinking reveals interaction patterns such as shared participation, silence and authority in decision making, that may be overlooked in linear models. Life limiting illnesses often intensify family roles and challenge the family's equilibrium. Some members might adopt protective positions, for example, become gatekeepers of information and decision making, while other members become marginalised, or actively avoidant of explicit discussions about dying (Asen, 1995). Changes in roles can be seen as adaptive responses to the emotional demands of impending loss (Rolland, 1994).

Within a medical context, heightened anxiety associated with terminal illness can increase triangulation with physicians drawn into family dynamics as mediators, allies or perceived authorities (Bowen, 1978). Boundaries between patients, families and

clinicians are constantly being negotiated and particularly in EoL care, boundaries may become more blurred as dependency increases and care becomes intimate. From a systemic perspective, instead of viewing physicians as the sole initiator of conversations and patients and families as passive respondents, meaning is recognised as a product of interaction between participants and influenced by broader social and cultural contexts (Bateson, 1972). Topics which are addressed or avoided in communication are seen to be influenced by the expectations, emotional responses and personal histories of everyone involved.

From a systemic perspective, *good* and *effective* communication in this context can be characterised by understanding, connection, and shared meaning. Back et al. (2009) suggest that key characteristics include empathy, attunement, attentiveness, honesty and responsiveness, together with the capacity to navigate complexity. Watzlawick et al. (1967) described communication as a process built on relationships, where meaning emerges through interaction. Watzlawick et al. emphasised that communication is circular; participants responses and behaviour continuously influence and shape the ongoing exchange. Therefore, silence and avoidance are considered just as significant as direct statements. In the same way, in the EoL context, every action or response from physicians, patients and family members actively shapes the progression of dialogue. This perspective highlights that communication is not merely about transmitting information but is constructed through the interactions of all participants. This understanding of communication aligns with the definition used in health care settings. Engle et al. (2023) define effective communication as:

‘a dialogical process between the patient and/or relative and health care professional(s) in which both informative and empathetic aspects are exchanged. Exchanging informative aspects includes sharing information about prognosis/treatment/care by the health care professional and sharing knowledge and experiences by the patient and/or relative. Exchanging empathic aspects related to maintaining or promoting the professional- patient relationship and addressing emotions by both the health care professional and the patient and/or relative’ (Engel et al., 2023, p. 891). The definition provided by Engle et al. enhances the systemic definition by acknowledging the interactive and reciprocal nature of communication, emphasising on both informational and emotional exchanges.

Communication can also be understood to be performative; it is shaped by people’s roles, identities and discourses which are available to them (Caddick, 2021). These processes are embedded within social, institutional and cultural contexts that influence what is said and avoided. Understanding EoL communication as a systemic process allows for a more nuanced appreciation of how physicians, patients and families navigate these conversations. It situates communication within familial, cultural, social and institutional contexts, highlighting complexity as an intrinsic feature of conversations, rather than a problem to be resolved.

Summary

In this chapter, I have provided background information to set the context for my study. I have introduced the wider contexts in which EoL communication occurs and discussed the evolving societal attitudes towards death and dying. In the next chapter,

I will provide a more detailed examination of key research literature on the topic of death and EoL conversations.

Chapter 3

Literature Review

Introduction

In this chapter I examine some of the theory and research from systemic psychotherapy, oncology care and palliative care (PC) literature, relevant to my research question. I have intentionally drawn on foundational systemic and family therapy texts to establish a theoretical framework for understanding relational processes in the context of illness and death, alongside empirical research from end-of-life care (EoL), PC and healthcare communication. Through review and integrating various bodies of literature, this chapter identifies trends and gaps in current knowledge. This review not only examines what happens in EoL conversations but how cultural, relational and familial systems shape what becomes possible to say, hear and navigate in the context of terminal illness.

While I have attempted to undertake a comprehensive search of the relevant literature, I have needed to make choices about what to include and what to leave out, in accordance with the criteria of relevance to this study. As such, this review is not exhaustive and serves more as a ‘map of the terrain’, highlighting literature specific to the research subject (Montuori, 2005). The review begins with an outline of the search strategy used to identify relevant literature. Following this, the review is presented in two parts: part one, provides an overview of systemic psychotherapy literature relevant to the research subject. Part two examines literature which addresses patient – physician communication in EoL care within oncology and palliative care settings.

Search strategy

To complete a systematic literature review in its true sense would require all the available information, relevant to the topic, to be incorporated in the review. Given the rigorous nature of a systematic review, it has not been possible for me to achieve the detail required, within my remit as a student and novice researcher (Aveyard, 2019). However, I have endeavoured to approach the review in a systematic way.

I initially created a table of key words relevant to my research question as shown in table 1.

Table 1

Key words from the title	Alternative words used in the search
Group 1 – Physicians	Doctors; oncologists; health professional; oncologist; clinician
Group 2 – End of life	Palliative; terminal care; dying; life limiting; advance disease; prognosis
Group 3 – Cancer	Tumour; disease; malignant; advanced disease; metastatic cancer; terminal disease
Group 4 – Conversations	Dialogue; communication; discussion; goals of care
Group 5 – Complexity	Uncertainty; negotiation; ethical issues; communication barriers

I then accessed the library database, via the University of Essex's online library system, which included databases such as PsycINFO and Medline. I used the advanced search engine and entered different combinations of key words (see table 2). I applied limitations to the search, i.e., limiting the search of key words to the title or abstract. This narrowed down the search and avoided thousands of unrelated results being generated (Aveyard, 2019).

Table 2

KEY WORDS/PHRASES/COMBINATIONS
1. Communication OR conversations OR discussion between doctor AND cancer patient AND terminal
2. Communication between physician OR doctor or Oncologist AND cancer patient AND end of life OR palliative care (applied SmartText Searching function)
3. Communication AND oncologist AND terminal cancer OR advanced cancer AND complexity
4. End of life AND communication OR discussion AND family OR patient and doctor AND uncertainty (applied SmartText Searching function)

5. Terminal cancer AND doctor - patient relationship AND prognosis discussion
6. Palliative oncology AND communication AND patient perspective OR physician perspective

The key words as shown in tables 1 and 2 do not include 'systemic therapy', as these words are commonly used in the medical context to explain effects of cancer treatment 'therapy' on the body. Therefore, to avoid confusion with 'systemic' as used in systemic psychotherapy, it was not included. Instead, a supplementary search was conducted using search terms such as 'family therapy' AND 'cancer' and 'family'.

Inclusion and exclusion criteria

I have incorporated both primary and secondary research studies, including qualitative and quantitative studies, predominantly from 2010 onwards that examine communication between physicians and terminally ill cancer patients and families. While most literature is from 2010 onwards, earlier citations have also been included where they represent seminal works, offer key theoretical frameworks or contribute to a deeper understanding EoL communication. The search was restricted to studies published in English. Engle et al. (2023) conducted a recent systematic review which examined effective communication in PC from the perspectives of patients and relatives, which served as a methodological comparator due to its relevance to the present study. Engle et al. explained their decision to focus on literature published from 2015 onwards, noting that 'from that time a growing patient-centered focus was found

in studies on communication in palliative care' (Engle et al., p. 891). However, the present review aimed to examine shifts over overtime and therefore, an earlier start date was appropriate. In addition, the initial searches which I completed indicated that literature published from 2010 onwards was sufficient to address the research question.

I included some studies conducted outside of the UK where they met eligibility criteria, with the intention to incorporate cross cultural perspectives and examine the operational differences in cancer care systems. These studies enabled more analysis and comparison to enhance interpretation. Research which involved patients who did not have a diagnosis of terminal cancer and literature on communication in paediatric care was excluded. Aveyard (2019, p. 88) states that electronic searches are not 100% comprehensive and may not identify all relevant literature. Further, the restrictions applied to the literature search i.e., the search terms used, may have resulted in some relevant papers being omitted. Therefore, to ensure a more comprehensive search, I combined different information retrieval techniques such as citation tracking, recommendations from experts in the field and hand searching relevant journals, such as Journal of Palliative Care (Engle et al., 2023). It may appear haphazard to employ a variety of methods to search for literature, but given the limitations of electronic searching, I felt that a wider search strategy is important (Aveyard, 2019, p. 89).

Systemic perspectives on end-of-life communication

Family systems theory, particularly, structural family therapy, presents foundational concepts that are relevant to communication at the EoL (Minuchin, 1974). This

theoretical approach considers hierarchies, boundaries and communication patterns that shape family functioning, focusing on identifying underlying patterns and rules that govern family behaviour (Hoffman, 1981). Instead of seeing problems as belonging to individuals, Minuchin's (1974) model locates difficulties within family interactions, providing a lens for understanding how families deal with illness together. A pioneering contribution was the 'psychosomatic family model' proposed by Minuchin et al. (1978), grounded in structural family therapy and observation research with families of children experiencing poorly controlled diabetes, for whom 'organic' explanations had been ruled out (Doherty et al., 1994, p. 36).

Systemic concepts identified by Minuchin (1974) are relevant to understanding how family involvement is navigated in EoL discussions. For example, in situations where family members are not physically present in consultations, their perceived beliefs and expectations may still influence how patients communicate i.e., a patient's silence or avoidance around prognosis and their preference not to inform relatives may function as a protective strategy between family members (Lin et al., 2018; Melis et al., 2021). Similarly, relatives may feel the need to protect patients from information about prognosis, to prevent them suffering from knowing the truth (Ibanez – Masero et al., 2019).

Bowen's (1978) family systems theory deepened our understanding of family dynamics by viewing illness and death as a phenomenon that activates the family's emotional response. Central concepts such as multigenerational patterns, differentiation of self, family projection processes and the functioning of open and

closed systems, offer a useful framework for understanding how EoL conversations emerge within families affected by terminal illness. In his essay on '*Family Reaction to Death*' as cited in Titelman and Reed's (2018), Bowen described how families respond collectively to the threat of death, often by reorganising roles, alliances and communication patterns, to maintain equilibrium. Here Bowen's distinction between 'open' and 'closed' relationship systems is relevant to EoL communication. He described 'open' systems as one in which an individual feels free to communicate their inner thoughts and feelings to others who can reciprocate. In contrast, 'closed' systems restricts the flow of expression and family members may avoid explicit conversations about death through silence, collusion or indirect communication (Bowen, 1978). The concept of 'differentiation of self' deals with the degree to which a person becomes emotionally 'differentiated' from the parent and moves towards their own emotional autonomy (Bowen, as cited in Titelman and Reed's, 2018, p. 25).

Bowen argued that these patterns affect how patients, families and physicians interact with one another and determine who can speak or what can be said, at different points in the illness trajectory. According to Bowen, physicians are integrated members of the family system rather than detached observers, often taking up roles such as acting as the gatekeeper of information and family allies (Bowen, 1978). While Bowen's perspective draws attention to a key aspect of the physician, patient and family relationship, modern healthcare is more fragmented than the 1970s. For example, patients now see multiple physicians rather than have sustained relationships with a single physician (Kern et al., 2024), which can sometimes contribute to challenges in care planning and communication. These developments suggest that while Bowen's

ideas about relationships remain valuable, how they are reflected in contemporary healthcare settings may look quite different.

Altschuler (2012), a clinical psychologist and systemic psychotherapist extends the family systems perspective to clinical practice in the context of serious illness and death. She emphasised that illness and death are experienced relationally, affecting both patients and their families and asserted that clinicians function as active participants in care and decision making, rather than impartial observers. Altschuler acknowledged the considerable emotional impact on professionals caring for patients facing illness and death, noting that such experiences may confront clinicians with their own mortality and potential powerlessness, which can result in complex responses. Additionally, she identified that unacknowledged and sustained exposure to stress may contribute to burnout, secondary traumatisation and compassion fatigue (Altschuler ,2012, p. 149). In her analysis about personal – professional boundaries, she noted that healthcare training prioritises emotional distance, caution around self-disclosure and physical contact with patients, to protect them. However, she also suggested that these practices may inadvertently serve to shield clinicians from the emotional demands of the work.

Similarly, Fredman (1997), a clinical psychologist and systemic psychotherapist, worked with families on a hospital ward where a family member had been given a diagnosis of terminal cancer. Her work broadens our understanding of EoL communication in health care settings by explicitly locating such conversations within relational systems involving families and healthcare staff. Consistent with Bowen's and

Altschuler's thinking, Fredman recognised clinicians as active participants in conversations about death and dying, rather than neutral persons conveying information. She highlighted that clinicians' level of comfort with discussing death is shaped by their personal beliefs and experiences, as well as professional views, reinforced by clinical training. Fredman further highlighted that tensions could arise when clinicians' personal views were at odds with professional expectations and discourses (Fredman, 1997). This reflects the interplay between personal, professional and institutional frameworks/belief systems and reinforces patterns of communication that may either facilitate or constrain dialogue about death and dying.

During the late 1970s, a new body of knowledge emerged in American Family Therapy, known as 'Medical Family Therapy' (MFT). This model adopts a biopsychosocial treatment approach underpinned by a systems paradigm, to work with families who have a member suffering from chronic illness. MFT bridges psychosocial and physical health, examining the correlation between individuals' physical functioning, family and context. A growing body of research suggests that using systemic approaches in cancer care may help patients and their families better adjust emotionally and psychologically (Hodgson et al., 2012; Linville et al., 2007; Doherty et al., 1994). For example, Hodgson et al. found that family members indicated a need for a systemic approach in cancer care. Both patients and family members reported that MFTs offered steady, reassuring support and helped patients feel cared for, which made coping with cancer easier.

Across PC and family therapy literature there is increasing recognition that experiences of cancer are not located solely within the individual patient but embedded within the family system, with significant emotional and relational consequences for family members (Laryionava et al., 2018; Forbat, 2020). Literature on the impact of cancer on families shows that illness generates considerable anxiety in the family system and often alters communication patterns, roles and relationships. This would suggest that caring for a dying patient necessarily involves attending to family dynamics as part of care planning and symptom management (Mehta et al., 2009). Several authors argue that family systems theory provides a useful theoretical framework for supporting patients with cancer and their families (Forbat, 2020; Mehta et al., 2009; Zaider et al., 2020). Empirical support for systemic interventions in PC is also growing. For example, Kissane et al. (2016) found that family focused therapy delivered to high-risk families during PC and continued to bereavement, was associated with reduced severity of prolonged grief (Kissane et al., 2016, p. 1921).

While grief is arguably a universal experience, the ways families cope with grief and express emotion can differ based on their cultural norms, beliefs and prior family functioning (Smid et al., 2018; Kissane et al., 2016). Within this context, Dumont and Kissane (2009) emphasise the value of systemic questioning techniques such as linear, circular, reflexive (Tomm, 1988) to support clinicians in exploring relational dynamics during EoL care. The use of this model of questioning illustrates how clinicians can facilitate conversations that attend to multiple family perspectives and patterns of interaction, shaping how families and patients make sense of illness and mortality (Dumont and Kissane, 2009).

A literature review by Forbat (2020) found relatively few empirical studies in the field of family therapy and cancer, highlighting the small direct evidence base in this field. However, the review showed a range of systemically informed approaches used in cancer care, including family therapy sessions delivered during advanced cancer, strengths based therapeutic conversations with family caregivers of an individual with advanced/final stage cancer, narrative orientated approaches and brief family therapy (Weber et al., 2019; Weber et al. 2020; Zaida et al., 2020; Petursdottir et al., 2019; Rajaei and Jenson, 2020). These approaches were examined using qualitative and mixed methods approach. For example, Zaider et al. conducted an evaluation of a manualised family – based intervention for families of patients with advanced cancer and reported improvement in communication. Petursdottir et al. used strengths based therapeutic conversations with family caregivers and observed noticeable increase in emotional and cognitive support post intervention as well as reduced stress symptoms, following the intervention. Despite variation in sample size, methodology and outcome measures across these studies, the review highlighted the importance of systemic interventions that addressed relational patterns when working with families affected by cancer. Together, it offers valuable insight into the relevance of systemic practice for managing the complexities of EoL communication (Kissane et al., 2016; Zaider et al., 2020).

While much of the literature specifically addresses systemic interventions delivered to families experiencing cancer, systemic theory provides a valuable framework for understanding how EoL conversations are structured within medical encounters.

Physicians, like patients and families, operate within complex systems that influence progression of EoL discussions. For example, the medical culture is often characterised by expectations of certainty, expertise and emotional composure (Gawande, 2014; Back et al., 2009) which can impede physicians' ability to engage openly and meaningfully with the uncertainty inherent in illness and dying. These influences are explored in greater detail later in this chapter but are mentioned here to illustrate that challenges in EoL communication should be understood as relational processes, influenced by professional cultures and institutions, rather than individual deficiencies.

Collectively, Bowenian family therapy, structural therapy, medical family therapy and systemically informed EoL literature conceptualises communication as a relational process, shaped by patterns of interactions, established hierarchies and emotional processes that are activated in families confronting serious illness and impending death. Further, Bowen (1978), Fredman (1997) and Altschuler (2012) recognised clinicians as integrated within the family system, whose personal and professional beliefs, their role and emotional responses contribute to shaping communication processes.

The role of families in end-of-life communication

Literature on EoL communication recognises that discussions about prognosis and treatment preferences extend beyond the patient - physician dyad and are embedded within wider family and institutional systems (Steinhauser, 2015; Forbat et al., 2018). Within this context, family members often present in consultations or are involved

indirectly, providing emotional, practical and financial support (Laidsaar – Powell et al., 2016; Francois et al., 2017; Pun et al, 2023). As such, family involvement is a central feature in EoL conversations, shaping how conversations unfold.

A recurring theme within the literature concerns misalignment between patients and relatives' expectations regarding the timing and content of EoL discussions (Collins et al., 2018b; Washington et al., 2019). Some studies have found that patients and families hold divergent views about treatment goals, which affects care planning. For example, findings from a recent review by Pun et al. (2023) showed that patients may wish to forego life sustaining treatment, while their families may advocate for continued treatment. These findings are supported by Shin et al. (2015) who completed a large-scale cross-sectional survey of 326 patient – caregiver dyads - their findings revealed that family caregivers do not generally concur with patients, in their preferences. Pun et al. also found that the complexity of EoL communication – requiring physicians to share detailed information, handle the emotions of all parties involved and manage family dynamics often causes delays in initiating EoL conversations. This creates challenges for physicians tasked with navigating competing views.

Family – patient – physician conflict can be further complicated by practices of non-disclosure, referred to in the literature as 'collusion', which happens when a patient's family, sometimes in agreement with the physician, withhold details of the illness from the patient, usually with the intention to protect the patient or preserve hope (Low et al., 2009). While it could be considered as a barrier to communication, in some countries, 'collusion' is framed as a culturally meaningful practice, shaped by family

responsibilities (Low et al, 2009; Pun et al., 2023). For physicians, such situations generate ethical dilemmas requiring the physician to manage patient autonomy with respecting family practices (Laidsaar – Powell et al., 2016). From a systemic perspective, practices such as ‘collusion’ can be understood as a negotiated response by the family who are facing the threat of death, rather than an ethical failure. Alongside these studies, other such as Washington et al. (2019) and Caswell et al. (2015) showed that family members played a vital role in providing emotional and financial support to patients. However, patient responses to family involvement can vary with some valuing family input, while others report feeling constrained or silenced when family members dominate conversations (Brighton and Bistowe, 2018). This suggests that family involvement can both enable and inhibit communication, depending on how roles and practices are negotiated within the family.

Brighton and Bristowe (2015) and Collins et al. (2018) demonstrate that many patients want to discuss EoL issues and that having these discussions early leads to improved decision making and better psychological outcomes for both patients and relatives. However, such conversations still tend to happen late in the illness trajectory (Rodenbach et al., 2016; Harnischfeger et al., 2023). Delays in engaging in EoL discussions have been linked to increased use of life sustaining treatment, reduced quality of life and poorer psychological outcomes for patients and relatives i.e., depression (Granek et al., 2017; Almack et al., 2012). Although family dynamics are often cited as a reason for the delay in starting EoL conversations, physicians’ own discomfort with death and concerns about handling family dynamics may also contribute to the delay. This is supported by Granek et al. (2017) who examined strategies and barriers to effective communication at the EoL - findings showed that

oncologists experienced discomfort with death and dying, which affected their communication with patients.

A recent systematic review (Engle et al., 2023) examined how patients and their relatives perceive effective communication in PC. Themes identified included the need for open and honest information, alignment to individual coping processes, empathy, clear and understandable language, space for positive coping strategies, committed professionals taking responsibility and recognition of relatives in their role as caregiver. This review highlighted that beside open and honest information, patients and relatives want health care professionals to pay attention not only to the patient's disease and symptoms but also to who the patient is beyond the illness and to the role of the relative.

Clinical empathy is considered an essential aspect of health care, the patient-physician-family relationship (Engle et al., 2023; Forbat et al., 2018) and is associated with patient satisfaction, trust and reduced anxiety (Hayuni et al., 2019). Empathy was initially conceptualised within social psychology during the 1950s as the ability to comprehend and experience another's individual's internal state (Kohut, 1959, as cited in Tan et al, 2021). Rogers, who pioneered person-centred therapy, defined empathy relationally as 'a very special way of being with another person' (Rogers, 1975). Empathy is now recognised as a complex, multidimensional concept encompassing cognitive, emotional and behavioural aspects (Tan et al, 2021). Within clinical settings, clinical empathy therefore involves not only understanding a patient's experience

cognitively but also communicating that understanding in ways perceived as genuine by the patient, highlighting its emotional and interpersonal dimensions.

Findings from Gleichgerrcht and Dececty (2013) and Pires and Barbosa (2025) showed that increased emotional labour can result in 'empathy fatigue' and 'burnout' amongst physicians. Forbat et al. (2018) highlighted that structured communicative practices such as family meetings may enhance perceived empathetic engagement and provide support for patients and families, but it may also mask the emotional labour that is required by physicians to sustain it. Further, the presence of families, particularly in situations of conflict, may intensify emotional labour that physicians are required to navigate.

Although reviews such as Engle et al. (2023) show that families play an important role in EoL communication, there are limitations in the evidence for this. While some of the studies have included multiple groups i.e., patient, physician, family, the analysis in these studies has often focused on the viewpoint of particular parties in isolation, limiting the extent to which meanings have been co constructed between the different parties. The review by Engle et al. also highlighted that studies provided no information on the level of PC expertise of the healthcare professionals involved and most focused on planned conversations with physicians rather than on the inclusion of other healthcare professionals. Engle et al. also identified that there was limited attention paid to the different cultural and religious backgrounds of patients and relatives. These gaps point to the need for a systemic approach towards research in this area, which

as a result of the emphasis on the different relationships in the patient – carer system, is aimed at capturing the complex and multivocal nature of EoL conversations.

Family involvement plays an important but complicated role in EoL communication. Research, including studies by Collins et al. (2018b), Washington et al. (2018) and Brighton and Bristowe (2018) shows that family members can act as advocates for patients but may also introduce tension, conflicts and delays to EoL discussions. Furthermore, cross cultural analyses of non-disclosure practices such as those presented in the review by Pun et al. (2023), illustrate how differing expectations regarding protection, hope and family responsibility can complicate physicians' ability to manage patient autonomy with professional responsibilities.

Beliefs and attitudes about death

In examining how beliefs and attitudes about death shape EoL conversations, this thesis draws broadly on two different conceptualisations of culture. The UNESCO definition is drawn upon as it is used within contemporary palliative care literature as cited in El – Khoury (2025); culture is defined as: 'The distinct spiritual, material, intellectual, and emotional features characterizing a society. It encompasses arts, lifestyle, human rights, value systems, traditions, and beliefs. Culture shapes individuals and societies, fostering unity through shared values and traditions.' By contrast, systemic theorists contextualise culture as an interactional and reflexive process embedded within relationships and contexts, rather than a fixed set of shared attributes (Krause, 2012). This thesis considers both perspectives to examine how meanings about death are negotiated across different systems. While the UNESCO

definition encompasses 'spirituality', this thesis distinguishes between 'religion' and 'spirituality' (Best et al., 2024) and draws on both, understanding religion to be a shared system of belief associated with specific faith traditions and 'spirituality' as a broader process of meaning making (Rego et al., 2020).

El Khoury (2025) and Hira et al. (2025) argue that culture and religious beliefs significantly influence how patients, families and clinicians perceive illness and death in PC. For example, these factors affect whether death is viewed as a medical failure or a transition, decision making about treatment, what topics are appropriate to talk about and determine who is regarded as having authority to speak. In this way, beliefs about death intersect with professional norms and family expectations to structure the content and timing of EoL conversations. Pun et al. (2023) report on the tension between family mediated communication and direct patient disclosure. Family members often play a key role acting as gatekeepers in EoL discussion and shaping what information is shared or withheld. These practices which are often embedded within cultural and religious frameworks and affect how people view death and whether it is considered acceptable to talk about it openly. For example, in Chinese culture which draws on Confucianism and Buddhism, parents typically become the recipients of their adult children's care, resulting in children being entrusted with EoL decision making responsibilities (Pun et al, 2023). Furthermore, family members generally hold the authority to decide whether to inform the patient of their medical situation (Pun et al., 2023). While such practices may align with collective understandings of care and responsibility within a specific culture, they may conflict with patient preferences for transparency and physicians' commitment to patient autonomy and consent (Brooks et al., 2019).

El Khoury (2025) highlighted that conceptualisations of death as a transition, spiritual event or biomedical endpoint can affect patients and family's readiness to engage in prognostic and EoL discussions. Patients and families who frame death as a transition often focus discussions on existential questions, meaning making and preparation, whereas a biomedical framing may prioritise treatment while avoiding explicit discussions about dying (Back et al., 2009; Hira et al., 2025). These framings interact with cultural and religious norms and show that beliefs about death not only affect attitudes towards illness and death but play an active role in shaping communication practices.

Spirituality and religion influence the communication process. While spiritual care in the UK traditionally fell within the remit of the chaplaincy services, there is now greater awareness of how spirituality can impact on physical, social and mental health and its potential to strengthen patient relationships with healthcare providers (Koenig, 2015; Best et al., 2024). Recent evidence, such as the study by Best et al. indicates that a significant proportion of patients would like their physician to enquire about their spiritual needs - however, as Best et al. suggest this is not reflected in practice, despite acknowledgement by health care providers that providing spiritual care is part of their role. Best et al. also suggest that the patient's perception that the physician lacks time and interest in having spiritual discussions and that spirituality falls outside the remit of medical consultations, constitutes a barrier to this kind of communication, possibly also reflecting underlying beliefs about professional boundaries and the prioritisation of medical matters.

Hira et al. (2025) found significant cultural differences in attitudes towards death and dying, highlighting the need for clinicians to recognise these variations. This is supported by El Khoury (2025) who drew attention to ‘cultural relativism’ as a framework for working with religious and cultural differences within healthcare, arguing that there is no universal standard to measure culture by. He suggested that providing culturally sensitive care is not just about understanding differences but navigating the intersection of these practices with modern medicine, in a way that fosters trust and open communication (El Khoury, 2025, p. 5). This awareness would help to ensure that EoL care aligns with each patient’s beliefs and values, as insensitive communication can exacerbate misunderstandings and patient/family suffering (Brooks et al., 2019; El-Khoury, 2025). For example, families from Asian communities may prioritise family mediated disclosure i.e., withholding information, whereas in many European contexts there is an emphasis on patient autonomy and direct communication (Van Bruchem-Visser, R. L. et al., 2020; Tang et al, 2019). However, it is important to avoid attributing patterns of communication to broad cultural categories i.e., Asian/European norms as this risks reifying culture as a static construct rather than a dynamic process, influenced by multiple factors including migration status, socio-economic position, social history, individual inclinations and health inequities (El – Khoury, 2025; Hussain et al., 2025).

Hussain et al. (2025) argued that people from ethnic minority and socially disadvantaged groups in the UK often experience poorer access to PC, inadequate communication and unmet spiritual and social needs. Too often institutions respond

with 'cultural competencies' i.e., providing prayer rooms and halal meals, which risks reducing culture to a set of preferences and stereotyping patients. Hussain et al. (2025) argue that cultural humility, defined as ongoing self-reflection and acknowledgment of bias at individual and organisational levels, is needed to redistribute power and ensure diverse values are recognised in decision making. Further, they highlight that current EoL care models often reflect normative, Eurocentric ideas which may not align with practices of many other cultural groups.

Clinicians' own attitudes and beliefs towards death may influence their capacity to engage in EoL conversations. Granek et al. (2013) found that barriers to communication about EoL included oncologists' discomfort with death and dying, which impacted on their ability to communicate with patients about painful matters. This is supported by Rodenbach et al. (2016) who found that for many clinicians, caring for dying patients affected their outlook on life and death and their own perspectives on life and death, both affected their approach to caring for dying patients. Further, it has been debated whether avoidance of death talk reflects culturally specific taboos or a universal human fear of death (El-Khoury, 2025) with societies developing rituals and beliefs to manage this fear and to give life meaning, as explained by Becker (cited in Yunt, 2024). These factors likely influence what topics are addressed, who participates and how decisions are reached. Additionally, studies including El Khoury (2025) and Hira et al. (2025) demonstrate that beliefs about death do not simply serve as background factors, they play an active role in guiding communication.

Barriers and tensions in end-of-life communication

This section builds on the previous one by examining how beliefs and meanings are enacted through interaction patterns which can lead to obstacles and tensions in communication. Studies such as Collins et al. (2018) and Granek et al. (2013) found that death is rarely named explicitly, instead communication typically focuses on 'symptom management' and 'pain management', which have been interpreted as strategies for addressing existential fears. This ambivalence has been conceptualised as 'middle knowledge' capturing a fluctuation between acknowledgement and denial of a terminal diagnosis (Kitta et al., 2021).

Collins et al. (2018) identified three key themes, 'death as unspeakable', 'palliative care as a euphemism for death' and 'palliative care as unspeakable'. Participants described that conversations related to death and dying were limited to the use of medical terms such as 'pain management' or 'symptom management' which suggested that professionals avoided the use of direct language to name 'death' and 'dying'. A sub theme revealed that patients themselves rarely spoke explicitly about death and instead developed their own euphemisms (Collins et al., 2018, p. 137). This is supported by Granek et al. (2013) who highlighted the 'death defying mode' in which focus on cure and overtreatment replaced conversations about the EoL.

Within clinical settings, tensions can arise when physicians attempt to initiate more explicit discussions about the EoL while patients prefer ambiguity (Back et al., 2014). Rodenbach et al. (2016) reported that physicians' approaches to EoL communication can vary considerably, ranging from indirect or selectively direct to more direct

discussions about prognosis and dying. These differences have been attributed to professional training, personal beliefs about death and wider institutional and cultural expectations. For many physicians, repeated exposure to dying patients, personal loss, cultural background and death anxiety can also impact their attitudes and confidence in facilitating EoL discussions, as noted by Rodenbach et al. (2016) and Harnishfeger et al. (2023). Physicians are required to manage not only the delivery of complex and uncertain prognosis but also patient and families' emotional responses, alongside their own reactions to caring for dying patients which can be emotionally demanding.

A recurring tension within EoL communication concerns conflicting interpretations of treatment intent. For example, physicians may identify a clear cut off point to end curative treatment based on their assessment of the progression of the disease. However, for patients and often their families too, these transition points may not have the same meaning. For instance, a patient with stage four cancer undergoing chemotherapy may understand treatment as continuing to manage disease, whereas physicians may regard it as palliative treatment. Such ambiguity can give rise to misunderstandings and delays in EoL conversations (Kitta et al., 2012). Related to this is the issue that patients are often referred from oncology care to specialist PC late in their illness trajectory (Pini et al., 2020; Allsop et al., 2018; Hui et al., 2014). The delay is often compounded by the lack of integration between oncology and PC services, unclear referral criteria, heavy clinical workloads and ambiguity around professional roles (Pini et al., 2020).

Bringing oncology and PC together is complex and affected by organisational, clinical and educational factors such as how clinicians are trained about PC (Bradley et al, 2025). The review by Bradley et al. found that even though healthcare systems differ across nations, many countries face the same difficulties in combining PC with oncology. Consequently, oncologists are often responsible for facilitating conversations about prognosis and the transition from disease directed treatment to PC. These pressures may intersect with professional identity and training. For example, Kruser et al. (2020) found that medical oncologists often perceive themselves as holding 'unique authority' over the timing of PC referrals, describing themselves as 'holding authority'. Such professional identity may be shaped by the orientation of oncology which traditionally focused on treatment and survival, compared to PC which focuses on comfort, symptom management and pain relief (Walsh et al, 2011).

Further, misconceptions and the stigmatisation around PC, for example, being equated with 'giving up', 'death' and a breakdown in the patient-physician relationship (Zhang et al., 2024; Bradley et al, 2025) are prevalent among physicians and patients, reinforcing late referrals to PC. Patients and families often lack awareness about PC benefits and experience distress about its introduction (Collins et al, 2018) which further compounds these challenges. Therefore, a combination of public health and professional education is necessary to build a shared understanding of what PC is and is not (Bradley et al, 2025, p. 7). The organisational divide between oncology and PC may shape how oncology physicians perceive their responsibilities in relation to treatment decision making and conversations about prognosis and EoL care.

Morgans and Schapira (2015) highlighted physicians' emotional responses to patient deaths or perceived treatment failure as factors which influence EoL communication. Such experiences of grief and loss often occur within professional settings, however such settings provide limited space for emotional processing and therefore, physicians may respond by adopting strategies such as distancing or withdrawal from patients, as a way of coping. Granek et al. (2013) found that emotional labour and moral distress amongst oncologists was intensified by family expectations, organisational contexts and professional norms, indicating that physicians' strategies in these circumstances are often functional responses to systemic demands, rather than personal shortcomings.

Barriers to effective EoL communication are often expressed through tensions and conflicts that emerge between families, patients and clinicians. Conflict frequently centres on issues associated with differing understanding of prognosis, goals of care and systemic factors such as time pressures and limited resources (Francois et al., 2017; Back et al., 2014). These tensions may be regarded as co-constructed wherein patient and family expectations, physicians' communication strategies and institutional frameworks collectively influence the timing and nature of EoL discussions. While many studies focus on clinician experiences of conflict, fewer studies explore how patients and families contribute or are affected by these dynamics (Scholz et al., 2020), revealing a gap in our understanding of the communication at the EoL. From a systemic perspective, barriers to EoL communication are not considered to be located within individual patients or physicians, rather they arise from relational tensions

embedded within clinical, family and institutional contexts. Such barriers can be understood as co-constructed responses to the emotional and moral complexity of death and dying.

Communication training practices

While early and effective communication regarding prognosis and EoL care is widely recognised as an essential part of oncology care (Harnischfeger et al., 2022), studies by Granek et al. (2013) and Rodenbach et al. (2016), showed that there are unique challenges including treatment decisions, prognostic uncertainty and physicians often feeling unprepared or uneasy about initiating these discussions. Structured communication skills training has been designed to address these gaps, ranging from generalist palliative care programs to oncologist specific interventions (Brighton et al., 2017; Harnischfeger et al., 2022). For example, the PALLI -COM program is a brief targeted intervention consisting of two 90-minute training sessions delivered via video conference. In a randomised control trial assessing the effectiveness of this program which involved a control group and intervention group, results suggested that oncologists in the intervention group showed improvement in core skills, such as reacting to emotions and showing empathy, providing hope and addressing EoL issues and explaining the concept of PC (Harnischfeger et al., 2022). Similarly, another randomised control trial assessing the effectiveness of the COM-ON-p training which integrates small group workshops, role play and coaching to help oncologists navigate PC and EoL conversations found that participants reported an increased confidence and improved communication skills particularly around family involvement and discussing care transitions (Goelz et al., 2011).

While both training programs illustrate that relatively compact interventions can improve physicians' competence and comfort in addressing EoL issues, Rodenbach et al. (2016) and Harnischfeger et al. (2023) highlight the need for further training for oncologists. They make an important recommendation which marks a shift from generic training which emphasises communication behaviour, to more focused training which supports oncologists to develop self-awareness about their own beliefs and fears. Rodenbach et al (2016) found that for many oncology clinicians, their own perspectives on life and death affected their approach to their patients, in positive and negative ways i.e., what clinicians bring to the patient encounter has to do with their own life experiences rather than learned techniques or skills (Rodenbach et al, 2016, p. 360). This highlights the relational aspect of the doctor-patient relationship in which both parties are affected. While physicians' self-awareness is imperative in this process, self-awareness must be seen in relation to the patient and the context that they both are in; the 'fear' of death will be different for physicians than for patients who are dying. The physician may identify with anxiety associated with death and may also see death as a form of 'defeat'. Whereas, the patient may fear the dying process i.e., what it will be like and worry about what death signifies. Harnischfeger, et al., (2023, p. 929) recommended spiritual training for oncologists, which may empower oncologists to be able to communicate about patient fears and to enable them to establish compassionate relationships with patients.

Structured clinical communication training is a standard part of the UK medical curriculum. The communication frameworks are usually delivered through experiential

learning, including role play, simulated patients and small group practice (Brown, 2008). As communication at the EoL presents with distinct challenges, as discussed earlier in this chapter, physicians providing EoL care require competencies that go beyond standard communication models. In response to this, UK medical education has increasingly emphasised empathy and reflective practice (Winter et al., 2023). These initiatives have included Schwartz Rounds - multidisciplinary forums that facilitate a structured space to reflect on the emotional and social aspects of caring for patients (Goodrich, 2012). Such forums have been associated with enhanced care for patients, greater empathy and improved relationships between staff (Goodrich, 2012; Maben et al., 2018). A recent survey of clinical empathy training at UK medical schools found that 26 of the 28 medical schools reported that they included some form of empathy training in their curriculum, however only a minority offered specific empathy modules or formal assessment of empathy. While there was a broad consensus that empathy should be taught, many considered that the current provision was insufficient (Winter et al., 2023).

This suggests that while undergraduate medical communication skills provide a foundation for consultations, it does not sufficiently foster therapeutic empathy through the provision of dedicated empathy modules and assessment. In EoL care, patients emotional and existential concerns are prominent, and empathy is crucial for effective communication between physicians and patients (Engle et al., 2023). This suggests a need for the medical curriculum to incorporate empathy training and reflective practice with standard communication training.

Summary

This review has examined what the existing literature tells us about how patients and physicians communicate at the EoL, with emphasis on family involvement, attitudes and beliefs about death, and barriers and tensions that affect EoL communication. Taken together, the literature describes EoL conversations as a multifaceted process influenced by family dynamics, professional roles and institutional cultures. Perspectives about death inform physicians, patients and family's approach to EoL conversations, while family participation can both support and hinder these discussions. These factors contribute to tensions that affect the timing of EoL discussions. Overall, there is a growing recognition of the relational, cultural and systemic contexts in which such conversations occur.

Much of the literature on EoL communication in the context of terminal cancer draws on qualitative methods such as semi structured interviews (Granek et al., 2013; Rodenbach et al., 2016; Collins et al., 2018; Kitta et al., 2021), with some studies adopting quantitative methods including randomised trials and questionnaires (Harnischfeger et al., 2023). These studies have generated important insights into how physicians and patients make sense of conversations at the EoL. However, despite increasing attention to physician-patient interaction, there seems to be a reliance on retrospective self-reported accounts, often focusing on clinician perspectives, with fewer studies incorporating patient or families' views.

Building on this body of literature, the intention in the present study is to introduce a different perspective to understand how conversations happen at the EoL, using a

systemic framework. Previously, systemic authors have demonstrated the value of applying systemic intervention and techniques to medical contexts and have made valuable contributions (Dumont and Kissane, 2009). In this research I hope to bridge the gap between systemic and medical models and contribute to the implications for practice, in both disciplines. The present study explores how patients and physicians separately describe their experiences of EoL conversations, attending to points of convergence and divergence within their narratives.

This study will address the following:

Main research question

How do patients and physicians navigate the complexities of conversations at the end of life, in the context of terminal cancer.

Sub questions

- How do beliefs and attitudes about death shape how these conversations unfold?
- What barriers or tensions complicate meaningful communication between patients and physicians?
- How is family involvement navigated?

Chapter 4

Methodology

Epistemological positioning

In this chapter, I will describe the choices I have made regarding the methodology and design, and the ideas I have drawn on to guide me in this research inquiry. My research took the form of a qualitative investigation. My decision to pursue this type of inquiry was influenced by my professional identity as a family therapist, my beliefs and understanding about what there is (ontology) and how knowledge can be obtained (epistemology) (Guba and Lincoln, 1994). The methodological question of how a researcher goes about finding out knowledge, based on what they believe can be 'known' cannot be reduced to a question of method; method must be fitted to a chosen epistemology (Lincoln and Guba, 1994, p. 108). Methodological choices have implications for the production of knowledge (Gunaratnam, 2003) and therefore, methodological choices are of ethical concern.

Different research methods are associated with different epistemologies. Within the paradigm of positivism, a single measurable reality is assumed to exist, and it is considered possible to obtain accurate knowledge of things in the world. This assumption is made on the basis that the investigator is 'written out' of the research, to avoid 'contamination' of the research process. If these conditions are met then the positivist researcher can claim to converge on the 'true' state of affairs (Lincoln and

Guba, 1994, p. 109). But is it possible for the researcher to be ‘detached’ from the research process? Barad (2007) suggests, ‘we do not obtain knowledge on the basis of standing outside of the world looking in, because we are of the world’ (p. 185). This is supported by Max Weber’s idea, as referenced by Giddens (1971) that “there cannot conceivably be any complete scientific description of reality” (p. 138).

My epistemological position has evolved over the course of this doctoral research, particularly in relation to where I stand on the continuum of ‘realism’ – ‘critical realism’ – ‘relativism’. At the onset, I was more closely aligned with the ‘relativist’ paradigm which assumes that realities are dependent on the ways we come to know them and that knowledge is constructed through social interactions (Coyle, 2021). However, as my thinking developed, I began to question the limits of relativism when applied to research concerned with death and dying. While the ways people understand and interpret death may vary across cultures, death itself remains an ontological reality. Edwards et al. (1995) provide a useful framework for navigating this tension through their discussion about ‘Death and Furniture’ – the non-negotiable realities. For example, furniture represents material realities while death represents existential reality - Edwards et al. argue that recognising objective phenomena does not undermine the insight that knowledge around these realities is socially constructed. This helped me to clarify my epistemological stance as a critical realist. In the context of EoL research, this means recognising that while death exists as an objective phenomenon, the way patients and physicians understand and communicate about death, is shaped by cultural and social processes.

According to a critical realist framework, reality consists of underlying structures and mechanisms, that exist independently of human perception and understanding, yet result in observable phenomena (Bhaskar, 1975). In the sphere of death and dying, these mechanisms may include social, cultural and institutional processes that influence behavioural patterns such as grieving, caregiving and communication. Mechanisms are context dependent and can lead to varying outcomes based on specific circumstances. My understanding of these mechanisms will inevitably always be shaped by my perspective and what is accessible through observation and interpretation (Coyle, 2021). From this perspective, detachment from the research process is neither possible nor desired. Experiences around my mother's death and my presence in the research process will have influenced the participants and how information was gathered, interpreted and represented, therefore, affecting the production of knowledge. In this way, no research is innocent of bias, evasion and interpretation (Gunaratnam, 2003).

'Insider' or 'outsider' epistemology?

Whether qualitative researchers should be 'members' (insiders) of the population that they are studying or not, is a frequently debated issue in research (Dwyer and Buckle, 2018). Rather than considering this issue from a dichotomous perspective, instead, I have reflected on the space in-between and considered the advantages and disadvantages of both positions, within my own research. There are several benefits which have been identified with taking an 'insider' position including a greater degree of acceptance of the researcher by the participants, which may in turn increase the level of trust and openness. The participants may be more willing to share experiences

based on the assumption that there is a shared status/understanding between them and the researcher. A potential risk associated with taking an 'insider' position is that the researcher may overidentify with participants which may in turn result in them failing to consider individual experiences of the participants, leading to an imbalance in power relations between the researcher and participant (Gunaratnam, 2003). Further, undue research influence might affect the data gathering and analysis process (Dwyer and Buckle, 2018).

My experiences as a bereaved daughter who lost my mother to cancer has led me to feel that I was operating more as an 'insider', at certain points. For example, during my observations of clinical consultations, I connected to the familiar smells in the hospital and the barren nature of a physician's consultation room. I noticed the clock ticking and a sense of anticipation as the patients and I waited quietly, to hear an update from the physician about the latest scan or news of the ending of treatment. Despite my strong sense of connection, at other times, I felt more like an 'outsider' as I tried to navigate the space between 'living' and 'dying', which separated me from some of the research participants. During the interviews, I did not reveal to the patients my personal experiences of my mother's illness. I wondered whether my own story might interfere with how they would tell theirs. On one occasion, when interviewing a physician, I shared some aspects of my experience. The physician responded with an acknowledgment of his own tendency to be 'insensitive' when speaking about matters related to life and death and he 'apologised' for anything which might have 'offended' me. I learned in that moment that my story would affect how others tell their story. This raised the question, how do I think with research participants about their stories and

develop sufficient resonance so that I can feel the nuances of their experience, while also thinking with my own story? (Frank, 1995).

I found myself straddling between the 'insider' and 'outsider' position, which influenced how I approached the interviews. Although my own experience gave me empathy and insight into the emotional realities of serious illness, I was careful not to presume a shared perspective with participants. During interviews, I took an inquisitive approach by inviting participants to clarify concepts that might otherwise seem self-evident. For example, when a physician described 'attending' to their 'own biases', I asked them to describe what such ideas meant within their own experiences, rather than assuming meaning based on my understanding of 'biases'. There were similarities and differences between me and the research participants, which both connected and separated us at different times. In whichever position I found myself, I tried to consistently engage with participants in an empathetic and human manner and was motivated by a deep interest in their experiences.

I have reflected on my positioning in relation to research participants. The patients I interviewed were very unwell and knew their 'time was running out' (Clarke, 2020) - I did not (do not) have reason to believe that my 'time is running out' in the same way. I entered the research process as a researcher and clinician with 'professional authority'. These differences have the potential to create power asymmetries within the researcher – participant relationship, as researchers can be perceived to have control over the research agenda and interpretation of participant accounts (Wiles, 2013). I tried to use the awareness of the differences between us and that 'I am not

where they are' to help me to sensitively navigate and take extra care, when interviewing patients. This awareness influenced how I approached the interviews, making me more attentive to participant cues and comfortable with pauses, silences and shifts in conversations. As Frank (1995) suggests, illness narratives are not simply descriptions of disease but the way individuals try to understand suffering and disruption, caused by illness. Similarly, Lawton (2001) discusses how dying patients remain active interpreters of their situation.

From this viewpoint, I aimed to acknowledge participants as storytellers whose narratives carried personal, relational and existential significance, while also concentrating on how patients interpreted the meaning of their illness. When thinking about the importance of 'dialogue' in research, I am influenced by the work of Martin Buber. I am interested in the distinction that he makes between the I-Thou relationship and the I-It relationship (Buber, 1937). I think Buber's ideas are fundamental to creating a therapeutic alliance with participants, in a research context i.e., if I want to relate to them, I must assume an I – Thou relationship which means that I consider participants as people searching for meaning instead of seeing them as malfunctioning and 'different' from myself. In the end, like them, I too am a mortal being.

An additional consideration related to the dynamics that arose during my interviews with participants. As a researcher with a background in family therapy, I recognised that my professional identity might influence my responses to participants' narratives. For example, on one occasion, when interviewing a patient in the presence of her sister and sister – in-law, the patient described "*Sometimes I just want people to give*

us a cuddle and say, 'it's alright' you know, it's okay'. Like, I miss that kind of, like my dad used to always cuddle me'. I sensed that 'touch' was important for this patient and signified her need for emotional connection and reassurance. The presence of her family created a context in which this could potentially be possible. Drawing on my family therapy skills, I invited the patient's relatives to respond to what they had heard. They moved closer to the patient and gave her a cuddle. Although this moment seemed significant for the patient and her family, it led me to consider my responsibility within the research setting, since my actions had shifted from an observation to something closer to a therapeutic intervention. On reflection, I realise that my actions were being guided by the patient's expressed need for connection and acknowledging her wish felt like the right thing to do. Demonstrating flexibility when conducting research with patients at the EoL has been identified as beneficial when creating a secure space for participants (Vickovaw et al, 2022).

Ethical considerations

The starting point was to apply for ethical approval to undertake this study. This proved to be a rigorous and lengthy process. It involved completing a series of documents which were submitted to The Integrated Research Application System (IRAS). My application was deemed inadequate by the first ethics committee who reviewed it and subsequently, the study was not approved (see appendix). I then had the task to revise the documents based on the conditions outlined by the ethics committee, after which I resubmitted my application. The study was eventually approved by West Midlands - Solihull Research Ethics Committee in October 2022 (see appendix). Further to receiving their approval, before the study could commence, independent ethical

approval was required from the NHS site where the research would be taking place. This was granted in March 2023. The study commenced in May 2023.

I have reflected on the process involved in obtaining ethical approval and the heavy focus that was placed on protecting participants. While I understand that protecting research participants from harm is the highest priority, my own experience has led me to question other aspects of the researcher-participant relationship and how sufficiently it is attended to in the ethics approval process i.e., what does it mean to engage with participants who are at the EoL (DeCamp et al., 2022) and how does the researcher manage unforeseen challenges which may arise during the course of the research. While patient engagement is widely accepted as ethical best practice it can also raise its own ethical issues (DeCamp, et al., 2022; Henry and Scales, 2012). Faced with some unexpected circumstances during the research process, I started to question the extent to which 'traditional research ethics principles' were compatible or could be applied to a range of real-life research dilemmas. For example, one participant experienced decline in their health just a couple of days before the scheduled interview. Although, ethical guidelines would suggest patient safety by postponing or cancelling the interview, the patient expressed a wish to proceed. To address this dilemma, I discussed the situation with the patient's allocated physician to assess if participation was appropriate, while simultaneously keeping in mind the patient's wishes. This approach allowed me to balance the principle of ensuring non maleficence with respect for patient autonomy (Tangwa, 2009).

It is encouraging to see that findings from previous studies have shown that some people facing death want to be able to participate in research, allowing them the opportunity to 'give something back' and to contribute, with the intention to improve services for others in the future (Pini et al., 2020; Murray et al., 2009). Feedback provided by research participants (patients) in the present study, supported these findings. This was a low risk, non-interventional study, however, I was acutely aware that there was a risk of interaction leading to harm, i.e., a participant becoming distressed and anxious when talking about difficult feelings and in the context of facing death. As an experienced family therapist, I hope I was able to manage the interview process in a sensitive, cautious and respectful way.

Conducting research at the EoL necessarily means engaging with patients who may be in extremely poor health and experiencing exhaustion, anxiety, and stress. I relied on the judgement of the physician involved in the patient's care to decide when the patient could be approached to discuss their participation in the study and whether the patient was considered 'fit' to participate. Participants initially provided consent to being contacted by me to discuss the research. Consent was taken again before an interview or participation in an observation of clinical consultations (see appendix). 'Ongoing consent' was an integral part of the research process and participants were regularly asked about their on-going involvement both in the interviews and as part of the observation of clinical consultations (Wiles, 2013).

Researcher positioning: early field exposure

Prior to commencing data collection, I undertook volunteer work within a hospice setting (see background chapter) as part of my preparation. Being in a hospice significantly enhanced my research, as it gave me first hand insight into the challenges and complexities of EoL care, including clinical communication practices which were utilised. I was able to directly engage with patients and observe how hospice staff engaged with patients, which provided me with insight into how to approach these conversations, in my interviews with research participants.

While this study utilises a qualitative interview methodology, prior to commencing the interviews, observations of medical consultations between physicians and patients, were completed, within the clinical setting. A small number of consultations were observed. The objective of this process was not to generate observational data for formal analysis, rather it was to deepen my understanding and attune myself to the sensitivities of EoL communication and the dynamics of patient – physician interactions. Completing observations in this way allowed me to step ‘outside’ of myself as a relative and step into ‘the field’ as a researcher (Berger, 2015), to observe how others navigated difficult terrains. The observations therefore functioned as a process of familiarisation, helping me to synthesise relevant concepts and refine the interview guide used in subsequent patient and physician interviews. Following the observations, I wrote notes which captured my own assumptions and emotional reactions, the physician -patient relationship and the content and process of the consultation, as I observed it. Below is an extract from my notes; a longer example of the observation notes is included in the appendix.

The patient expressed repeatedly that she did not want any treatment to prolong life but just to ease her pain. The consultant reiterated that the treatment was to reduce pain. The patient's daughter was visibly distressed at this point. Looking at her daughter, the patient said that she did not want to prolong her life because she did not want her daughter to suffer. To this, the consultant responded, 'she is already suffering'. I observed there to be a misunderstanding in their communication leading the consultant to feel that he needed to defend himself by saying 'I am not the enemy'.

Observing these situations led me to think about how misunderstandings might arise in EoL communication as well as how patient choices might be influenced by concerns about the impact of their illness on family members. These insights guided the questions I asked about family involvement. My experience of doing observation was that of being in an evolving intersubjective relationship with patients and physicians, in which we were each influencing and being affected by the process. Observations are complex processes and the observer's "gaze" is influenced by their theoretical positioning, personal inclination as well as the local and wider contexts (Madden, 2010). Von Foerster (2014) suggests that observations are not absolute but relative to the observer's point of view. Qualitative literature recognises that early exposure to the field of research can function as a means of developing 'sensitising concepts' that help to orient the researcher (Blumer, 1954). Overall, the observations enabled me to develop a broad framework which later helped with the refinement of the interview guide and improved my ability to recognise and follow emergent lines of enquiry during interviews. This preparatory stage also supported reflection and awareness enabling

me to better manage the potential influence of my own experiences, during interviewing.

Sampling and recruitment strategy

Recruitment was conducted using purposive sampling to ensure that participants had direct experience relevant to the objectives of this study (Dempster and Hanna, 2015). I worked closely with a Consultant Oncologist (CO), based at the hospital site where the research was completed, who was instrumental in making arrangements to carry out the clinical observations and to recruit participants for the research. The CO initially discussed details of the research with his colleagues during clinical team meetings and in 1-1 meetings, at the hospital site. He provided potential participants (physicians) with an information sheet (see appendix). Once prospective physicians were identified and consent to contact them was provided (see appendix), their details were then passed to me. I had a follow up discussion with each physician and provided further information about what they could expect during the research process. Identification of eligible patients was completed during routine clinic consultations. Prospective patients were approached initially by their physician who had a preliminary discussion with the patient and provided details about the research (see appendix). When consent to contact the patient was provided, their details were passed to me.

Purposive sampling is widely used in PC research as it enables recruitment of participants with direct experience of the phenomena under investigation (Dunleavy et al., 2023). Physicians were provided with details of the inclusion criteria to guide the identification of patients, while encouraging variation in patient demographics. By

involving physicians in the process meant that recruitment was undertaken sensitively and ethically. However, reliance on physician judgement for patient identification, introduced potential selection bias which may have limited the diversity of the sample (Dunleavy et al., 2023). The resulting sample for my study consisted of eight participants (four patients and four physicians). The demographic was diverse and offered culturally rich data. Within the patient group there were three women and one man and in the physician group, there were 2 women and 2 men who were interviewed. Participants across the two groups were of different ethnicities including white British, African, British Asian and white European.

A sample of eight is methodologically acceptable for several reasons. Qualitative interview research is not governed by principles of statistical representativeness, instead, adequacy of the sample is judged by the depth and relevance of the data collected, in relation to the research aims (Guest et al., 2006). Guest et al. demonstrated that thematic saturation, defined as identifying around 90% of themes in a set of qualitative interviews (Wutich et al, 2024, p.1) could be reached within 6–12 interviews, suggesting that relatively small samples can yield meaningful analytical insights. The analytical approach used in the present study is reflexive thematic analysis (RTA) (see further explanation below) which is compatible with small information rich datasets and values detailed reflective engagement with data and prioritises depth of interpretative engagement over breadth of cases (Braun and Clarke, 2022). Although data saturation is often publicised as ‘gold standard’ for determining sample size, Braun and Clarke argue that data saturation is conceptually incompatible with RTA and problematic when applied as a rigid criterion. They suggest that sample size should be determined pragmatically, based on research aims and

practical considerations. A recent review by Wutich et al. (2024) supports the position that thematic analysis does not require a predetermined minimum sample size. Although some researchers such as Naeem et al. (2024) have proposed structural approaches to assessing saturation within thematic approaches, there is no agreed numerical standard.

Instead, Braun and Clarke. (2022) recommend concepts such as *information power* (Malterud et al., 2016) which shifts the focus away from numerical sample size to the richness and relevance of the data provided by participants. *Information power* is increased when study aims are focused, interviews are in depth and analysis is theoretically informed. In my study, the research aims were narrow and focused, the sample was highly specific - terminal cancer patients and physicians directly involved in EoL communication, and the interviews produced detailed narrative accounts. Further, the advantage of smaller samples is that it allows for sustained analytical immersion, detailed coding and close attention to the nuances within individual interviews.

Small samples are common in palliative and EoL research contexts (Giehl et al. (2025), where sensitivity, participant wellbeing and trust inform methodological decisions. Interviewing terminally ill cancer patients raises practical, ethical, emotional and methodological challenges which are factors that can complicate recruitment and data collection (Sivell, 2019; Giehl et al., 2025). These include fluctuating health status of patients, limited availability, potential participant distress and clinical gatekeeping.

Therefore, I believe that these factors collectively justify the use of small samples, in the context of EoL research.

Interviews

This study is methodologically grounded as an interview based qualitative study. Qualitative interviewing is suited to research that seeks to understand how individuals interpret experiences (Walton, 2021). After completing the clinical observations, I conducted interviews with patients and physicians which were semi-structured, lasting between 60-90 minutes. I took the view that conducting interviews of extended durations enabled participants to provide detailed accounts on complex matters such as EoL communication, producing rich data. Patients were offered the option to have a family member or support person present (Pleschberger et al, 2011); three of the four patients chose to attend alone, perhaps indicating a preference for private reflection. The structure of the interviews was loosely informed by an interview/topic guide (see appendix), which enabled me as the interviewer, to explore predetermined areas of interest relevant to the research aims, while also allowing flexibility to pursue topics that arose during the discussions (Walton, 2021). In this way, the conversations evolved and moved in different directions, at times exploring stories of the past and at other times, stories of death and the 'afterlife'. Interviews were understood as interactive encounters in which meaning was shaped through dialogue between participants and me (Tietal, 2002). I have reflected on how my presence affected whether participants told their story, for example, whether they might see me as a sympathetic ally or a threatening adversary (Phoenix, 2013, p. 80).

These considerations informed my approach to building rapport with participants, pacing the interviews and responding sensitively to participant's disclosures. Interviews were audio-recorded and transcribed (verbatim) afterwards, by me, as lead researcher, which facilitated close engagement with the data. Transcripts were anonymised and stored on a password protected device, ensuring participant confidentiality.

The aim of my study was to compare how patients and physicians spoke about their experience of EoL communication, rather than conducting interviews with both parties present. Given the vulnerability of terminally ill cancer patients and the sensitivity of EoL communication, this approach enabled participants to talk about their experiences without fear of judgement or anticipating the reaction of others. While dyadic or triadic interviews may have been better aligned with a relational and systemic approach, it could have constrained participants' ability to speak freely about sensitive topics, potentially limiting insight offered around beliefs and attitudes, which are key components of the research questions.

Research in palliative and EoL care supports this approach. For example, Gysels et al. (2008) found that on occasions when the patient and their partner were interviewed together, it could lead to difficulties, if one partner had not wanted to disclose certain information. Similarly, Gumede et al. (2019) found that participants sometimes revealed information in individual interviews that may have remain hidden in joint interviews. While joint interviews offer benefits such as observing real time interactions, in my view and in the context of my study, the risks such as potentially

silencing one partner or causing emotional distress, outweighed the advantages. Conducting individual interviews therefore maximised the ability to explore participants personal experiences in depth.

As the aim of this study was not to reconstruct specific previous conversations or generate linked accounts between physician, patient and potentially relatives, a case study design was not adopted. Instead, the study focused on the broader conceptual meanings and processes that shapes how each party navigates EoL conversations. A cross-sectional design enabled systematic exploration and analysis of these meanings without requiring participant accounts to relate to shared encounters. Analysis examined individual stories while also comparing accounts across patients and physicians, highlighting areas of agreement and divergence in how each group interpreted and navigated EoL conversations. This approach casts light on one aspect of systemic practice; it does not assume that meaning resides in a single shared account of an experience, instead it recognises that individuals construct narratives based on their histories, roles, context and values (Hedges, 2005). In this study, physicians and patients accounts are treated as complementary narratives that reveal, for example, how conversations are shaped by individual beliefs about death. Conducting a cross-sectional design with separate accounts also helped to mitigate potential power imbalances between patients and physicians. By examining patient and physician accounts separately, the study preserved the integrity of each participant's story while still enabling patterns across the data set to be identified. Phoenix (2013) in the context of narrative analysis, highlights the importance of attending to the 'local' context, meaning, where the interview takes place, the interviewer-interviewee relationship and the influences of the wider societal contexts

– all of which can influence the interview process and shape what participants say. I understand these considerations to be equally relevant to qualitative interviewing more generally.

Rationale for choosing reflexive thematic analysis

The analysis for this study was initially conducted using dialogical narrative analysis (DNA) as outlined by Arthur Frank (2010). DNA offered a framework for understanding how stories are ‘performed’ in different contexts. What drew me to narrative analysis was the emphasis it placed on keeping stories intact, honouring the fidelity of peoples lived experiences, across time. By focusing on stories without attempting to ‘break them down’, I understood narrative analysis aimed to track people’s lives over time and provide rich insights into past, present and future intentions (Phoenix et al., 2007). In addition, because stories develop within relationships and are influenced by broader social and cultural narratives (Smith, 2021), DNA initially appeared to be a valuable framework for exploring how patients and physicians create meaning collaboratively during Eol conversations. However, during the process it became apparent that while DNA privileges the narrative performance of individual accounts, the research question guiding the present study - *how do patients and physicians navigate the complexities of conversations at the end of life in the context of terminal cancer*, required a different analytical emphasis. This study sought to identify patterns of meaning across participant accounts, rather than detailed interrogation of individual narratives. For this reason, the dataset was re-analysed using reflexive thematic analysis (RTA) as developed by Braun and Clarke (2022) which turned out to be an appropriate method for analysing data in this context.

Thematic analysis (TA) is commonly used to analyse qualitative data but there are multiple versions of TA rather than one standard approach. Scholars have distinguished between ‘small q’ often referred to as coding reliability thematic analysis, and ‘Big Q’ qualitative approach such as RTA. ‘Small q’ approaches focus on structured coding and reliability, while ‘Big Q’ approaches see knowledge as interpretative and recognise that researchers play an active role in meaning making (Braun and Clarke, 2021, p. 130). I utilised RTA which aligns well with critical realism, relativism or constructionism epistemologies (Braun and Clarke, 2021, p. 131) and highlights the active interpretative role of the researcher in constructing themes through reflexive engagement with the data (Braun and Clarke, 2022). In this approach, themes are not understood as patterns waiting to be found in the data, instead researchers create themes through engagement with the data (Braun and Clarke, 2022).

The choice of RTA is also consistent with the orientation of systemic practice. As a systemic therapist my work centres on exploring relationship dynamics and understanding how meaning is constructed within and between individuals. RTA provides a methodological framework to examine these dimensions in-depth while allowing critical reflexivity regarding my own assumptions, experiences and positionality. On occasions when I experienced strong responses during analysis of the transcripts, I paused to think and reflect, to ensure that my interpretations were grounded in the participants’ own words, rather than shaped by my feelings and experiences. For example, in one interview with a physician, they shared how they

handled a situation with family members who had only just learned about their father's terminal diagnosis. The physician recounted telling the family '*I know this is the first time you are hearing about it. This is not about you. This is about him. Stop making it difficult for him to die peacefully.*' My initial impression of the physician's account was it sounded authoritative and possibly dismissive of the family's distress. On further reflection and revisiting the transcript, I considered an alternative perspective that the physician's action could also be understood as an attempt to enforce a boundary and perhaps advocate on behalf of the patient (as discussed in the findings chapter). This iterative process of re-examining the data and exploring multiple interpretations, formed part of the reflexive approach, consistent with the principles of RTA (Braun and Clarke, 2022).

Prior to beginning the re-analysis of data, I contacted Victoria Clarke, one of the founders of RTA, to discuss my research objectives and rationale for choosing RTA. In her response, she provided guidance and shared several articles including a recent paper (Braun and Clarke, 2024) which focuses on 'supporting best practice in reflexive thematic analysis reporting in palliative medicine' together with a supplementary document, 'reflexive thematic analysis reporting guidelines' (RTARG). These guidelines offer a framework to ensure methodological coherence in the reporting of RTA. Crucially, RTARG highlights that reflexivity is a strength rather than a limitation of RTA. These two articles together with Braun and Clarke's Thematic Analysis: A Practical Guide (2022) has guided me in my data analysis. RTA has increasingly been applied in oncology and PC research to explore experiences of illness and communication practices. For example, Janouskova et al. (2025) applied RTA to explore how patients with advanced illness understand hope and prognostic

awareness, while Collins et al. (2022) used RTA to explore how oncology clinicians introduce early palliative care to patients. These studies, alongside methodological guidance such as (RTARG) show that RTA is well suited to examining the nuanced dimensions of EoL communication, while maintaining analytical transparency and reflexivity.

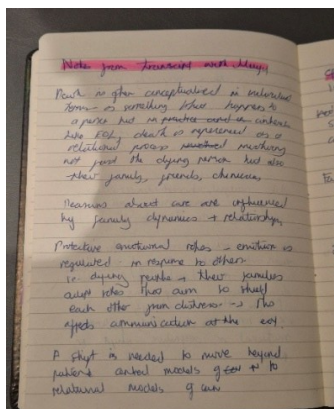
The analytical process

In accordance with recommendation provided by RTARG, my presentation of the analytical process is clearly described using figures (photos) that illustrate key stages of analysis. I present these below - this is consistent with the examples provided in Braun and Clarke (2022). RTA offers a six-phase process that progresses methodically from data familiarisation through to coding and development of themes. In practice I found the process was more iterative than linear (Braun and Clarke, 2022; Trainor and Bundon, 2021). For example, when identifying preliminary themes, I found myself returning to early stages of coding to ensure that the themes were grounded in the data.

The first phase of RTA is to familiarise oneself with the data. I had already transcribed each interview verbatim shortly after the interview was completed. Transcribing had marked the start of the analytical process and as I transcribed, I started to orient myself to the participants. When I started the reanalysis of data using RTA, I re-read the transcripts again to become familiar with the data and made notes about things that were of interest and 'casual observations about the data' to remind myself of potential

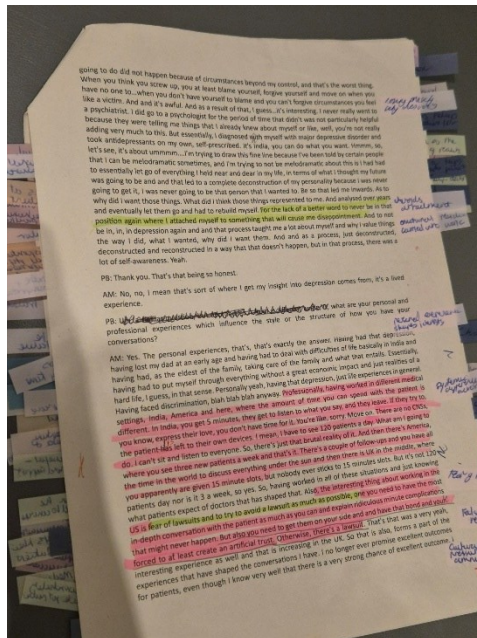
analytical insights for further exploration during the coding and theme development phase (Braun and Clarke, 2021).

Figure 1 - extract from initial notes



The second phase of applying RTA involved generating codes. I carefully went through each transcript twice and where I noticed segments relevant to my research question, I assigned a code. Some segments were assigned multiple codes to capture multiple meanings. Semantic codes which capture surface meaning and latent codes which interpret underlying implications of data, were employed (Braun and Clarke, 2022). Coding can be conducted manually or supported by qualitative analysis software such as NVivo. I chose a manual approach - writing code labels on printed sticky notes and attaching them to printed transcripts (Braun and Clarke, 2022). I found this facilitated closer engagement with the data and heightened awareness of my interpretative process (Maher et al., 2018). I was also mindful that software assisted coding could make the process mechanical and might cause data to become overly fragmented.

Figure 2 – example of coding



Once I finished coding the transcripts, I began phase three which involved identifying initial themes - shared patterns of meaning across the data set. I printed out my list of codes and cut them so that I could physically group those that connected to similar concepts and ideas (figure 3). In developing initial themes, I was guided by three questions suggested by Braun and Clarke (2021, p.137)

- Is the theme relevant to answering my research question?
- Does the theme capture more than one or two data items?
- Can I easily identify a central organising concept for this theme?

Further, Braun and Clarke (2021; 2022) recommend compiling data extracts linked to specific codes that are important to develop analysis. I completed this process for each transcript (figure 4).

Figure 3 – example of clustering codes and initial themes

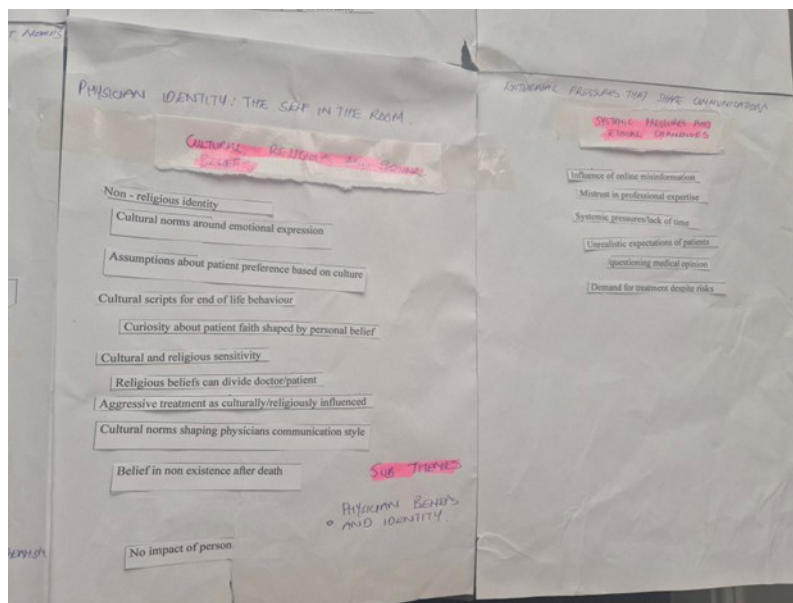


Figure 4 – example of codes and extracts

Extract	Codes
I guess what surprises me sometimes is the level of denial when everybody knows that everyone's going to die, but the sheer level of denial that does surprise me and those patients are more challenging. They'll be running around for second opinions, they'll be googling stuff on the internet, they'll be wanting this, that, and I think just to get them to understand that it is quite hard. And there will be a significant amount of pressure coming from family as well, in those cases. I think it's some sort of a microcosm of an equal chamber of immortality or something like that in that household where everyone thinks that you have to do absolutely everything, pull out all stops with regardless of the cost to try to gain the extra few months weeks (pg.2) I think that's the most important challenge and I mean, there is challenges of oncology and there are challenges of the NHS, those are two different things. I mean pure oncology; it would have to be unrealistic expectations of patients. I mean it is amplified significantly by the pressures from the NHS and the fact that you can't get anything done on time and you feel that you that you are letting them down because of factors beyond your control. Patients not willing to engage or not willing to understand the limits of medicine poses this biggest challenge (pg. 3).	Denial as an obstacle Emotional labour for physician Patient mistrust in professional expertise Patient questioning medical opinion Family pressure Family influence on treatment decisions Denial of mortality Unrealistic expectations of patients Systemic pressures of NHS Physician feelings of helplessness Perceived unwillingness of patients Limits of medicine

Phase four involved ‘development and review’ of themes. I engaged in an iterative and reflective process of reviewing themes which involved carefully distinguishing between topic summaries and themes, ensuring that each theme was organised around a central organising concept. This process led me to merge some initial themes where meaning overlapped and removing some themes completely. Drawing on Braun and Clarke’s guidance (2022), I was mindful that hierarchal thematic structures i.e., overarching themes and sub themes can risk fragmenting the data and reduce the analytical depth of the interpretation, therefore, I chose not to include sub themes or overarching themes.

In phase five I moved from reviewing themes to defining final themes (Braun and Clarke, 2022). I discussed this in supervision and with the support of my supervisor, we explored the core meaning of each theme and how it contributes to the overall narrative in relation to the research question. This prompted me to revise the names of the themes, for example, I changed the theme originally titled ‘*Emotional navigation and professional boundaries*’ to ‘*Navigating emotional labour: managing empathy and burnout*’. This was with the intention to more accurately capture the focus of the theme. I also revisited the table of extracts that I compiled earlier in the process to ensure it provided a fair representation of the dataset and participant voices.

In the final phase, I produced a report. I carefully selected data extracts and integrated detailed analytical commentary, drawing together the themes into a narrative that addressed the research aims. Braun and Clarke highlight two main ways of treating data extracts – the *illustrative* approach using extracts to illustrate the claims made

and the *analytical* approach where comments relate to specifics of the actual data excerpts (Braun and Clarke, 2022, p. 142). Following the examples outlined in Braun and Clarke (2022, p. 137), I opted to use slightly longer extracts to provide sufficient context for interpretation and in this way, adopted an analytical approach.

Reflexivity in research

As a researcher investigating how physicians and patients experience and navigate conversations at the EoL, I was aware of the influence that my own experiences could have had on the research process. I have personally experienced the challenges of navigating EoL conversations with physicians, witnessed the ravaging effects of cancer and experienced a profound loss. There were moments of resonance in my interviews with participants which I experienced as a deeply moving process and at times, emotionally charged. In interviews with patients, their stories evoked strong emotions in me i.e., I felt guilt and sadness associated with my knowledge of their illness prognosis - I was 'living', and they were 'dying'. In my interviews with physicians, certain contributions sometimes triggered negative reactions in me. For example, physicians' descriptions of interactions with patients reminded me of the challenges my mother and I experienced, and I noticed similar shortcomings in their approach.

It has been suggested that in qualitative research it is necessary to be absorbed by participants' stories and empathically touched by participants (Raheim et al., 2016). I became aware early in the research process that my own experiences will make me vulnerable and influence my emotional state. While I cannot erase my personal memories completely, I recognised that it could both colour my perception of the

narrative of participants, while also providing a basis for curiosity and empathy – qualities essential for research in this field. To mitigate potential bias and maintain an ethically responsible approach, I processed personal experiences with my supervisor and also attended individual therapy to process my grief. In addition, I kept a reflective journal documenting thoughts and reflections about the research process. Supervision offered a safe space to discuss dilemmas and feelings, and feedback helped me increase self-awareness, challenge my own assumptions recognise potential pitfalls which I might not have otherwise been aware of (Pizzolato and Dierickx, 2023).

As part of this reflexive process, I wrote imaginary letters to each of the patients (see appendix). These letters, which were not sent, allowed me an opportunity to reflect on what I had appreciated and learned from their narratives and to acknowledge the effect their stories had (Frank, 2022). As I analysed the data, I also began to see myself as a ‘vulnerable reader’. Frank (2022, p. 6) writes:

‘Vulnerable reading most often begins by seeing how a story mirrors our own sufferings. In that reflection, I reimagine suffering that had seemed uniquely mine, now knowing it is shared. The suffering reader and the suffering character in the story greet each other in a you too relation.’

Rigour and trustworthiness

Maintaining rigour and trustworthiness is essential in qualitative research (Tracey, 2010). Rather than relying on one single procedural step, the integrity of qualitative research is demonstrated through the overall design, conduct and transparency of the process (Coyle, 2021). The chapter has outlined the methods used to ensure rigour

in this study, such as conducting in-depth semi structured interviews. I aimed to approach both the interviews and data analysis with an open and curious stance, drawing on Cecchin's (1987) concept of curiosity, to remain attentive to participants stories and meaning. I tried to create an interview environment where participants felt able to speak freely and openly about their experiences. Interviews lasted 60-90 minutes which gave participants the opportunity to provide detailed accounts of their experience of EoL conversations. The methodology was thoughtfully evaluated; although DNA was first employed as the analytical method, RTA was subsequently adopted as it more effectively aligned with the aims of the study. This transition improved 'meaningful coherence', indicating the extent to which the study achieved its stated purpose (Tracey, 2010).

In my view, this study fulfils Tracey's (2010) criterion of *worthiness* as it explores how patients and physicians navigate EoL communication – a topic of significant importance given the universal relevance of mortality. Credibility understood as the 'trustworthiness' of qualitative findings (Coyle, 2021) was supported through sustained and iterative engagement with the data. Transcribing the interviews myself facilitated early familiarisation with the data and the analytical process. The process of RTA involved multiple readings of the transcripts, thorough manual coding and ongoing refinement of themes to ensure that interpretations were grounded in participants accounts. Transparency was maintained by documenting each stage of the process and on-going reflexivity was central to maintaining methodological rigour. Together these practices support the trustworthiness and credibility of the study.

Summary

Engaging in this research has been transformative. During the first phase of analysis using DNA, I recognised that I was grieving for the loss of my mother, which shaped how I responded to the stories of participants, as described earlier in this chapter. By the time I embarked on the second phase of analysis, using RTA, I was pregnant with my first child. Writing about death and EoL experiences from the perspective of creating new life – feeling my baby move and grow – created a profound counterpoint to grief. This dual awareness of life and death enabled me to reflect on themes such as suffering and loss, living and dying, in a deeply personal yet methodically relevant way, which I believe enhanced my analytical insight and approach to analysis,

In this chapter I have provided an overview of my epistemological position, the research methodology used for this study and shared personal reflections. In the next chapter I present the findings of this study.

Chapter 5

Findings

This chapter presents the findings from interviews with physicians and patients. The findings are presented in three parts. Parts one and two present the themes that emerged from interviews with physicians and patients. Part three integrates these findings and examines points of convergence and divergence between the physician and patient perspectives, to illustrate how end of life conversations is jointly navigated. Direct quotes from the interviews are included to illustrate and support the themes discussed.

Part one

I have constructed five main themes that reflect central patterns of meaning that emerged from the interviews with physicians. Rather than dividing themes into sub themes, each theme is presented as a multifaceted narrative. This allows for a more integrated representation of the complexities explored in this study which is aligned with the interpretative principles of reflective thematic analysis (RTA) (Braun and Clarke, 2022). In this thesis, patterns of meaning refer to recurring themes identified across participants' accounts that address the research question. These patterns reflect my interpretations of the data set, developed through sustained engagement with the data.

Themes generated

- The inner life of physicians: cultural, religious and personal experiences
- Navigating emotional labour: managing empathy and burnout
- Balancing professional responsibility with patient anatomy: navigating denial
- Family involvement as supportive and disruptive
- Learning on the job: gaps in communication training

Research participants: Robert, Alfred, Maya and Tanya

(The names of participants have been changed to maintain confidentiality).

Name	Sex	Religious Background	Ethnicity	Position
Robert	Male	Atheist	White (Australian)	Consultant Oncologist
Alfred	Male	Muslim	Asian	Consultant Oncologist
Maya	Female	Atheist	Indian	Oncology Registrar
Tanya	Female	Non religious	- White (European)	Junior Oncologist

Theme 1: The inner life of physicians: cultural, religious and personal experiences

All four physicians reflected on how their worldviews, whether shaped by atheism, faith or personal experiences, intersected with their clinical identities. The physicians expressed a need for professional boundaries by enforcing a clear separation between personal values and clinical practice. This theme explores how physician's cultural, religious and personal experiences influence their approach to EoL communication.

Alfred, a practising Muslim, expressed a need to separate his faith from his professional role, although he expressed moments of personal alliance with patients who shared his beliefs.

'I do believe in afterlife and all of that stuff. But I don't let that come in the way. I don't presume to lecture. I keep that completely separate. I mean, sometimes I do have Muslim patients, and you can connect with them on that level and say, well, you know, I'm doing my best, I leave it to God to do the rest. But for the majority of the patients, I do not bring that in, I keep it to be really separate and that also, I learned. I mean, I always did, but I was still burned by it'. (Alfred)

While Alfred's beliefs in an 'afterlife' could provide a resource for connection with patients, particularly patients who share a similar faith background, he intentionally separates this part of his identity, from his clinical work. His remark *'I was still burned by it'* highlights the emotional risk of disclosing too much about himself. The statement

'I keep it to be really separate' may indicate a self-protective mechanism and a boundary which is required within a clinical setting, which prioritises objectivity and neutrality. The emphasis on separation suggests that neutrality is not simply assumed but actively maintained as part of Alfred's professional identity, in which he manages the coexistence of his personal faith and professional role. There is perhaps also a subtle moral dilemma for Alfred in relation to how he can stay true to himself and manage his own values and beliefs, while also respecting professional boundaries and individual patient needs. His reference to *'all that stuff'* appears to downplay his religious beliefs which may indicate an orientation to professional norms, which renders spirituality/religious talk as inappropriate within clinical encounters. His account highlights a tension at the intersection of science and faith; while medicine seeks certainty, in some contexts like EoL care, medical professionals are confronted with existential questions that medicine alone cannot answer.

Maya reflected on her non-religious views and how personal experiences shaped her perspective.

'I don't, don't really have any religious beliefs, but I do feel like my own experiences of death and dying in my family kind of led me to like, to be, a bit more spiritual. But I don't know how that impacts to be honest, in the way that I interact with patients. I don't think it does. I guess I'm more kind of empathetic or like understanding of other people's religious beliefs in becoming slightly more spiritual, I guess, but I don't think it would impact anyway. I tend not to like get too involved in their (patients) personal lives and ask too much and I think that's more of a self-protective mechanism rather than it being, me being insensitive.' (Maya).

Here, Maya reflects on an internal tension between her personal experiences of loss and her professional role. While she claims that these experiences have led her to '*be a bit more spiritual*' and describes herself as '*I am kind of empathetic*' she appears to downplay the effect this has on her clinical encounters. Perhaps indirectly, her experiences of death in her family have shaped how she shows empathy and relates to patients. Her assertion that she tends not to get involved in patients' personal lives as a self-protective mechanism is perhaps an indication of the emotional boundary which is necessary to manage the emotional labour involved in EoL care. Maya's account reveals a tension between acknowledgement and minimisation; she attributes empathy to personal experiences while insisting that it does not influence her clinical practice. This indicates that physicians may compartmentalise aspects of themselves and limit the extent to which their 'personal' self is expressed in clinical encounters.

The idea of not '*getting too involved*' with patients' personal beliefs was also alluded to by Tanya, who identified as an atheist.

'If somebody mentions something I will say, 'OK, well do you think it would be helpful for us to get the chaplain to come and talk to you. It might be quite nice if you wanted to have someone to talk to where their focus isn't on the physical side of things.'
(Tanya)

While Tanya demonstrates a respectful approach, her choice to not engage directly with the patient about their beliefs and instead refer to the chaplain who she understands as the appropriate person, indicates a boundary between what she

understands as her clinical role and the patient's spiritual needs. This reflects a similar approach to Alfred and Maya.

Like the other physicians, Robert expressed a clear boundary around what he considered was within the scope of his role.

'I think they (patient) get a lot of that (spiritual support) from their family and community and don't really need me stepping into that world for them. I think most oncologists are asked of their patients just to manage their pain and their cancer as best they can and other matters of life and death they tend to manage themselves.'

Robert, like the other physicians, constructs an explicit division between his clinical role and existential matters. He locates the latter outside of his clinical domain suggesting that patients receive spiritual support from '*family and community*' and therefore, '*they don't really need me stepping into that world*'. The way he frames this indicates that it is a considered response centred on patient needs and, in this way, naturalises the boundary he is establishing. His statement that oncologists are asked of patients '*just to manage their pain and their cancer as best they can*' highlights medical care as the central focus of his professional role. Robert's account suggests that such boundaries enable him to maintain professional authority while limiting exposure to existential elements of care. While the specific content of physicians' beliefs varied, it seems that in navigating the complexities of EoL conversations, physicians intentionally draw a professional boundary which prioritises medical care and places spiritual or existential concerns, outside of their remit.

Beyond the influence of religious and spiritual frameworks, two physicians talked about their early life experiences that encompassed moments of psychological struggle and confrontation with their own mortality. In response to a question that related to Alfred's reference to self-awareness and personal biases, he recounted a period in his life when nothing was going right, during which time he suffered from what he described as a major depressive disorder. He described how this shaped his perspective on life and relationships.

'To never be in that position again, where I attach myself to something that will cause me disappointment. And to not be in depression again and that process taught me a lot about myself and why I value things the way I did, what I wanted, why did I want them. And, as a process, just deconstructed and reconstructed in a way that it doesn't happen but, in the process, there was a lot of self – awareness'. (Alfred)

This extract reveals a pivotal period in Alfred's life marked by hardship and psychological distress. The emotional detachment described by Alfred appears to be a learned response that developed following earlier painful experiences and through the process he described as '*deconstruction and reconstruction*' of self. Through this 'transformation' of self, he appears to have developed new ways of managing emotions which he associates with greater self-awareness. Alfred's emphasis on ensuring that he is never '*in that position again*' indicates a deliberate strategy for self-regulation which may explain his orientation towards boundaries in clinical practice. In this way, Alfred's narrative shows how personal and earlier life experiences can shape how physicians respond in emotionally charged situations, such as those in oncology settings.

When the question of ‘confronting mortality’ was explored, Robert recounted a time during his oncology training when he had recurring dreams about his own death to cancer.

‘I had trouble in that second year (of oncology training) sort of coming to terms with, I guess my own mortality in that time. I remember there was a period there where I dreamt, I had cancer and was dying almost every night for months, and that was very tough. And I remember asking my other registrar colleagues, ‘like do you dream you are dying of cancer like vividly’. And I think that was part of the process of coming to terms with the line of work I’ve chosen to work in. But you make peace with it eventually. And I think, you know, I developed the ability to have a good rapport with patients and see them as human beings and not just cases’. (Robert)

His narrative reveals a personal confrontation with death and the process of psychological reckoning appears central to Robert’s capacity to relate to patients as *‘human beings and not just cases*. The vivid dreams he describes suggests that his awareness of mortality was not abstract/one off event but a process which he went through, during his second year of training. The recognition that it was *‘part of the process’* suggests that Robert was actively grappling with mortality through dreams, as part of his own development, rather than as an impediment to his work. The narratives provided by the physicians indicate that their approaches to communication at the EoL are influenced not only by religious/cultural frameworks and clinical training but also by personal histories. While physicians did not always draw explicit connections between their personal experiences and their clinical practice, their

accounts illustrate how early experiences and encounters with mortality may subtly shape how they relate to patients and negotiate boundaries.

Theme 2: Navigating emotional labour: managing empathy and burnout

All physicians reflected on the emotional labour involved in communication at the EoL. While empathy was regarded as central to meaningful conversation, physicians also described the strain of remaining emotionally present in the face of repeated exposure to patient suffering and increased workloads. This theme explores the tensions inherent in environments that require emotional availability as well as professional detachment.

Tanya described the emotional toll of sustained empathetic engagement with patients.

‘You know, it’s exhausting. And at the end of it, even if you don’t feel emotional, it is very draining to be empathetic. But for the really difficult consultations, the way to do it well is to give empathy and the problem with having too many patients and with the whole burnout thing as well, is that it’s very difficult to keep giving that’.

Tanya reflects on the tension between needing to consistently offer empathy which she understands as central to doing ‘it well’ while simultaneously dealing with exhaustion and managing the effects of burnout. Empathy is portrayed as a form of emotional labour which can be difficult to sustain. The extract also highlights how organisational pressures such as heavy caseloads, lead to burnout and limit the physician’s capacity to engage empathetically.

Similarly, Maya described the emotional toll of empathic engagement in a particularly distressing interaction with a patient.

'I was telling her all the information, but then she kept interrupting because she (patient) was in so much distress that she was just crying and then we had to keep starting again. But then I wasn't sure how much she'd taken in. (.....)I think in a way because it took so long and it was so stressful, my empathy for the patient was kind of waning towards the end and I just wanted to like kind of have a breather myself. Like, it was just a really really difficult patient.'

Maya's account illustrates the dynamic nature of empathy which can fluctuate depending on the emotional demands of the situation at the time. Unlike stories of burnout that often focus on long term exhaustion, this extract shows how emotional labour can become overwhelming within a single interaction. Maya's interaction with this patient led to empathy fatigue, indicating that empathy is not limitless. *'I just wanted to like kind of have a breather myself'* suggests an inclination to want to step back when feeling overwhelmed. Both Tanya and Maya's narratives highlight that in order to continue to provide care, physicians may temporarily split off or distance themselves from patients, as a protective strategy, while remaining professionally engaged.

Robert described a working environment in which emotional labour appeared to be a routine part of the work.

'In all honesty, I would say there is some, there is some discouragement of not being able to handle it as a medical oncologist. I think we all firstly, not many of us struggle with it after so long. You know, you do have the tough case, it really takes it out of you. But most of us can handle it pretty well, dealing with death and destruction. It does start to burn you out a little bit and I definitely notice on holidays if I've been away for more than a week or two, I do feel a lot happier'. (Robert)

Robert emphasises *'most of us can handle it pretty well'* while also acknowledging emotional fatigue *'It does start to burn you out a little'*. This juxtaposition suggests that physicians may experience a tension between the professional expectation to be 'competent' and the personal impact of repeated exposure to illness and death. He seems to present burnout and emotional fatigue as an inherent part of oncology practice. By describing the conditions of oncology as manageable, Robert appears to normalise the emotional strain of the work.

When exploring with Alfred how he managed personal emotions and reactions when confronted with dying patients, Alfred described psychological distancing as a necessary part of his role. Reflecting on the frequency of EoL conversations he remarked,

'you do it so many times (conversations), it becomes ... even though it is hard every time but there is still going to be a barrier. There are multiple barriers between patients and me.' There is a point where it sucks for a couple of days but then life takes over and yeah, you realise everyone is going to die and you're going to die too. (Alfred)

The reference to *multiple barriers* suggests that detachment may be a learned adaptive strategy, enabling physicians to maintain engagement with patients, in stressful environments. Alfred's reflection '*you realise everyone is going to die and you're going to die too*' carries a subtle duality; it may function as a distancing mechanism to manage the emotional intensity of such conversations, while also signalling an awareness of his own mortality, that could bring him closer to the realities faced by his patients.

In contrast to the narratives shared by Alfred and Robert which focused more on how they maintained emotional boundaries, when Maya was asked about managing empathy and burnout, she recounted a period in her professional life when her emotional boundaries collapsed. She described her experience of working in a hospice and reflected on the close relationships she had developed with patients, and their families which eventually became overwhelming.

'There's the obvious (obstacles) like empathy, burnout from like being too involved [...]. I would get you know, the whole point of palliative medicine is that you can spend an hour with each patient, you really get to know them. You get to know their whole family. You get really involved and then literally all those patients die on you'. (Maya)

Maya explained that working in a hospice resulted in her having depression for the first time in her life. In this extract, her account contrasts with Robert's emphasis on '*most of us can handle it pretty well dealing with death and destruction*'. For Maya, sustained empathetic engagement with dying patients appeared to carry a significant emotional cost, particularly in a hospice setting where close relationships with patients

and families were encouraged and death was a frequent occurrence. Her account shows the demands placed on physicians when empathetic involvement is prolonged and repeated which in Maya's case, led to her emotional harm which manifested in depression. Her narrative illustrates the fragility of emotional boundaries and the cost of getting too close to patients and their families.

Collectively, these narratives illustrate the varied nature of emotional labour which can be influenced by personal experiences, individual resilience and the culture of the workplace. Further it shows that empathy requires effort and even compassionate physicians' experience periods of emotional fatigue. It seems that physicians are required to continuously navigate their stance between showing empathy and care while managing personal emotional exhaustion. This is sometimes achieved by implementing strategies like psychological distancing and compartmentalising feelings.

Theme 3: Balancing professional responsibility with respect for patient autonomy: navigating 'denial'

This theme examines the ethical issues physicians encounter when engaging in prognostic discussions with patients approaching the EoL. Physicians noted the ongoing challenge of balancing their professional duty to communicate essential information to patients, particularly around prognosis, with the ethical responsibility to assess each patient's readiness to receive such news. This tension was heightened in situations where patients were perceived by physicians to be in 'denial' or have

‘unrealistic expectations. Descriptions of patient denial were common among physicians and often framed as a barrier to communication and care planning.

‘One of the biggest challenges is patients who are unaccepting of their own mortality and their death. And often you have to make a call, because we’re always figuring out this balance between is the treatment I’m giving you harmful or helping. (Robert).

When confronted with patient denial or patient resistance to medical facts, this can create tension for physicians. As revealed in this extract, while the physician’s role is to support the patient to face the reality of their prognosis, this may be at odds with the patient’s wishes about how much information they want to know. The tension is often amplified by institutional pressures and constraints as highlighted by Alfred.

There are challenges of oncology and there are challenges of the NHS, those are two different things. I mean in pure oncology; it would have to be unrealistic expectations of patients. I mean it is amplified significantly by the pressures from the NHS and the fact that you can’t get anything done on time and you feel that you are letting them down because of factors beyond your control.’ (Alfred)

This extract illustrates the differences between individual and institutional constraints. It also addresses the ethical dilemma physicians may face when their intention to provide timely and effective care is undermined by institutional limitations, often resulting in feelings of disempowerment. ‘*You are letting them down*’ conveys a sense

of conflict between Alfred's professional ideals to respect patient autonomy while also managing the practical limitations. It also indicates an internal sense of responsibility on the part of the physician and the emotional strain associated with patient care.

While Alfred and Robert framed 'denial' as a barrier in communication, Maya's approach to working with patients perceived to be in 'denial' appeared notably gentler and more compassionate.

'If they're like in denial completely, you're gonna see them quite often, cause if they aren't curative then they're probably gonna be on chemos. They're gonna have to come to terms with that at some point because you'll be seeing maybe three weeks on treatment. So, you get to like check in with them and then at some point the conversation will come up like, 'you know, we're nearing the end of the cycle or three cycles, probably need to do a scan'. And then you know, you gotta discuss it again in the scan.' (Maya).

Here, denial is not identified as a static state but rather something that evolves and requires the physician to revisit through multiple conversations. Maya does not confront denial, instead her approach demonstrates a careful navigation between preparing patients for future discussions while being sensitive to the patient's emotional readiness. This contrasts with Robert's account in which he describes *'you have to make a call'* for patients who are *'unaccepting of their own mortality'*, reflecting a more direct approach. This contrast suggests a variation in how denial is interpreted and managed with some clinicians adopting a more relational approach while others adopt a more direct approach. These differences in approach may be shaped by social

and institutional factors including gender, professional positioning and professional hierarchy.

Alfred's comment '*you feel you are letting them down because of factors beyond your control*', refers to the pressures inherent within the NHS but may also reflect an emotional discomfort associated with repeated exposure to dying patients and the responsibility of delivering bad news. In this way, denial should perhaps be considered not only as a response by the patient but as something which is part of the dynamic between patient and physician i.e., when confronted with dying patients, physicians may also be forced to come to terms with their own finitude and may withdraw or seek to protect themselves, by avoiding or limiting contact with patients. This may in turn lead to a breakdown in communication.

The variability illustrated in these accounts reflect one of the core complexities of EoL communication. It shows that physicians use different strategies to manage states like denial, but it also highlights that the framing of denial is an interpretation i.e., what one physician deems as denial another physician may deem as a patient's way of coping.

Theme 4: Family involvement as supportive and disruptive

A recurring tension evident in physician narratives was the dual role that families played in EoL conversations. Family members were often described as essential for providing emotional support to patients but at times their input was perceived to be

disruptive. This theme examines the ways in which families contribute to but also complicate the communication between physicians and patients.

When asked what obstacles might make it difficult to have effective conversations, Tanya explained,

'A lot of the time, I feel like, you know, having family members there is absolutely necessary but a lot of the time I find that problems are where a family member has read up on something that they think is going to be helpful and they keep detracting from the main conversation by going, but 'why aren't we using immunotherapy?' Or 'why, why don't we just irradiate the entire liver?' is one I've had, in someone who had really terrible metastatic cancer and that was a conversation of, 'I'm afraid that time is now short, prognosis is poor, and we need to focus on quality of life.' With the family member going, 'but why don't we just irradiate the whole liver?' (Tanya)

This extract highlights a central tension - while family involvement is seen as *'absolutely necessary'* their presence can also distract from important conversations about prognosis and quality of life for the patient. The suggestion from the family member *'why don't we just irradiate the entire liver?'* may indicate a misunderstanding about what is medically possible, but it may also highlight resistance from the family member in accepting the reality of the patient's illness. Examples used earlier in this chapter illustrated physicians' perception of patients they believed to be in denial about prognosis - the above extract shows how a similar dynamic can also play out through family members who may struggle to accept the patient's situation.

'I won't ever dismiss. I will answer their questions. I will explain why as much as I can, I'll talk about the evidence. But a lot of the time the final thing that does it is that they will get a second opinion.' (Tanya)

In response to the family's repeated questioning, Tanya explained how disruption was managed. She engaged with the family in a transparent way using clinical evidence to support her claims, rather than dismissing or shutting down their suggestions. Supporting the family to get a second opinion may function as another outlet for the family, through which they may reach acceptance and understanding of the situation.

Alfred shared a similar view

'The majority of the time it's helpful because they're (family) offering the emotional support that the patient needs at that point. So, I don't have to, you know. So, and then you can also inform conversations in terms of their wishes and their assessments of what's realistically possible. It helps to have a well-rounded discussion majority of the time'. (Alfred)

Alfred also echoed the difficulties highlighted by Tanya

'Sometimes the relatives are being difficult about it, when the patient is more accepting and that's a much harder discussion to have'. He gave an example of a difficult conversation that he had with a family,

'The patient hadn't told his family about his diagnosis until he was dying. And then the first they heard was that he's on his deathbed and they just couldn't make sense of it, like their dad's dying. But they didn't know he had cancer. They didn't know he was terminal, and they're like going, 'do this, do that'. So, I took them to a room and said 'stop that, you need to think about dad. His wishes. I know this is the first time you are hearing about it. This is not about you. This is about him. Stop making it difficult for him to die peacefully.' They got it.' (Alfred).

In contrast to Tanya's approach, Alfred adopted a more directive yet compassionate approach to navigating family conflict. This extract reveals several layers of complexity i.e., a patient's decision to withhold their diagnosis, a family caught by surprise hearing the news of impending death and their urgent need to fix the situation *'do this, do that'*. Alfred's decision to take the family to another room to may indicate an intention to protect the patient's autonomy while simultaneously establishing a boundary around the interaction, as reflected in the statement *'this is not about you. This is about him'*. His intervention positions him as a mediator and advocate, illustrating the active role of physicians in managing family dynamics in EoL care. This extract also draws attention to the emotional and ethical demands placed on physicians' when patient wishes and family responses are misaligned.

Maya reflected,

'I do think there's like a, a bit of a balance as to, you know, family members and how they're coping, on how the patient copes. I think patients can have a really horrible death if they don't have the concern and worry from their family members, that they suddenly don't have to be strong.' (Maya).

This extract reveals the importance of family involvement as emotionally and functionally significant, '*patients can have a really horrible death if they don't have the concern and worry from family members.*' Family presence creates the space for the patient to release their own need to be strong which in turn can allow them 'a better death'. This extract reaffirms the importance of family presence.

Robert offered insight from another perspective, emphasising how cultural factors can influence patient and family expectations.

'I would say Middle Eastern patients are some of the most difficult to manage expectations. I think, now I am no expert on these things, but I think a part of the Islam faith... Islamic faith, is to do everything you can to maximise life. They tend to push a lot more for aggressive treatments and tend to be less accepting of death. They prefer to die on a ventilator in ICU, having a terrible end of life experience, but that's just culturally what they want to do. They want to squeeze out every bit of life to the very bitter end. So, it's a different discussion in these groups of people. And you have to tailor your conversation to your... you have to be culturally appropriate in your discussion of prognosis and what you can offer a patient. In our system here we wouldn't let someone die with metastatic cancer on a ventilator in ICU. It is cruel and wastes a lot of resources in my opinion.'

Robert acknowledges the importance of culturally sensitive communication; however, his account simultaneously relies on broad generalisations about Middle Eastern patients, whom he describes as '*some of the most difficult to manage expectations*'.

He attributes treatment preferences to what he understands as Islamic beliefs about prolonging life, using these assumptions as a framework for interpreting decisions made by patients and their families. Although Robert's account reflects an awareness of cultural differences, he also positions such beliefs as a barrier to accepting death. This is evident in his statement '*aggressive treatment*' leads to a '*terrible end of life experience*', indicating that expressions of cultural awareness may coexist with judgements shaped by clinical norms.

Physician accounts suggest that family involvement introduces both support and disruption within EoL communication. Interactions are shaped by relational, emotional and cultural factors which can both facilitate and hinder communication, requiring the physician to carefully navigate patient needs and family influence. Physicians describe navigating these situations through a range of communication strategies such as boundary setting, modulating their tone between empathy and directiveness and adapting their stance, depending on the circumstance.

Theme 5: Learning on the job: gaps in communication training

Communication at the EoL, in the context of terminal cancer, involves emotional challenges and relational dynamics as identified in this chapter, requiring careful navigation and sensitivity. All physicians were asked about formal training that they have received. While they varied in their views, they generally described training as ad hoc, inadequate and emotionally disconnected. This theme explores how physicians came to learn how to communicate with patients and families at the EoL.

Maya recalled her experience of communication training in medical school, involving actors and video feedback. She described,

'You watch yourself back, giving someone bad news and stuff which is really embarrassing and it's in front of a massive group of people and you're like constantly thinking about what they're thinking of you. So, it's not the most natural thing'. (Maya)

The artificial setting and performative nature of this type of training appears to have created discomfort for Maya, an experience which felt 'embarrassing' rather than fostering confidence. The training appeared somewhat disconnected from the realities of clinical life. She reflected, *'There's nothing for doctors by doctors. It's just ad hoc, you just learn on the job.'*

Like Maya, Robert also spoke about his experience of role play as a medium for learning communication skills, but he questioned the timing and prior experience necessary for such training.

'It can be confronting, and it's best done after registrars have at least seen a few people dying of cancer, because then you get a better feel for it. For medical school it is too soon. You know, these are babies, they don't know how to have these conversations. They haven't even come to terms with life and death themselves.'
(Robert)

As noted earlier in this chapter, Robert described having vivid recurring dreams during his medical training when he imagined himself dying of cancer. This spoke to his own

struggle of coming to terms with mortality as a trainee physician. Against this backdrop, his perspective on communication training becomes more significant. He advocates that such training should be delivered after registrars *'have seen a few people dying of cancer'*. This implies that some experience is necessary for effective learning and that communication skills cannot be taught in isolation from a physician's own emotional development.

While Maya and Robert spoke about specific communication skills training, Tanya's perspective drew attention to a different way of learning, through observation and personal trial and error.

'As a very junior doctor, when you're following the consultant around or the registrar around you will be witnessing a lot of breaking bad news'. (Tanya)

Reflecting on her own development as a trainee physician Tanya described learning through observing her colleagues and noticing how communication happened in real time. She also reflected on learning through evaluating her own mistakes and in this way, her style of learning appeared embedded in self-awareness and reflection.

'I've seen things that don't work well where I'm like 'ohh probably shouldn't have done that'. And I've done that with myself as well, as I've watched reactions where I've, you know, I've kind of said something. And I've seen that actually, oh that didn't land like I expected it to'. (Tanya)

This extract adds a distinct perspective in relation to the theme about gaps in communication training. To engage in the type of learning described by Tanya, it requires the physician to be emotionally attuned and inclined towards critical self-reflection.

While Tanya's account highlights the relational nature of learning through experience, Alfred expressed a sceptical view about training and admitted his lack of willingness to engage with it.

'I don't think there is good training... there might be, I don't know, I've not been exposed to it..... Having said that, if I had been given the training, would I have even listened? Probably not.' (Alfred)

Instead, Alfred framed effective communication as something which relies on insight into one's 'personality' and 'psyche'.

'It's more about the effort that you put in and your personality that helps you guide that and just trying to understand human behaviour, human psychology, ect. But also, I think the biggest thing is having an insight into your own psyche is a very important thing. What, why do you react to things the way you do and getting yourself and your biases out of the picture and delivering that communication that way, I think is more, the more important thing.' (Alfred).

Alfred's account highlights that the gap in communication is not only a result of insufficient or unstructured training but also relates to an individual's level of insight

into their own *psyche* and maturity. Similarly, as illustrated earlier in this chapter, Robert's perspective reinforces the idea that effective communication requires physicians' to have come to terms with their own mortality, noting emotional maturity as a precondition for effective EoL communication.

These accounts suggest that gaps in communication training are not only indicative of inadequate and unstructured training but also relates to how physicians understand the nature of communication. These accounts show the variability in experiences - for one physician developing communication skills involved a personal process of self-reflection and learning, while for another physician, learning to be an effective communicator emerged only after an internal emotional shift i.e., coming to terms with their own mortality. But what unites these perspectives is the sense that physicians are generally left to navigate complex encounters alone, occasionally having the opportunity to shadow senior colleagues but generally there is no structured support such as supervision, in place.

Summary

In summary, an analysis of physician narratives revealed several interrelated themes. The findings highlighted the complex interplay between physicians' personal emotions, experiences and professional identity. Related to this was the theme of emotional labour in EoL communication which prompted physicians to implement strategies such as psychological distancing and compartmentalising feelings, as a way of coping with the emotional demands of their work. Physicians also identified 'patient denial' as a moral and ethical challenge in their work, creating tension between their professional

role in supporting patients to confront their prognosis and respecting patients' wishes regarding how much information they wanted to receive.

Another significant theme concerned the variation in family involvement in decision making. Physicians described family members as being both sources of emotional support and potentially obstructive. Navigating these situations requires active management through using strategies such as boundary setting and redirecting discussions towards patient priorities. Their accounts also suggest that physician approaches are not only shaped by clinical knowledge but also ethical judgements, cultural interpretations and personal dispositions, highlighting the complexity inherent in EoL communication. Lastly, the narratives point towards broader systemic issues, including gaps in medical training and highlight the need for targeted intervention and support, to equip physicians with the skills to better manage the emotional and ethical dimensions of the work.

Part two

Three principal themes were identified that encapsulate central patterns of meaning across the patient interviews. As with part one, rather than dividing themes into sub themes, each theme is presented as a multifaceted narrative.

Themes generated

- Finding acceptance through belief and meaning
- Relationships with physicians

- Navigating family involvement

Research participants: Fia, Janet, Judith and Peter

(The names of participants have been changed to maintain confidentiality).

Name	Age	Sex	Religious Background	Ethnicity
Fia	64	Female	Christian	Black (African)
Janet	74	Female	Christian	Black (British)
Judith	56	Female	Catholic	White (English)
Peter	79	Male	Non-religious	White (English)

Theme one: Finding acceptance through belief and meaning

When examining how patients navigate the complexities of EoL communication, a significant theme identified was that many patients came to accept their illness and impending death through their personal beliefs, often rooted in faith, spirituality and

their views about the natural order of life. This theme explores the ways in which personal beliefs functioned as an anchor for patients in navigating conversations about the EoL.

Janet recalled growing up in Jamaica with her grandmother, who she described as a 'Godly person'. She frequently visited the church with her grandmother, and this was how Janet '*really started believing in God*'. When asked how Janet used her faith to make sense of her illness, she described,

'I still believe in God and trust in him. I know whatever his decision is his decision, and I abide by his decision. So, when I pray to him now, I know that he has the power to heal me or he has the power not to heal me and I said this, 'your decision and going to leave it in your hands'. But my faith is strong in him.'

'When after the chemo, when (name of doctor) told me it hadn't worked, I accepted it because my first thought was, you know, it's God. You know if he wanted it to work, he would make it work, you know, that was my first thought. But at the same time, he could still work with me if he wants. I still haven't given up my faith there, you know, until the last minute, I would not give up my faith'.

This extract illustrates how faith functions as a framework for meaning through which Janet navigates prognostic uncertainty. Janet positions God as the ultimate arbiter of the illness trajectory. In this way, she seems to relocate authority from the medical world to the spiritual realm, in which Janet can maintain a sense of autonomy. Janet's account also reflects the coexistence of acceptance and hope, she remarked '*I accepted it because my first thought was, you know, it's God*'. She also maintained

hope and faith '*he could still work with me if he wants*'. Such positioning can introduce complexity into the patient-physician relationship at the EoL, as medical outcomes such as treatment failure may be understood differently by patients whose belief systems allow for possibilities outside of medical explanations. i.e., the possibility of divine intervention. Similarly, faith – based *acceptance* as expressed by Janet may be misunderstood by physicians as a possible avoidance, denial or unwillingness to accept the prognosis.

The theme of faith also featured in Fia's story. She described her faith as an anchor for coping with illness.

'I know death is inevitable. What I always say to myself, cancer is not going to kill me. As a Christian, we all believe death is inevitable. I'm not afraid of death. When it comes, it comes. I still have that faith. I still have the belief that I'll sail through this'.

Here again, faith is used as the framework to accept death as '*inevitable*' while simultaneously allowing Fia to hold on to hope '*I will sail through this*'. This indicates that seemingly opposite positions can exist side by side, enabling a patient to live meaningfully with uncertainty, while also maintaining a hopeful stance, rather than passively '*surrendering*' to a diagnosis.

In contrast to Janet and Fia who found acceptance through faith and belief in God, Peter described finding his path of acceptance through detachment. He described,

'I believe, ok, so supreme being made the world but, um, don't think they interfere in human affairs. I don't believe that they're going to interfere with my cancer. I think it may have an advantage. Because I've come across a few people who've had cancer and, I've formed the opinion that religious people, perhaps are a little more difficult because they were expecting divine intervention. And when it didn't happen...they were very, very disappointed. So, I think this sort of attitude may have some advantage'.

When this perspective was explored further, Peter explained that his framework for thinking was a product of his professional experiences. He described working as a ship engineer for twenty years – work that exposed him to diverse cultures, people and experiences. He described,

'More or less my thinking would be with something like, say, the cancer happens. It's just another event in your life. There's nothing to worry about. That's funny. It's a rather bizarre notion to have but um, this being diagnosed with this thing, isn't, it's not really bothering me'.

Peter's reflections show that meaning at the EoL can be constructed in different ways, including adopting non-religious perspectives. By framing his illness as *'just another life event'* and by situating death as part of the natural order of things, this philosophy appears to have allowed for autonomy and control in a situation that is otherwise unpredictable. Peter's approach appears to serve as a coping strategy and a form of self-protection. His account broadens the theme of 'finding acceptance through belief and meaning' illustrating that acceptance can emerge through multiple pathways.

While Peter approached mortality with a more pragmatic philosophy, Judith's perspective on death and the afterlife was marked by ambivalence. She used memories of her past as a resource to help her to make sense of her present circumstances. She referred to her *Catholic upbringing* but stated that she was not a practicing Catholic. Her narrative was marked with mixed feelings. She explained,

'I wouldn't say I believe, and I wouldn't say I don't believe, a bit like ghosts, you know. If somebody was to say to me, 'what do you think happens', I think you just literally go to sleep and that's it. I don't think you can like watch down and see what your friends and family are doing. I don't think you can. And I hope I am wrong'.

She then expressed her hope to see

'My mam, my nana and other people that I've known are there.' But I, I, I just kind of think, I think you go to sleep and that's it. If I am honest, that's the answer. I hope I'm wrong. I hope there is something. I will try and let you know'.

Initially, Judith imagined death as you *just literally go to sleep and that's it* but at the same time she expressed a hope to be reunited with loved ones. This uncertainty may function as a strategy for navigating the unknowns of death. Judith reflections also appear to be influenced by her relationships with family members and her wish to be reunited with them in the afterlife, may indicate a need for ongoing connection. Unlike the accounts provided by other patients, Judith's perspective suggests that a

framework for meaning does not always depend on faith or rational explanations but can emerge through tolerating uncertainty.

These extracts highlight how patients in this study drew on different belief and outlooks to navigate conversations about the EoL and ultimately how it helped them to move towards a position of acceptance while holding hope. It is possible that such beliefs may have also influenced how they communicated with physicians and how physicians understood patients. For example, patients' expressions of hope through divine intervention may be misunderstood as denial or, philosophical pragmatism might be interpreted as emotional withdrawal, by physicians.

Theme 2: Relationships with physicians

Across the interviews, patients' relationship with physicians emerged as central to how patients made sense of their prognosis. What constituted as 'good' communication varied between patients, revealing a complex interplay between personal experiences, preferences and beliefs about death and dying.

For Janet and Judith, experiences of empathy and warmth from their physician functioned as a crucial anchor in EoL conversations. Janet described,

'When you first met him, he's very friendly. Makes you very relaxed and the way he explains things you understood. And I think that's very important for patients, especially when they're going to get news, as you know, as we have. It's very important to have someone who shows empathy for you, and I think that (name of doctor) does

that you know. So, I was very happy that he was my consultant you know, very happy with him'.

Janet seems to construct empathy, in this particular context, as an essential component of communication. She described her physician as empathetic, 'very friendly' and someone who 'makes you feel very relaxed', implying that his ability to share information clearly and with a friendly approach, made it easier to receive and process distressing news. When asked how Janet experienced empathy, she explained,

'You can see the empathy coming through and I think I could see that, you know. He really felt sorry that it didn't work. You know, so, that for me was a big help as well, you know.'

This extract illustrates that Janet's physician showed emotional support through his expression of feeling sorry, which fostered a human connection and ultimately helped Janet to feel supported in the face of receiving challenging news.

A similar sentiment was expressed by Judith who highlighted her physician's sustained eye contact and gentle manner during consultations, enabling her to feel comfortable. She described,

'His approach, his demeanour, everything about him was just, he was spot on. He never ever and (name of friend) picked up on this ...and I tend to look around when I am talking to somebody, but (name of doctor) never took his eyes off me. I mean that

was just... he just took his time and explained it in layman's terms, and he didn't baffle me. I felt really comfortable with him, and I felt like I could ask him absolutely anything. He was amazing'.

Judith's account portrays her physician's attentiveness and use of accessible language, as expressions of respect towards her. She depicts her physician not merely as a provider of medical information but someone who fosters a sense of safety within the clinical encounter. This suggests that emotional attunement may play a role in addressing potential power imbalances inherent in the physician – patient relationship.

Unlike Judith and Janet who valued empathy and connection, Peter, who was the only male participant interviewed, believed that emotional distance in the physician and patient relationship was appropriate and necessary. Peter explained,

'I wouldn't have an expectation the doctors would be too chummy because they'll be wasting their time. You know, not necessarily with me, but with anybody. I think because they have to keep it on the strict professional and sort of accepting facts. I mean, their job is very different from politicians. Politicians can get away with wishful thinking'.

For Peter, it appears that reassurance and familiarity risked distracting from the reality of his situation. By comparing physicians with politicians who *'can get away with wishful thinking'* Peter implies that professionalism requires boundaries, clarity of facts and an avoidance of emotional engagement, which may bring about unrealistic

expectations. This account illustrates how personal preferences shape expectations in the patient-physician relationship and suggests that emotional reserve can function as a protective strategy in itself.

This became clearer when exploring Peter's working life as a ship engineer, he shared the following,

'I know from my own working life that um, about human error and all that and they, how um, genuine mistakes can be made. I'm a bit guardish about inquiries and things like that. And investigations and the things that happen. And often when these things are enquired about in court or somewhere else, there's a very different picture painted then what may have really happened'.

I'm very tolerant of mistakes. If during my medical treatment I um, I thought somebody had made a mistake, I might not have even mentioned it. If I thought, it was really careless or unprofessional I'd probably mention it to the person themselves first. But I would be very reluctant to mention it to anybody else'.

Drawing on twenty years of working as a ship engineer, Peter appeared to interpret medical interactions through the lens of his professional experience, and this affected how he engaged in consultations and expressed himself. He positions himself as someone who understands *human error* and is *tolerant of mistakes* and therefore leans towards protecting physicians, by withholding complaints. This indicates that perhaps maintaining boundaries is not an avoidant strategy but an ethical stance, shaped by personal and professional values. This positioning shapes how he navigates conversations by limiting emotional engagement in favour of boundaries.

Fia recounted two 'bad news' conversations that she had with physicians. When asked about the details of these conversations, Fia explained that when she first learned about her cancer diagnosis, in 2018, she was lying in a hospital bed while the physician and junior doctors, stood over Fia and told her *'you won't live for more than two weeks'*. She reflected,

'For you (physician) to stand there and say 'you won't live for more than two weeks' – I'm a believer, as a Christian, you (physician) are not God. You did not give me my life, so you can't tell me when I'm dying. I refused. I said to her 'cancer won't kill me'. They looked at me as if I was mad, but I was not mad'.

'Diagnosis, you need to discuss it with a patient. But for you to categorically say 'oh with this diagnosis, you won't live for more than two weeks', no, you don't have that power. Death does not send an invitation'.

The physician's communication style appears to have actively ruptured the relationship with Fia - she experienced this encounter as inappropriate and offensive. In line with her Christian beliefs, Fia rejected the medical certainty of the diagnosis. She demonstrated how she used her religious beliefs as an act of resistance, in the face of a terminal diagnosis. Fia appears to reclaim her identity and assert herself by stating *'cancer won't kill me'*. Consequently, there was a strong power dynamic which emerged in Fia's relationship with her physician; on the one hand, her physician imposed a time limit on Fia's life *"you won't live for more than two weeks"* and in response to this, Fia introduced a 'higher power' – God, as the decision maker.

Five years on from her experiences as described above, Fia was now under the care of a different hospital. She reported a positive experience with physicians, which chimed with the experiences as described by Janet and Judith. Fia reflected,

'In (name of hospital) all the doctors are angels. (Name of doctor) and her team, the communication is superb. They so put me at ease, their reassurance. [...] I felt so much at ease and the two nurses that did the assessment, the reassurance was so much there. That's all somebody needs'.

Fia's contrasting accounts of her two experiences suggest that it was not the prognostic information itself which determined how she responded but rather, how she perceived 'medical authority' to be enacted. In the first scenario, medical authority appeared to be presented as 'absolute' which Fia resisted. When it was conveyed with reassurance and care as seen in Fia's description of doctors in the second scenario, she embraced this experience, even describing doctors as 'angels' – a metaphor that positions doctors as compassionate mediators rather than decision makers. This highlights communication style as central to whether prognostic information is received by the patient as threatening or containing.

While most patient narratives highlighted empathetic communication as effective, Judith was the only patient who spoke about the role of 'touch' as a nonverbal expression of empathy. She recalled her interactions with a nurse during a hospital admission,

'She would come at nighttime and just little things like. She'd just sit on my bed and stroke my arm, or you know, just little things like that. She'd say, 'if you want a cuddle, just put your hand up'.

When asked about the importance of touch, Judith explained that it reminded her of her relationships with family and friends, *'I miss that, like my dad used to always cuddle me and you know, my friends'*. Judith's story sheds light on another dimension of empathetic care which is often overlooked, emphasising that receiving care is not only about verbal reassurance but also the importance of gentle physical touch. Although Judith refers to a nurse rather than physician, it has been included here because it highlights the qualities she valued in clinical encounters more broadly, which gives useful insight about her expectations of physicians.

The variation in these accounts illustrate that patient- physician relationships are negotiated in diverse ways. For some patients' empathy and relational presence fostered a safe environment and for others, professional distance created a sense of safety and autonomy. This theme emphasises that instead of a single standard of 'good communication' in EoL conversations, there exists a spectrum of expectations shaped by individual patients' preferences, experiences and their worldviews. Further, it demonstrates that communication is not merely a technical task but rather a moral encounter, requiring the physician to navigate different patient expectations.

Theme 3: Navigating family involvement

It emerged that family played a significant yet complex role in EoL conversations, however their involvement was not clearly reported as positive or negative. Except for Judith, the other patients reported difficulties in handling their relatives' reactions to the news of illness, balancing information sharing and privacy, while also acknowledging the importance of family. This theme explores how patients manage complex interactions when relatives are involved.

Peter explained that he preferred to attend appointments alone and would be reluctant to share medical information with others, except for his stepdaughter, as she had previous experience of supporting her mother and father who both had cancer.

'I think it's the best way (attending appointments alone) if you are, if you are capable of understanding what's been said. Then you can edit it afterwards if somebody is becoming too fussy or too concerned. [...] I think the family have to give some support, but not get too much involved because different family members will have different attitudes and they'll have different opinions and um, I think that can be confusing for the patient'.

Peter frames his attendance at appointments (alone) both as an expression of autonomy and a strategy for managing the potential emotional impact associated with sharing medical information. Peter describes family involvement as necessary for providing support but also potentially disruptive, fearing that relatives can become *too fussy or too concerned*. Considering this perspective in the context of Peter's wider

narrative, his approach may be related to his tendency of being 'mistrusting' of others and his fear that people may *distort* information related to him/his illness.

The issue of relatives causing a '*fuss*' was also present in the account provided by Fia. Like Peter, she described a cautious stance towards involving relatives in medical appointments.

'There was a time I brought um, a relative to my appointment and we left there, and she was telling people, 'Oh, this is what, this is also'... So, I don't, even my children, I don't bring them to the appointments. I don't like to involve them. I don't like to put worries on people. The way I take things, it is not the way other people.... because I thought my cousin, she was so tormented. It's not everybody that think the same as I think you know. We all have different perspectives. She will say in her language 'this is what they said' you know, not goodo... help them to spread that negative perception. No, I don't like it'.

Fia frames her previous experience of involving a relative in her consultation as an episode that led to emotional turbulence, referring to her cousin as '*so tormented*' and someone who spreads '*negative*' news, which likely amplified the distress within the family and social networks. Fia's disapproval '*no I don't like it*' perhaps signals her need to keep relatives at bay so that she can maintain authority over the details of her illness story. Fia's tendency to avoid family involvement may not be a rejection of support but instead a strategy to protect relatives from the burden of distressing news. It may also function as a strategy to protect herself from the ripple effects of relatives' distress.

Janet shared a similar perspective to Peter and Fia. She acknowledged the importance of family support, but she also recognised that family responses were a source of distress. She described,

'Family is important at times like this, you know. I think it's so important that everybody get involved. [...] When I was diagnosed and I'm telling my sisters and my aunts and that; they all seem to take it worse than I did. You know, they were in tears and they were crying and they could not accept it'.

Janet may face an emotionally challenging situation due to her family's lack of acceptance, requiring her to cope with feelings related to her illness, as well as managing the feelings of others.

Connected to the theme of family involvement are Peter and Janet's narratives of their previous caregiver roles for their respective spouses, who both died of cancer. These accounts seem to have influenced how they told their illness narratives and the approach they took towards managing family dynamics. For example, Peter described that his wife *'held up very well until the last probably four or five months of her life'* but then *'in the last few months she became vicious towards people that didn't deserve it'*. Peter's memory of occupying the 'carer' role previously, may have created a heightened sensitivity towards the emotional burden that he imagines relatives carry. This may result in Peter's reluctance to involve relatives, other than his stepdaughter, to avoid repeating past dynamics and evoking distress in the family system. More

broadly, this may indicate that how patients navigate family dynamics in the present is reflective of a process built from earlier experiences.

When asked about Janet's relationship with her husband, she reflected on the long life that they shared. Having met at the age of fifteen, they spent nearly sixty years of life together. She described,

'I cared for my husband. And um, I think it helped me in many ways. I can see now what he was going through, you know'.

She then told a story about her interactions with the local pharmacist. Janet explained that she shared her prognosis with the pharmacist and in a humorous way said *'ooh, my husband wants me to come, come and be with him, you know'* (referring to Heaven). *So, I'm not bothered. So, they're laughing (pharmacist), they said 'don't say that' 'don't say that'.* While this was expressed in a humorous way it seems to serve an important function i.e. Janet appears to manage the reactions of others by presenting death in a softened way. Having witnessed her husband's decline she seems attuned to the discomfort that illness can evoke when she says, *'they always feel sorry for me'*. Similar to Peter's story of bereavement, Janet's previous experiences of caregiving seem to shape her tendency to protect others where she anticipates there is distress.

While family remained important and valuable for patients, these extracts reveal that patients navigated family involvement in different ways, often shaped by personal histories and anticipation around how relatives might respond. For most patients, it

seemed that attending appointments alone functioned as a strategy to protect relatives from the emotional weight of clinical encounters as well as a need to maintain a degree of autonomy and privacy.

Summary

In summary, an analysis of the narratives shared by patients revealed three main themes illustrating the complexity of navigating conversations at the EoL. Patients' beliefs functioned as important frameworks for making sense of illness and how patients processed and interpreted their situation. Related to this was the patient-physician relationship which appear to be shaped by individual preferences and personal histories. For some patients, empathy and attentiveness fostered safety whereas others valued professional distance. A further layer of complexity concerned the role of the family, with patients balancing the value of family support with the need for autonomy and a wish to protect relatives from distress.

Part three

Based on accounts from patients and physicians, two notable differences are identified in how EoL communication is navigated. The first concerns the role of empathy; most patients described physicians as empathetic and attentive, whereas physicians reported the emotional strain of repeated exposure to illness and dying and described feeling 'empathy fatigue'. These two positions may reflect different standpoints rather than contradictory positions. Physicians reported working in pressurised environments and carrying an accumulative emotional load of caring for many patients over a long

period of time. This may eventually lead to a depletion of energy reserves and empathy fatigue.

Patients however, interacted with physicians intermittently and only for short periods of time. They described experiencing empathy through attentive gestures and non-verbal communication. Perhaps during these brief periods of interactions, physicians were able to perform surface level expressions of empathy which was experienced by patients as impactful. Patients did not have knowledge of the other side of their physician's experience and were unaware of the emotional strain physicians are often under. Perhaps this divergence highlights a tension between 'felt empathy' as described by patients and 'performed empathy' by physicians. It also reinforces the idea that empathy in the context of the EoL is a negotiated practice interpreted through different perspectives i.e., patients may often look for empathy because of their vulnerability whereas physicians may see empathy as part of their professional identity which must be maintained, while simultaneously emotionally demanding.

The second area of divergence is in attitudes towards death. Patients spoke about faith and referred to philosophical frameworks which enabled them to approach mortality with a level of acceptance and peace. However, physicians sometimes told a different story; they spoke about 'patient denial'. Physicians tended to characterise patient behaviour that did not align with medical discourse i.e., explicit acknowledgement of prognosis and impending death, as 'in denial'. This highlights that concepts such as 'denial' and 'acceptance' are not 'fixed' states but are socially constructed, shaped by cultural, professional and social contexts. In this way, labels

such as 'denial' may reflect a physician's expectations rather than aligning with patients lived experience.

A point of convergence between patients and physicians concerns the role of family members in EoL conversations. Both groups acknowledged the importance of family support yet expressed concern about the ways in which family involvement could complicate communication. While patients described the value of family support, most patients attended their appointments alone. This likely functioned as a strategy to protect relatives from distressing news and enabled the patient to maintain autonomy. Similarly, physicians adopted strategies to protect patient autonomy in decision making. Physicians echoed the sentiment that families are essential in providing comfort and support to patients, however they also gave examples of when family presence evoked tension in consultations i.e., relatives insisted on continued treatment even when prognosis was poor or resisted prognostic information altogether. Such dynamics increased the chances of escalation and conflict in consultations.

The patterns discussed here highlight the complex nature of communication at the EoL requiring patients, families and physicians to navigate competing needs and expectations. The next chapter will examine these dynamics in greater detail and connect them to existing theories.

Chapter 6

Discussion Chapter

The aim of the present study was to explore how patients and physicians navigate the complexities of conversations at the EoL, in the context of terminal cancer. In contrast to many previous studies which have tended to focus on examining the views of patients, families and physicians in isolation, this study brings the views of patients and physicians together and examines how communication unfolds in the ‘space’ between them. The discussion chapter is organised around key themes that emerged from patient and physician interviews, including beliefs and meaning around death, the negotiation of professional responsibility with patient autonomy, family involvement and the emotional dimensions of the physician – patient relationship. The findings will be discussed in relation to the existing literature, as outlined in chapter two.

Orientations towards death and meaning making in end-of-life conversations

This section addresses sub research question one, examining how beliefs and attitudes towards death shape EoL conversations. The findings from my study show that patients’ religious and philosophical beliefs provided important frameworks for making sense of their illness and mortality; this is consistent with the findings from El Khoury (2025) and Hira et al. (2025). Hira et al. noted that strong religious and cultural beliefs particularly within traditional family structures, can influence how physicians and patients approach EoL decision making, such as choices regarding treatment options. A similar dynamic was found in my study, for example, one physician described that patients and families from the Middle East were perceived as more

likely to pursue aggressive treatment. This perception shaped how the physician conducted prognostic conversations with families, from this community. Other studies such as Best et al. (2023), Kowalczyk et al. (2022) and Peteet et al. (2013) have also noted that religious and spiritual beliefs significantly influence the care of cancer patients, including impacting on medical decision making. However, across physicians' accounts, there was clear avoidance of discussing patient's religious and spiritual beliefs, and a greater focus on clinical objectives. These findings suggest that there is a misalignment between physicians' expectations about what should be discussed at the EoL and what patients really want to talk about. The present study therefore extends previous work by highlighting the potential for greater alignment. For example, if physicians considered patients' belief frameworks it might influence the content and nature of EoL conversations, enabling opportunities for discussions that better reflect patient perspectives.

The findings from my study raise the question about whether the avoidance of addressing patients' personal beliefs, might prevent the possibility for some physicians and patients to have meaningful conversations, particularly in situations where religious beliefs are a crucial factor which informs patients' approach and attitude towards illness and death, such as, for example, sustaining hope even beyond death. Perhaps such conversations may also bring the physician closer to addressing the deeper issues of the meaning of life and death, both their own and of their patients and hence, diminish the gulf between them. This would align with the study by Rodenbach et al. (2016) which found that oncology clinicians' own views about life and death affected their approach towards dying patients. The authors recommended greater physician awareness about their own mortality as an important component for

having meaningful conversations at the EoL. This was supported by the findings in the study by Harnischfeger (2023).

While the present study is based on a small number of physician interviews and does not aim to generalise, the findings do extend the literature by drawing attention to physicians' personal histories. The detailed narratives shared by physicians in this study indicate that their earlier life experiences, personal beliefs, together with their medical training, shaped how they positioned themselves in relation to patients, particularly in relation to detachment and the management of professional boundaries. Alongside the influence of physicians' biography and professional training, the existential perspective suggested by Becker (as cited in Yunt, 2024) offers useful insight. Becker argued that culture functions as a method of managing death anxiety; in this way the medical culture can be understood to offer a framework for managing the impact of mortality. From this perspective, 'professional detachment' and focus on clinical objectives, as was found in my study, may operate as a strategy to enable physicians to continue to work in the face of repeated exposure to death and dying. Together, these findings highlight the systemic nature of EoL communication in which the physician's biography, professional training and personal beliefs intersect, and in some instances even clash, with patients' experiences and belief systems.

When viewed through this lens, communication challenges are less about individual deficiencies but a reflection of misalignment between different belief systems. Further, the findings from my study suggest that beliefs about death shape EoL conversations not only through what is said but through what is prioritised, avoided or left unexplored

within clinical encounters. The importance of incorporating patients' beliefs as part of holistic care, is corroborated by a recent systematic review which found that unaddressed spiritual care is associated with poorer patient outcomes (Garcia et al., 2023).

Constraints in end-of-life communication training

The findings from my study highlight constraints in physicians' preparation for EoL communication. Physicians reported structured training opportunities were limited after medical school and described that their skill development primarily occurred through informal, on the job experience. These findings echo those of Granek et al. (2013) and Rodenbach et al. (2016) who identified gaps in professional training. Some physicians in my study expressed negative attitudes towards communication training and a lack of interest in pursuing it, indicating that limited engagement may be shaped by structural constraints such as the absence of formal training programmes but perhaps also influenced by the modelling of senior physicians, who do not advocate for training. This is supported by the findings from Perron et al. (2015) who described obstacles at several levels, including competing clinical priorities, supervisors sometimes performing poorly as role models and doctors and clinical supervisors having negative attitudes towards communication training.

My study also highlighted how some physicians drew on personal experiences that informed their approach with patients, for example, one physician described coming to terms with their own mortality when they were a medical student, which enabled them to foster better relationships with patients. This is supported by Rodenbach et al.

(2016) who suggested that physicians require greater support to reflect on their own attitudes toward death which may help them communicate more effectively with patients. The combination of the limitations identified here, and the professional culture may reinforce a focus on biomedical tasks, while psychosocial or culturally sensitive aspects of patient care may receive less attention.

Negotiating professional responsibility and patient autonomy in the face of death

This section addresses the second sub research question, exploring the barriers and tensions that complicate meaningful communication between patients and physicians. Findings from my study showed that tensions in EoL conversations often arose in the context of discussing prognosis with patients. Physicians described the ongoing challenge of balancing their professional responsibility of communicating prognostic information with respect for patient readiness. This tension has been identified in previous studies such as Back et al. (2014). Some physicians in my study referred to patients as being in 'denial', describing this as a barrier in communication. Denial has often been applied as a relevant concept in cancer care, especially when it develops into maladaptive patterns leading to increased psychological distress and poorer family relationships, as outlined in the study by Pene and Kissane (2019). From this perspective, what physicians identify as patient denial might stem from emotional responses such as fear or anxiety, instead of purely resistance to information. This suggests that when physicians describe patients as being in denial, they may be observing challenges in both interpersonal interactions and management of patients'

coping mechanisms, indicating that EoL communication involves emotional and relational complexity, rather than simply a breakdown in communication.

Other scholars such as Elisabeth Kubler – Ross (1969) described denial as one of the five stages of grief and conceptualised it as a potentially healthy and adaptive response that can protect people from overwhelming emotional distress, following a terminal diagnosis (Kubler-Ross, 1969). From this perspective, denial may serve as a psychological mechanism that facilitates gradual adjustment to distressing information. This perspective challenges the way that physicians in my study described denial - a barrier to communication and instead suggests that what physicians see as problematic may be a normal coping strategy. However, Kubler-Ross's model has been criticised for being too formulaic as some scholars have argued that denial is just one potential reaction among many within a broader emotional process (Avis et al., 2021). It is also useful to consider the label of 'patient denial' in the wider context of 'death denying' discourse in PC literature (Zimmerman, 2007), to enable a more nuanced interpretation. Such discourse can function as an obstacle to conversations about dying, suggesting that denial is not only a patient response, but also a social and professional construct which shapes how physicians interpret patient behaviour. From this viewpoint, describing patients as 'in denial' may reveal clinical assumptions of how patients should respond to their prognosis, highlighting that communication difficulties emerge from the interaction between professional frameworks and patients' responses.

While physicians in my study framed some patient responses as being in 'denial', patients themselves described making sense of their prognosis through religious or spiritual frameworks, suggesting that they had engaged in a process of acceptance, rather than avoidance. Furthermore, patients' voluntary engagement in this research, which focused explicitly on EoL communication, indicates that they were actively engaged with thinking about mortality. Taken together, these findings suggest that barriers to meaningful EoL communication may stem less from patient resistance and more from mismatched worldviews and interpretative frameworks between patients and physicians. Scott's (1981) work provides a useful lens for understanding how such mismatches may arise. He proposed that preparing for death involves the active participation of the physician and patient, while also acknowledging that fear of death is universal and often managed by avoidance or repression of such fears. Importantly, he argued that these ideas are reinforced in medical education, influencing how physicians respond to death and dying (Scott, 1981, p. 1817). When applied to the findings of my study, this perspective suggests that physicians' interpretations of denial may be influenced by professionally sanctioned scripts and biomedical frameworks, as well as the physicians own personal fear of death.

Findings from my study also indicate that the physician-patient relationship during EoL conversations, is shaped by underlying power differences. Patients were often positioned in a heightened state of vulnerability, while physicians occupied roles that enabled them to regulate the pace, tone and content of the conversation. This authority was particularly evident during prognostic discussions, suggesting that power in EoL communication is conveyed not only through empathy or the absence of it but also through clinical expertise and the management of the interaction.

The framing of patient responses as ‘denial’ also appears to carry a moral dimension by indirectly implying that there is a normative/acceptable way of engaging in prognostic conversations and perhaps reference to spiritual or religious meaning making, fall outside of these standards. While the accounts of physicians and patients in my study do not necessarily refer to the same clinical encounters, their separate contributions highlight how different orientations towards death and dying may complicate EoL communication, more generally. This is supported by the work of Seale (1998) who suggested that the cultural scripts in medicine shape how illness and the process of dying are constructed and discussed. Further, studies have found that physicians who avoid EoL conversations are often fearful of destroying hope for the patient (Kitta et al., 2021). However, in contrast, Enzinger et al., (2015) found that prognostic conversations led to substantial benefits without harming patients’ emotional wellbeing. Paradoxically, medical scripts, the way they are structured, performed and restricted may constitute a barrier against more robust and open conversations.

Family involvement and the negotiation of roles, boundaries and meanings

This section addresses the third sub research question by examining how family involvement is navigated by patients and physicians. The findings from my study indicate that family involvement in EoL discussions is experienced by both patients and physicians as beneficial yet complex. On the one hand, it was acknowledged by both parties that family members often provide emotional and practical support, on the other hand, family presence appeared to introduce an additional layer of complexity in

clinical consultations. Physicians described situations in which family members can have unrealistic expectations, particularly when treatment options had been exhausted. In such encounters, physicians reported having to balance the emotional reactions of the family with their responsibilities towards patients, which was described as emotionally demanding. These results are consistent with research by Pun et al. (2023) which showed that physicians often experience family resistance as one of the most challenging aspects of EoL communication, creating a barrier to communication.

In contrast, patients offered different narratives in relation to the work involved with managing family involvement. Rather than focusing on conflict within consultations itself, patients described actively managing family participation in advance of clinical consultations. Patients described strategies they used to regulate family involvement, including attending appointments alone or selectively sharing information with relatives afterwards. These strategies were implemented by patients with the intention to protect relatives from emotional distress, preserve personal autonomy and maintain some control over how their illness stories were circulated within wider family and social networks. Findings from my study also revealed that patients approach to family involvement was often influenced by prior caregiving roles and bereavement experiences. Together, these findings indicate that the family dynamics and conflict often observed by physicians during consultations likely reflect the outcome of a longer negotiation process, conducted by patients outside of the clinical setting. Further, these findings suggest that training programmes which focus on EoL communication may be improved by not only teaching conflict management techniques used during consultations but also emphasise the importance of assessing family dynamics that may influence how patients behave in consultations.

Some physicians in my study suggested that family beliefs about death, often influenced by religious and cultural frameworks, can make discussions about treatment more difficult. Although physicians recognised the importance of communicating in culturally sensitive ways, their perspectives often relied on broad cultural categories such as referring to families as 'Middle Eastern' or 'Asian' families. Some studies such as Brooks et al. (2019) and El-Khoury (2025) noted the inadequacies of such general cultural categories suggesting that clinicians need to understand cultural differences in a more subtle way, to handle EoL conversations effectively. Further, physicians need to have a better understanding of how different cultural frameworks influence how families organise themselves around illness and how kinship roles and responsibilities change, in response to illness, as noted in the study by Pun et al. (2023).

All in all, my study adds to the existing literature by showing that family involvement in EoL discussions is a collaborative process, negotiated by patients, families and physicians. Family beliefs about responsibility, protection and past family experiences influence whether relatives are included or excluded from EoL discussions. Recognising this complexity has important implications for clinical practice, highlighting the need for physicians to attend not only to observable family dynamics during clinical encounters but also to the patient's role in navigating these interactions. This perspective is supported by Bowen's (1978) assertions that physicians function as integrated members of the family system and that interactions between patients, families and physicians are affected by established family patterns.

The emotional aspects of the physician-patient relationship

The emotional aspects of the patient-physician relationship are widely recognised in the literature as fundamental to effective EoL communication. Engle et al. (2023) in their systematic review, identified factors including empathy, openness and alignment with individual coping processes, as central to patient and families experience of high-quality care. Clinical empathy is linked to improved trust and reduced patient anxiety (Hayuni et al., 2018). However, studies such as Gleichgerricht and Dececty (2013) and Pires and Barbosa (2025) highlight that ongoing emotional labour can have a negative impact on physicians, particularly due to repeated exposure to patient suffering, it can lead to empathy fatigue and burnout.

As outlined in the literature review, clinical empathy includes both cognitive understanding and emotional attunement. The findings from my study show that empathy is experienced asymmetrically within the patient – physician relationship. Patients commonly described physicians as empathetic and attentive with empathy experienced through brief but meaningful cues such as eye contact, clarity in the delivery of information and perceived emotional presence. In contrast, physicians described empathy as emotionally demanding work due to the strain of repeated exposure to illness and dying, compounded by heavy caseloads and work pressure, leading to empathy fatigue. From a systemic perspective, this suggests that the experience of empathy is relational and negotiated in the relationship but also dependent on external factors. Physicians described the need to regulate emotional closeness and proximity to patients through adopting strategies such as

compartmentalisation and detachment, to maintain professional functioning. While such strategies may serve to protect physicians from emotional exhaustion, it may also impact on the quality of the relationship with patients and what can be discussed in the consultation. At the same time, the emotional work involved in sustaining empathetic engagement may remain largely invisible to patients. Drawing on Goffman's (1959) idea of frontstage and backstage interaction, patients likely notice the frontstage presentation of empathy such as good eye contact and attentiveness, while the backstage efforts made by physicians, remains largely invisible.

Patients described variation in their expectations and experiences with physicians; women patients described experiencing empathy and warmth that fostered trust and emotional containment. The only male participant in this study expressed a preference for professional distance. While the study found differences in patient expectations and experiences with physicians, the small and purposive sample means that the observations are intended to be illustrative rather than generalisable. The variation in patient accounts about their expectations from physicians may be shaped by social positioning, including gender and socio-economic status. Research suggests that socioeconomic status can influence patterns of physician – patient communication. For example, Allen et al. (2020) found that patients of low socioeconomic status were more likely to take a passive role in medical consultations and are less likely to raise concerns. Their study also found differences in levels of 'sociable talk' between physicians and patients i.e., physicians spent more time engaged in 'relational talk' with patients who were closer to their own socioeconomic status. This suggests that reciprocity and mutual influence shaped by social demographics, may have an influence on what happens in medical conversations.

As outlined above, women patients in my study frequently described feeling supported by their physician and experienced them as empathetic; their accounts invite consideration of the role of gratitude in PC. Arantzamendi et al. (2023) highlights that in PC, gratitude and satisfaction correspond to a patient's experience of being 'recognised' by their physician as a person in their entirety, rather than just being identified as a sick patient. Gratitude is connected to essential characteristics of PC including professionalism, emotional support and humanity (Borelli et al., 2022). Centreno et al. (2010) examined letters written by relatives of deceased patients, who experienced PC, addressed to PC staff in two hospitals in Spain and Portugal. They found that all the letters expressed gratitude and there were no complaints, raising the question of whether this is reflective of the exceptional circumstances surrounding the EoL, leading some patients and relatives to experience a combination of different emotions, including gratitude (Glyn-Blanco et al., 2023). Alternatively, there may be cultural influences at play, for example, in cultures where there is great respect for authority, patients and relatives might feel a stronger sense of gratitude for their physician. Findings from a study by Poncin et al. (2024) suggested that gratitude has ambivalent features i.e., it can give rise to positive emotions and strengthen the patient's will to live but it can also be experienced as a necessity in relationships of care dependence, as the only way to return other's favours. For the patient, it may also be intertwined with feelings of burden and self-perception of powerlessness (Poncin, et al., 2024, p. 118).

My study found that physicians and patients communication results from the interplay between patient preferences, physician approaches and individual histories. These dynamics can be understood through Bowen's (1978) distinction between 'open' and 'closed' systems which provides a conceptual lens for interpreting how relational context shape interaction. From this perspective, EoL conversations are influenced by the extent to which the clinical environment permits emotional expression - more 'closed' systems tend to restrict expression and reinforce professional distance, whereas more 'open' systems facilitate vulnerability and engagement. This interpretation is supported by Fredman's (1997) hospital-based observations that tensions arise when clinicians' personal views conflict with professional expectations and discourses, a pattern consistent with communication occurring within relatively closed systems. Taken together, my findings suggest that navigating EoL conversations involves more than the exchange of information; it requires patients and physicians to actively negotiate empathy, proximity and authority within environments that either restrict or enable emotional expression.

One additional finding which was raised by one patient, draws attention to the significance of touch between patient - physician relationship. Although it was not a focus of the literature review, this observation highlights the role of intimacy in a context of EoL care. Interpreted through Bowen's concept of 'open' and 'closed' systems, such moments of touch may signal contexts in which emotional expression is permitted and shared. When considered from an attachment perspective, approaching death is likely to increase a patient's need for a 'secure base' (Bowlby, 1988) and for connection. Rhodius's (2023) notion of the 'palliative paradox' offers a useful perspective, suggesting that while dying poses a threat to connection, the presence of a secure

base or reliable attachment figure amidst the process of separation, makes it possible to die connected (Rhodius, 2023, p. 58). Within this context, the presence of the physician and relatives can serve as a powerful intervention to reassure the patient that they are not alone (Gerretsen and Myers, 2008).

This interpretation is supported by Milberg and Friedrichsen's (2017) study, which explored patients and family caregivers' experiences of attachment figures during palliative home care. The authors suggested that medical professionals should identify patients' attachment figures early in order to facilitate the patient's sense of security, as well as recognising that they themselves (health professionals) may be considered attachment figures, for the patient. Importantly, their study acknowledged the potential impact of loss on family members as well i.e., adjusting to the loss of the patient who was once a source of security for the family (Milberg and Friedrichsen, 2017). In this way, by involving family members in consultations, patients and relatives can potentially provide a secure base for each other, which may enhance quality of life for the patient and support to the family. While this finding cannot be generalised on the basis of my study, it has relevance as it highlights an underexplored dimension of EoL care that may warrant further examination. It also raises important questions about how emotional connection and boundaries are negotiated in EoL care. Further, it invites consideration of how professional norms, cultural expectations and personal preferences may influence the use or avoidance of touch.

Summary

In summary, the findings of my study suggest that EoL conversations are negotiated through an ongoing and at times complex process of balancing professional responsibilities, relationships, personal beliefs and emotional regulation. Barriers and tensions arise when mismatched worldviews/beliefs intersect, further compounded by professional scripts, family dynamics and institutional pressures. While patient denial was identified as one of the challenges of working in oncology, physicians themselves are not immune to feelings of fear, discomfort or denial, when faced with their own mortality and the mortality of their patients. Medical scripts (Seale, 1998) and the clinical setting also constrain their ability for sustained empathy. Consequently, both physicians and patients contend with challenges of illness and mortality which creates a complicated dynamic that affects how conversations evolve.

There was an apparent mismatch between how physicians and patients conceptualised the purpose of clinical consultations. Physicians appeared to regard these as more 'transactional' i.e., focusing on prognosis and treatment decisions, whereas patients gave more attention to the existential matters, i.e., finding meaning in illness. There is a sense that both patients and physicians were vulnerable and 'suffering' (Cole et al., 2009) though the nature of their suffering was different. Patients suffered because of their illness and the uncertainty surrounding the implications of illness, while physicians experienced burnout and moral distress in response managing patients and the challenges of working in oncology. Within this context, the way each participant approaches the situation may unintentionally reinforce the perspective of the other. For example, a physician's focus on tasks and decisions may

be shaped by perceived patient need for clarity and reassurance, whereas patients may emphasise existential issues, when medical decisions seem insufficient. This ongoing exchange could prompt both sides to strengthen their stance, which may result in both physicians and patients experiencing unmet needs. Notably, patients also expressed appreciation for their physicians, suggesting that these tensions coexist with acknowledgement of care and effort rather than simply reflecting dissatisfaction.

Conclusion

As I bring this thesis to an end, I have reflected on my research journey which began in 2019. I recognise that it has been a transformative experience, both personally and professionally. From my personal experience of loss and the challenges I experienced in communication with physicians who were involved in my mother's care, I was motivated to delve deeper and to understand how physicians and patients navigate conversations at the EoL. This was with the intention to improve experiences for others, in the future. On a personal level, this research has helped me to reframe some of my own thoughts about how concepts such as denial, fear and hope intersect in the context of conversations at the EoL. While this journey of seven years has been hugely worthwhile it has not been easy. It has been marked by frustration as I experienced a long wait for ethics approval to commence my study, together with periods of uncertainty as I grappled with my own grief and regrets. Through my conversations with participants, which has been a great privilege, I gained profound insight into what it means to live and to die and what happens in the spaces in between. The stories shared by participants in this study are a reminder that eventually, we will all have to face our mortality, and this is why I believe my research is so important – it enhances our understanding about the complexity surrounding death and dying and how we can become better at talking about it.

What this study contributes

This study examined how physicians and patients navigate the complexities of conversations at the EoL, within the context of terminal cancer. Findings indicate that conversations often occur within distinct, sometimes conflicting frameworks,

influenced by beliefs about death, professional roles, emotional capacity and family relationships. Physicians typically approached these discussions from a more 'transactional' and 'detached' perspective, concentrating on clinical matters and care planning, often to manage the emotional demands of their work. Conversely, patients tended to navigate these conversations by drawing upon religious and spiritual/philosophical frameworks to understand illness and death. These differing orientations towards discussions about death contributed to tensions around perceived denial and emotional connection, while family involvement functioned as both supportive but also a barrier to meaningful conversations. Together, the findings show that EoL communication is shaped less by a lack of willingness but more by different belief systems, institutional constraints and asymmetries in emotional labour between physicians and patients.

This thesis contributes to knowledge by providing a systemic understanding of how physicians and patients navigate EoL conversations within the context of terminal cancer, in an oncology setting. While communication skills remain a crucial aspect of effective practice, the findings from the present study indicate that meaningful EoL conversations extends beyond these skills, to wider emotional and organisational experiences and circumstances. By bringing together the perspectives of both physicians and patients, the study extends existing literature by conceptualising EoL conversations as a relational process, shaped by the interplay of beliefs about death, emotional labour, clinical uncertainty, family involvement and organisational contexts. In doing so, this thesis offers a more embedded understanding of EoL conversations and provides insights that have

implications for education, communication training and support for physicians working in oncology.

Physician accounts suggest that challenges arising from communication stem less from a lack of specific techniques and more from managing personal responses and navigating tensions arising from differing beliefs about prognosis in EoL care among patients and families. Accordingly, the findings highlight the need for training in oncology settings, that go beyond behavioural competencies to incorporate opportunities for self-awareness, emotional processing and self-reflection, which may influence physician – patient – family communication. While it may not be feasible to reduce the level of suffering that oncologists experience or are exposed to, providing opportunities for reflection and emotional processing may positively impact their perceptions of these experiences. Simultaneously, this study also showed variation in patients' preferences and expectations of physicians, which highlights the need for training which emphasises flexibility over prescriptive approaches. Although this study is based on the perspectives of a small qualitative sample, these insights suggest that by incorporating established reflective spaces such as Schwartz Rounds (Goodrich, 2012) into existing training frameworks, may enhance clinical practice.

The study revealed a noticeable divide between the medical world and the wider community. Oncology clinics, providing expert cancer treatment, are often seen as separate institutions, rather than part of a community (Krause, 2016) where physicians and patients have equal access and share in broader human experiences. Cancer is not only a medical phenomenon but is part of human experience which cannot always

be rationalised. From this perspective, there may be benefit for oncology clinics to be 'brought nearer' to patients by being considered part of the community, something like GP practices (Asen et al, 2004) and for clinical consultations to be a space where physicians and patients navigate illness together. A space which allows them to address not only the physical aspects of care but also consider the emotional and existential aspects of illness.

Strengths and limitations

As outlined in the methodology chapter I experienced several challenges during the early stages of applying for ethical approval to commence this study. Once approval was granted, I started the process of recruiting participants. Conducting research within EoL context, necessarily involved ethical and practical challenges given the sensitive nature of conversations and the physical vulnerability of patients with advanced illness. Despite these challenges, participants were successfully recruited, allowing for an in-depth exploration of their experiences.

The was a small-scale study, limited to English speaking participants and conducted at a single hospital site which restricts the transferability of findings to other contexts. However, consistent with the aims of qualitative research, the focus of this study was not generalisability but to gain in-depth understanding and represent unique experiences of participants (Elliott et al., 1999). The sample included patients and physicians of various ages, ethnicities and cultural backgrounds, although there was an overrepresentation of female patients. It is acknowledged that recruitment bias may have been present; for example, physicians who volunteered to participate may have

had a particular interest in or motivation for participating in a study about EoL communication. In addition, the sample may not reflect the full range of professional approaches and attitudes, in this area. Nevertheless, this study contributes a nuanced and deeper understanding of the lived experiences of patients and physicians, by foregrounding the psychological, emotional and systemic dimensions of EoL conversations. The study identifies challenges faced by patients who are approaching the EoL, as well as providing insight into the perspectives of physicians and the challenges they face when caring for patients with an incurable illness. In this way, the study offers a rich contrast in experiences which provides a comprehensive view.

Although family involvement emerged as a key aspect of EoL conversations, this study did not include interviews with family members themselves. Instead, family roles were examined through the accounts provided by patients and physicians. The findings show how family members are positioned in EoL discussions and how they shape interactions. Including family members as participants would have enabled a richer exploration, and future research studies would benefit from incorporating these perspectives to offer a deeper understanding and to capture the complexity of patient-family-physician dynamic at the EoL. This study used a cross-sectional design which involved separate interviews with patients and physicians, rather than analysing their reflections on the same consultations. This methodological choice shaped the level of analysis that was possible. Rather than examining how a specific EoL conversation was experienced and retrospectively reported by participants, this study attended to patterns across multiple accounts. As a result, the findings cannot address the similarities and differences in how patients and physicians understand the same conversations. A case study design would have allowed for a more fine-grained

analysis of interaction, nonetheless, this study enhances our knowledge of the broader communicative context in which EoL conversations are situated.

The methodology used for this study was semi structured interviews. This was a suitable method which allowed me to delve deeply and explore the experiences of participants. While a semi structured interview guide was used to provide consistency across interviews, I became increasingly aware of the need for flexibility to respond to participants' preferences for discussion, as the interview guide reduced the natural flow of conversations (Dempster and Hanna, 2015). Adapting my interview approach in this way enabled participants greater control over how they articulated their experiences.

I have reflected on the challenges that I experienced during the research, in relation to possible interpretation and participant bias (Hewitt, 2007). In the interpretation of data, I had to manage the delicate balance between representing the participants' voices (accounts) and my voice (my interpretation). To reduce the risk of researcher bias in the analysis and writing of this thesis, I have shared aspects of my own experiences to illustrate how it informed my thinking. As Andrews (2013, p. 205) states, 'All of us bring to our research knowledge which we have acquired through our life experiences, and indeed how we make sense of what we observe and hear is very much influenced by that framework of understanding'.

Accounts generated in research interviews can be understood as socially situated and to some extent, performative (Reissman, 2008; Goffman, 1959). In this study,

participants were invited to talk about their experience of EoL conversations, and these conversations may have been shaped by how participants wished to be perceived by me as the researcher. For example, patients may have felt inclined to present themselves as 'good patients', potentially minimising expressions of dissatisfaction with professional care, while physicians may have downplayed their uncertainties and vulnerabilities to align with expectations of professional competencies. These dynamics were considered during analysis, particularly in relation to how accounts were interpreted rather than taken as direct representations of experiences.

Self-reflexivity

In the methodology chapter, I reflected on my doubts about the extent to which 'traditional ethical principles' are compatible with real-life dilemmas that can unravel in research, particularly in the context of EoL. In the process of doing this study I learned that there is a need to sometimes supplement traditional ethical principles with a more person-centred approach, which is based on the ethics of care i.e., values of connectivity, attentiveness and dialogue and empowerment (Haraldsdottir et al., 2019).

I learned that doing research at the EoL introduces profound ethical, emotional and professional challenges. As the researcher, I was not in the same position as the patients, who were facing death. 'I was living' and 'they were dying'. In my interview with participants, I acknowledged the emotional and psychological intensity of the research topic and made them aware of their right to only answer questions and to talk about topics which they felt comfortable with. I reiterated that they could decline

participation at any time, without fear of judgement. I approached my meetings with participants as collaborative, emphasising that their input was crucial for understanding their experiences. By encouraging open dialogue, I aimed to reduce any perception of myself as researcher, and 'authority' figure.

There are mixed opinions about researcher self-disclosure as a strategy used in research. Traditionally, interviewers would have been expected to keep their 'selves' out of the research process as this could influence participant responses (Holstein and Gubrium, 1995). I made the choice not to disclose any details about my own experience of loss and the death of my mother to patients. I thought my narrative may unintentionally influence their responses and I did not want to shift the focus away from their experiences. Except for one interview with a physician with whom I shared some details of my mother's illness (relevant to the discussion about my understanding of the cancer pathway), I did not disclose details about my experience to the other physicians who participated. As with the patients, this was motivated by the need to keep the focus on their experiences and not mine. On later reflection, having thought more about the dual influence of interviewer and participant in meaning-making, I have considered whether more self-disclosure could have influenced the interview process i.e., it may have signalled to participants that I could relate to some of their experiences and therefore created a greater degree of openness.

As a trained family therapist, I felt I was equipped with the skills to manage the interview process and navigate participant experiences in a sensitive way. In addition to this, I was able to work relationally by holding in mind 'many perspectives' while also

trying to make sense of the different contexts that influenced participants' constructions of EoL encounters. I acknowledge my limitations as a novice interviewer in the context of research. For example, in reading the transcripts, I noticed there were moments in the interviews where I could have asked different questions which may have led to new avenues for exploration. At times, I also experienced a tension between my two roles as researcher and therapist. For example, I have reflected on the ethics of 'endings' and saying 'goodbye'. At the time of my interviews with physicians, I felt confident that there would be an opportunity to meet them again and to share with them a copy of this thesis. But in my interviews with patients, I was aware of their prognosis and that they did not have much time left. I knew it would be my only meeting with them. I had formed a connection with each of the participants but due to the finality of the patients' circumstances, this made it more difficult for me to navigate the boundary between my professional role and the personal feelings that their circumstances evoked in me. For example, I did not know if it was acceptable to express some emotion and whether the patients may have appreciated a more personal goodbye. I could not find the words beyond thanking them for their time and this felt inadequate. I regret not having said more. This became the stimulus for my decision to write a letter to each patient, as an opportunity to acknowledge the relationship, to honour their story and their contribution to this research. While these letters were not sent, I hope they can represent a lasting acknowledgement and tribute to the patients (see appendix).

Implications for practice

The results from this study have implications for how communication, training and professional support for physicians working in oncology and palliative care, might be conceptualised. Previous studies demonstrate that communication skills training (CST) in oncology has traditionally prioritised behaviours and techniques, often overlooking the significance of physicians' underlying beliefs, attitudes and emotional responses to death and dying (Rodenbach et al., 2016; Harnischfeger et al., 2022). Findings from the present study are consistent with this literature suggesting that physicians' perspectives towards death and sense of professional responsibility may influence how they approach EoL communication. This points to the potential value of communication training that extends beyond technical skills to incorporate reflective practice. Training approaches that encourage reflection on self-awareness may therefore represent a useful addition to existing communication skills training - this aligns with broader developments in medical education which emphasise reflective practice and empathy alongside technical competencies (Winter et al., 2023).

In addition to training, the findings highlight the potential importance of ongoing professional support for physicians, working in oncology. Physicians' accounts point to the emotional demands inherent in EoL conversations, raising questions about how access to reflective spaces such as peer groups, supervision or mentoring, may support physicians in making sense of their experiences and managing the anxiety and stress associated with their work (Harnischfeger et al., 2023). While the present study does not evaluate specific training or interventions, it highlights the potential value of supportive working environments and opportunities for reflection, which might

contribute to physicians' capacity to engage more meaningfully with the complexities they face. One example of a reflective supervision model used within general healthcare education is Conversations Inviting Change (CIC) (Launer, 2018) as outlined in the background chapter. CIC is referenced here solely as an illustration of the types of reflective approaches that exist to support clinicians in attending to professional positioning and emotional processes in communication. This model is not examined or evaluated within the present study and further research would be required to explore the relevance of such a framework within oncology and palliative care settings.

Findings also identified variation in how physicians and patients understood and navigated the involvement of family members in EoL discussions. This suggests that physicians may benefit from more support in exploring patient preferences and family dynamics, while remaining attentive to potential tensions between patient wishes and family involvement. Overall, the findings highlight the complexity of EoL communication and the importance of flexibility and sensitivity in negotiating preferences. Given the small, exploratory nature of the study, the findings are not intended to be generalisable, however, from a reflexive perspective, physician accounts highlight concerns regarding whether certain professional attitudes may inadvertently hinder opportunities for effective communication with patients. By examining their own beliefs and behaviour and assessing the impact on patient interactions, physicians can potentially increase self-awareness (Back, 2020). However, I think it is also important to consider whether efforts to guide physicians towards a more relational approach and increased self-awareness could potentially be perceived by physicians as interfering with their primary clinical responsibilities.

Areas for future research

This study focused primarily on the perspectives of physicians and patients. Building on these findings, future research could examine how family members participate in EoL conversations. In particular, further research could explore how family members' emotional responses, cultural beliefs and expectations around death and dying shape decision making and treatment planning, as well as how family views are negotiated alongside patient preferences. The findings also point to a need for further investigation into the spiritual and religious dimensions of EoL care. Participant accounts suggested that such issues were often avoided, indicating that there is a need for further research which examines how spiritual or existential concerns are addressed or not addressed, in clinical encounters. Differences in patient experience need more investigation. For example, women patients reported positive experiences with physicians, however, given the small sample size, these findings are preliminary. Future research could explore gender related communication preferences and how gender intersects with professional roles and cultural backgrounds.

The findings from this study show that EoL discussions are influenced by differing experiences, priorities and emotions. Findings showed that physicians may experience empathy fatigue even as patients sense empathy. Similarly, there were contrasting views towards death such as patients' acceptance and physicians' perception that patients were in denial. Although these insights are based on a small sample, they offer tentative hypotheses for future research. On the one hand, communication tends to be mutually satisfactory when professionals balance empathy

with professional boundaries and acknowledge patient's coping strategies rather than viewing them negatively. On the other hand, breakdown in communication is more likely when empathy fatigue is high, expectations between physicians and patients differ, or family dynamics introduce conflict priorities. These hypotheses establish a foundation for future studies into what fosters and impedes communication during the EoL process.

Another potential area for future research relates to the organisational context in which oncologists conduct EoL conversations. Although this study did not specifically examine the interactions between oncology and PC services, all physicians interviewed in this study gave examples of caring for patients whose illness had progressed to the point of imminent death, indicating that discussions about EoL and prognosis was a regular part of their professional duties. However, as discussed in the literature review, oncology and PC are separate specialities, each with distinct training pathways and clinical orientations. Although the small sample used in this study does not allow for conclusions to be drawn about the impact of these differences on communication practices in oncology, it does highlight the possibility that the division between oncology and PC services may influence the timing and approach to EoL communication as well as contribute to the perceived difficulties that arise in this area. Further research which includes a broader range of clinicians such as PC consultants, may be valuable in exploring how structural and institutional factors affect communication practices in oncology settings. It could be helpful to look at how PC physicians and their patients describe EoL conversations and then compare these descriptions to those from oncology contexts. This also leads to considering how PC

physicians talk about their own training in conversational skills and whether this differs oncologists' experiences.

Messages for participants

I hope that the physicians who participated in the study recognise that many of the difficulties encountered during EoL communication stem not only from a lack of communication skills, but also from the emotional and relational complexities involved in caring for people with a terminal diagnosis. These findings highlight the importance of reflective practice and professional support as well as targeted communication training. For the patients who generously shared their experiences, it is hoped that their contributions will help future patients and families by promoting greater awareness of the beliefs and values that shape conversations at the EoL. Ultimately, the findings reinforce the importance of a sensitivity which recognises patients' beliefs, involves families and ensures that there is space for meaningful conversations to occur.

Closing thoughts

This study offers exploratory insights into how physicians and patients experience and navigate conversations at the EoL, emphasising the emotional, relational and contextual aspects of communication. The findings highlight the need for a holistic approach that addresses the emotional, social, psychological and spiritual aspects of patient care. Despite certain limitations, this research adds valuable perspectives to ongoing discussions about EoL communication in clinical practice. It reveals the complexity of these exchanges and the challenges both patients and physicians face

in navigating uncertainty. It is hoped that this study will prompt further questions and guide future research in EoL care.

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Appendices

Appendix No.	Document
1	Ethics – Unfavourable Opinion
2	Ethics – Favourable Opinion
3	HRA Approval TREC Approval
4	Participant information sheets for interviews and observations. (Patients)
5	Participant information sheets for interviews and observations. (Physicians)
6	Participant information sheets for interviews and observations. (Relatives/Companions)
7	Consent forms
8	Interview guides (Patients and Physicians)
9	Letters to patients
10	Observation Notes

Appendix 1

Health Research Authority
London - Bromley Research Ethics Committee

Temple Quay House
 2 The Square
 Temple Quay
 Bristol
 BS1 6PN

27 May 2022

Miss Pooja Bhambra
 Systemic Psychotherapist
 West London NHS Trust
 48 Glenthorne Road
 Hammersmith
 W6 0LS

Dear Miss Bhambra

Study title:	From curative to palliative care: How are end of life conversations experienced by doctors and patients?
REC reference:	22/LO/0391
Protocol number:	N/A
IRAS project ID:	301926

The Research Ethics Committee reviewed the above application at the meeting held on 19 May 2022. Thank you for attending to discuss the application.

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
<https://www.hra.nhs.uk/planningand-improving-research/application-summaries/research-summaries/>

Ethical opinion

The members of the Committee present decided to issue an unfavourable opinion for the following reasons:

Number	Reasons for the Unfavourable Opinion
1)	The committee felt that the research proposal lacked empathy and understanding for patients and did not acknowledge the difficulties that they could be going through. The Committee felt that the emphasis was placed on physicians more than the patients. For example, the PIS document mentioned that there were no anticipated risks to participants despite the highly sensitive topic of End of Life care.
2)	The Committee did not feel that there is an appropriate procedure in place for if participants became distressed during the study, and what would happen if this distress was a result of the Chief Investigator.

3)	The Committee agreed that a topic guide for the interview stage would need to be reviewed. Please include this when re-submitting.
4)	The Committee did not feel that relevant and appropriate training had been completed by the Chief Investigator. Please ensure relevant GCP and consenttaking training has been completed by the CI before re-submission.
	Other issues to be addressed
5)	The Committee agreed that the Participant Information Sheets (PIS) should be made clear that other family members may/will be present for the observations and/or the interviews. If the family members or other companions will be present in either the observation or interview stage, a separate Informed Consent Form (ICF) and PIS will be required for review. The Committee also suggested that, due to the sensitivity of the conversation topic, that it would be best to provide patients with the option to bring a family member with them to the interviews.
6)	The Committee was unclear from the study documentation which End of Life (EoL) conversations would be observed. Please ensure it is clear in the re-submission that EoL conversations in which the clinical team are initially informing a patient of their terminal illness diagnosis will <u>not</u> be observed, and that only follow-up conversations will be observed.
7)	The Committee agreed that all PIS documents should explain that the Chief Investigator could be required to break confidentiality due to issues such as professional malpractice when observing the consultations.
8)	The Committee felt that the PIS lacked detail and ask that the documents use HRA template guidance when re-submitting.
9)	The Committee remains unclear whether the research is ethnographic research. Please ensure this is clear in re-submission and justification provided.

10)	The Committee felt that the documentation was unclear regarding the 'conversation' element that would be included at the observation stage and agreed that the conversation element should be explained clearly in the PIS documents. Please ensure you are clear in resubmission where and when the conversations will take place and about your study methodology.
11)	Please make the following changes to the PIS documentation: a) Include a statement to inform participants that there will be an option for breaks during the interview and that participants would not be required to answer all of the questions. Please also provide an explanation of how potential distress will be handled. b) Include information explaining that physicians will identify the most appropriate patients for the observation and interview stages and the factors they would base this decision on. c) Please use Patient and Public Involvement (PPI) on the PIS documentation when re-submitting. d) Include an independent contact for complaints such as PALs.
12)	The Committee agreed that relatives should have the option to be informed about the results of the study.
13)	Please be clear in the study documentation during re-submission about which specific data the research team will have access to. The research team are discouraged from accessing personal data.

I regret to inform you therefore that the application is not approved.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact
Bromley.rec@hra.nhs.uk

Options for further ethical review

You may submit a new application for ethical review, taking into account the Committee's concerns. You should enter details of this application on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application. Please highlight any changes made to study documentation and include a revised version number and date on the documents where applicable.

The application should be booked via IRAS and would be allocated for review in the normal way.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify us in writing within 90 days of the date of this letter. If the appeal is allowed, another REC will be appointed to give a second opinion within 60 days and the second

REC will be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the meeting of the second REC and will be able to attend and/or make written representations if you wish to do so.

The contact point for appeals is:

Charlotte Allen, Quality and Performance Manager, Health Research Authority, Email: appeals@hra.nhs.uk

Documents reviewed

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
IRAS Application Form [IRAS_Form_06052022]		06 May 2022
Participant consent form [Consent form for interview]	1.0	18 April 2022
Participant consent form [Consent form for observation]	1.0	18 April 2022
Participant consent form [Patient consent to contact form]	1.0	28 March 2022
Participant information sheet (PIS) [Participant information sheet for interviews (patients)]	1.0	28 March 2022
Participant information sheet (PIS) [Participant information sheet for interviews (physician)]	1.0	28 March 2022
Participant information sheet (PIS) [Participant information sheet for observation (patient)]	1.0	18 April 2022
Participant information sheet (PIS) [Participant information sheet for observation (physician)]	1.0	28 April 2022
Research protocol or project proposal [Project Proposal]	1.0	18 April 2022
Summary CV for Chief Investigator (CI) [Summary CV for chief investigator]	1.0	18 April 2022
Summary CV for supervisor (student research) [Summary CV for Supervisor]	1.0	18 April 2022

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-thehra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and-improvingresearch/learning/>

**IRAS Project ID: 301926
correspondence**

Please quote this number on all

Yours sincerely

pp. Bxarle

Dr Koula Asimakopoulou Chair

Email: bromley.rec@hra.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Dr Brian
Rock

Lead Nation

England: approvals@hra.nhs.uk

Appendix 2**West Midlands - Solihull Research Ethics Committee**

Equinox House
City Link
Nottingham
NG2 4LA

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval.

25 October 2022

Miss Pooja Bhambra
Systemic Psychotherapist
NHS
48 Glenthorne Road
Hammersmith
W6 0LS

Dear Miss Bhambra

Study title:	From curative to end of life care: How do physicians and patients experience conversations about the end of life?
REC reference:	22/WM/0208
Protocol number:	N/A
IRAS project ID:	301926

Thank you for your letter of , responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and the Vice Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device

- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers](#)).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

- Reporting results

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Cover Letter [REC Response Letter]	-	29 September 2022
Covering letter on headed paper [Covering letter]	1.0	03 August 2022
Interview schedules or topic guides for participants [Topic guide (physicians)]	1.0	10 July 2022
Interview schedules or topic guides for participants [Topic guide (patients)]	1.0	10 July 2022
IRAS Application Form [IRAS_Form_15082022]	-	15 August 2022
IRAS Application Form XML file [IRAS_Form_15082022]	-	15 August 2022
IRAS Checklist XML [Checklist_16082022]	-	16 August 2022
Other [Project Proposal]	2.0	02 August 2022
Other [Topic guide (patients)]	1.0	10 July 2022
Other [Consent form for interview]	3.0	03 October 2022
Other [Consent to contact form]	2.0	29 September 2022
Other [Participant information sheet for interviews (patients)]	3.0	30 September 2022
Other [Participant information sheet for interviews (physician)]	3.0	30 September 2022
Other [Participant information sheet for interviews (relative)]	2.0	03 October 2022
Other [Participant information sheet for observation (patient)]	3.0	29 September 2022
Other [Participant information sheet for observation (physician)]	3.0	30 September 2022
Other [Participant information sheet for observation (relative)]	2.0	30 September 2022
Participant consent form [ICF for observation (relative)]	1.0	13 July 2022
Participant consent form [ICF for observation (patient and physician)]	1.0	18 April 2022

Summary CV for Chief Investigator (CI) [Summary CV for chief investigator]	2.0	04 August 2022
Summary CV for supervisor (student research) [Summary CV for Supervisor]	1.0	18 April 2022

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

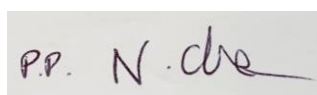
We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS project ID: 301926 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Rex J Polson Chair

Email: solihull.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

investigators – [After ethical review guidance for sponsors and Non CTIMP Standard Conditions of Approval](#)

Copy to: Mrs Elisa Reyes-Simpson

Lead Nation: England: approvals@hra.nhs.uk

Appendix 3



Miss Pooja Bhambra
Systemic Psychotherapist

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

NHS
48 Glenthorne Road
Hammersmith
W6 0LSN/A

25 October 2022

Dear Miss Bhambra

HRA and Health and Care

Study title:	From curative to end of life care: How do physicians and patients experience conversations about the end of life?
IRAS project ID:	301926
Protocol number:	N/A
REC reference:	22/WM/0208
Sponsor	The Tavistock and Portman NHS Foundation Trust

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

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

The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document “[After Ethical Review – guidance for sponsors and investigators](#)”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

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

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **301926**. Please quote this on all correspondence.

Yours sincerely,

Rekha Keshvara

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: Mrs Elisa Reyes-Simpson **List of Documents**

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Cover Letter [REC Response Letter]	-	29 September 2022
Covering letter on headed paper [Covering letter]	1.0	03 August 2022
Interview schedules or topic guides for participants [Topic guide (physicians)]	1.0	10 July 2022
Interview schedules or topic guides for participants [Topic guide (patients)]	1.0	10 July 2022
IRAS Application Form [IRAS_Form_15082022]		15 August 2022
IRAS Application Form XML file [IRAS_Form_15082022]		15 August 2022
IRAS Checklist XML [Checklist_16082022]		16 August 2022
Other [REC Unfavourable Letter]	1.0	27 May 2022
Other [Project Proposal]	2.0	02 August 2022
Other [Topic guide (patients)]	1.0	10 July 2022
Other [Consent form for interview]	3.0	03 October 2022
Other [Consent to contact form]	2.0	29 September 2022
Other [Participant information sheet for interviews (patients)]	3.0	30 September 2022
Other [Participant information sheet for interviews (physician)]	3.0	30 September 2022
Other [Participant information sheet for interviews (relative)]	2.0	03 October 2022
Other [Participant information sheet for observation (patient)]	3.0	29 September 2022
Other [Participant information sheet for observation (physician)]	3.0	30 September 2022
Other [Participant information sheet for observation (relative)]	2.0	30 September 2022
Participant consent form [ICF for observation (relative)]	1.0	13 July 2022
Participant consent form [ICF for observation (patient and physician)]	1.0	18 April 2022
Summary CV for Chief Investigator (CI) [Summary CV for chief investigator]	2.0	04 August 2022
Summary CV for supervisor (student research) [Summary CV for Supervisor]	1.0	18 April 2022

The Tavistock and Portman

NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699
<https://tavistockandportman.nhs.uk/>

28 October 2022

By Email

Dear Miss Bhambra

Project Title:	From curative to end of life care: How do physicians and patients experience conversations about the end of life?
Researcher:	Pooja Bhambra
Programme of Study	Advanced Practice and Research (Systemic Psychotherapy)

I am writing to confirm that the application for the aforementioned HRA and Health and Care Research Wales (HCRW) Approval - **IRAS project ID is 301926** has received TREC ethical approval and is sponsored by the Tavistock and Portman NHS Foundation Trust (the Trust).

Please note as a condition of your sponsorship by the Trust, your research must be conducted in accordance with HRA and Health and Care Research Wales (HCRW) Approval and any requirements specified as part of your ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Tavistock Research Ethics Committee by emailing academicquality@tavi-port.nhs.uk.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

With the Committee's best wishes for the success of this project.

Yours sincerely,



Paru Jeram

Quality Assurance Officer (Research Degrees and Research Ethics)
For and on behalf of the Chair of the Tavistock research Ethics Committee

Appendix 4: Participant Information Sheet (Interview)



Participant Information Sheet (Patient)

Research Study

How do physicians and patients experience conversations about the end of life?

I would like to invite you to take part in a research study. Before you decide whether to take part, please read this information sheet to find out why the research is being done and what it involves.

Purpose of the study

The purpose of this study is to understand how conversations take place between doctors and patients in the context of end-of-life care. I want to try to understand what the obstacles are to having meaningful conversations and to explore how different viewpoints of doctors and patients reflect the way they think about dying.

I hope that by doing this research it will create change in how conversations happen between doctors and patients and to improve patient experience at the end of life.

Who should take part?

I would like to interview patients with a diagnosis of advanced cancer. I am hoping to interview approximately 4-6 patients.

Why have I been invited to take part?

You have been invited to take part because you are a patient with a diagnosis of advanced cancer, and you are currently receiving medical care and support at the clinic where this research is being conducted. This information sheet has been given to you by your doctor because of your stage of treatment and the experiences you have had as a patient.

Do I have to take part?

No. It is up to you to decide whether to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw from the study at any time up until 14 days post interview, when I will be analysing the interview. Your decision to take part will not affect the clinical care you receive in any way.

What is involved?

After you have read the information sheet and if you make the decision that you would like to take part, your allocated doctor will ask you to sign a 'consent to contact' form. Your doctor will then pass your details to me. I will then have a discussion with you and provide information about what you can expect during the research process and offer an opportunity for you to ask any questions. You will then be asked to sign a 'consent to participate' form. A suitable time and place for the interview will then be arranged.

The interview will take place in a quiet room at the hospital where you are receiving medical care. If this is not possible or convenient for you, the interview will take place on zoom, the video conferencing service. The interview will be audio-recorded and will last between 60-90 minutes. You will have the option of taking breaks during the interview. You would not be required to answer all the questions if you do not want to. Interviews will be transcribed afterwards by me, as the lead researcher. You can request a copy of your interview transcript if you would like to read it. It is expected that you will be involved in the study for a period of one month. This may be extended if you chose to receive a copy of the transcript of the interview, however, this is optional.

Due to the sensitive nature of the conversation topic, you may wish to bring a relative or friend with you to the interview. If you would like to bring somebody with you, they will be provided with a separate information sheet and they will be asked to sign a consent form.

Will my taking part in the study be kept confidential?

Any issues discussed during the interview will be kept confidential. All of the responses you give to questions will only be seen by me and my research supervisor. Your doctors and nurses will not have access to this information, and it will not be placed in your patient records. A study number will be allocated to you and any identifiable data will no longer be used. I may use direct quotes from the interview, but individual participants will not be identified in any results arising from this study.

To protect the security of the audio recordings an encrypted recording device will be used. After the research is completed, all of the audio recordings will be destroyed. Anonymised transcripts of the recordings will be stored securely in The Essex University storage repository for a period of 5 years

All data will be processed in accordance with the General Data Protection Act 2018. Responsible members of the Tavistock and Portman Foundation NHS Trust may be given access to data for monitoring and/or audit of the study to ensure the study is being carried out correctly and complying with regulations. Access to paper and electronic files would be given

to authorised people, which would be set up on a limited basis for the duration of the monitoring/audit period. All involved will have a duty to you to maintain confidentiality as a research participant. See <https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/> for more information.

There is one important exception to the guarantee of confidentiality. If you tell me something that suggests that you or others are at risk of harm or that there are concerns raised about professional malpractice, I am obliged to pass this information on to an appropriate person. I will talk to you about the procedures involved before the information is shared.

What are the possible benefits of taking part?

It is possible that you might find it helpful to discuss your experience of your conversations with your doctor, with another person. I hope that the information you provide will contribute to improving services for patients and their families in the future. However, there cannot be any promise that you will have any direct benefit from taking part in the study.

What are the possible risks of taking part?

There is a possibility that you may find talking about your experiences upsetting or distressing. If this happens to you, I will offer my support and if required, I will arrange for you to access independent support, from psychological services at the hospital. You will be free to withdraw from the interview, at any time.

What will happen to the results of the research study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Advanced Systemic Psychotherapy Practice and Research at The Tavistock and Portman NHS Foundation Trust. The research may also be published in academic journals or presented at conferences.

What would happen if I don't want to continue with the study?

You are free to withdraw from the study without having to give a reason. Withdrawing from the study will not affect the clinical care you are receiving. You will be able to withdraw the information that you have shared during the interview up until the analysis of this has commenced, after which withdrawal will no longer be possible as the information will have been anonymised and/or committed to the final report. If you choose to withdraw from the study before this point your information will be destroyed.

Further information/independent advice

If you have a problem or concern about the study and you feel that it has not been responded to satisfactorily, you can contact Patient Advice and Liaison Service, (PALS) which is an independent service available to patients, relatives and carers. You can contact PALS using the details below:

imperial.PALS@nhs.net:

020 3312 7777

You can also contact the Trust Quality Assurance Officer using the details below.

Simon Carrington: academicquality@tavi-port.nhs.uk

Quality Assurance

The Tavistock and Portman NHS Foundation Trust

120 Belsize Road

London

NW3 5BA

Who has reviewed this study?

This study has been reviewed by an independent group of people, called a Research Ethics Committee who are there to protect your safety, rights, well-being and dignity. This research has been formally approved by the Tavistock Research Ethics Committee and by the NHS Health Research Authority. The views of patients and doctors have been incorporated in the design of this information sheet.

If at any point you have questions or concerns regarding this study or would like to receive a report on the findings of the study once completed, please contact:

Pooja Bhambra

Tel: 07983 217 109

pooja.bhambra@westlondon.nhs.uk

Participant Information Sheet (Observation)



Participant Information Sheet Patient

Research Study

How do physicians and patients experience conversations about the end of life?

You are invited to take part in a research study. Before you decide whether to take part, please read this information sheet to find out why the research is being done and what it involves.

Purpose of the study

The purpose of this study is to understand how conversations take place between doctors and patients in the context of end-of-life care. It is to understand what the obstacles are to having meaningful conversations and to explore how different viewpoints of doctors and patients reflect the way they think about dying.

It is hoped that by doing this research it will create positive change in how conversations happen between doctors and patients and to improve patient experience at the end of life.

As part of the research study, I would like to undertake an observation of the consultation process between doctor and patient during a clinic lasting a total of four hours, which will include your consultation. With permission from you, your doctor and anyone else who is part of the conversation, I will observe how communication takes place.

Why have I been invited to take part?

You have been invited to take part because you are a patient with a diagnosis of advanced cancer, and you are currently receiving medical care and support at the clinic where this research is being conducted. This information sheet has been given to you by your doctor because of your stage of treatment and the experiences you have had as a patient. To hear your views and to understand your experiences as a patient, is a very important part of this research.

Do I have to take part?

No. It is up to you to decide whether to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw from the study at any time. Withdrawal from the study will have no impact on the clinical care you are receiving.

What is involved?

After you have read the information sheet and if you make the decision that you would like to take part, your allocated doctor will ask you to sign a 'consent to contact' form. Your doctor will then pass your details to me. I will then have a discussion with you and provide information about what you can expect during the research process and offer an opportunity for you to ask any questions. You will then be asked to sign a 'consent to participate' form. After observing the consultation, I will take detailed notes about what I have observed. The notes will be saved on a password protected computer. The notes will not include any patient identifiable data.

Will my taking part in the study be kept confidential?

Any issues discussed during the observation will be kept confidential. The notes I take will only be seen by me and my research supervisor. The information will not be placed in your patient records.

All data for the research will be processed in accordance with the General Data Protection Act 2018. Responsible members of the Tavistock and Portman Foundation NHS Trust who is the sponsor for this study, may be given access to data for monitoring and/or audit of the study to ensure the study is being carried out correctly and complying with regulations. See <https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/> for more information.

There is one important exception to the guarantee of confidentiality. If there are concerns raised about patient/public safety or professional malpractice, your doctor or myself are obliged to pass this information on to an appropriate person.

What are the possible benefits of taking part?

I hope that the information gathered from the observation process will contribute to improving services for patients in the future.

What are the possible risks of taking part?

You may have objections about a researcher being present in a consultation where you will be discussing important and possibly distressing matters with your doctor. If during the consultation you feel uncomfortable or change your mind about the consultation being observed, you can ask me to leave at any time.

What will happen to the results of the research study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Advanced Systemic Psychotherapy Practice and Research at The Tavistock and Portman NHS Foundation Trust. The research may also be published in academic journals or presented at conferences.

Further information/independent advice

If you have a problem or concern about the study and you feel that it has not been responded to satisfactorily, you can contact Patient Advice and Liaison Service, (PALS) which is an independent service available to patients, relatives and carers. You can contact PALS using the details below:

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Pooja Bhambra

Tel: 07983 217 109

pooja.bhambra@westlondon.nhs.uk

Appendix 5: Participant Information Sheet (Interview)



Participant Information Sheet

(Physician)

Research question

How do physicians and patients experience conversations about the end of life?

I would like to invite you to take part in a research study. Before you decide whether to take part, please read this information sheet to find out why the research is being done and what it involves.

Purpose of the study

The purpose of this study is to understand how conversations take place between doctors and patients in the context of end-of-life care. I want to try to understand what the obstacles are to having meaningful conversations and to explore how different viewpoints of doctors and patients reflect the way they think about dying.

I hope that by doing this research it will create change in how conversations happen between doctors and patients and to improve patient experience at the end of life.

Who should take part?

I would like to interview approximately 4-6 oncologists, registrars or palliative care doctors who are providing care to adult cancer patients who have a diagnosis of advanced cancer.

Do I have to take part?

No. It is up to you to decide whether to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw from the study at any time up until 14 days post interview, when I will be analysing the interview.

What is involved?

After you have read the information sheet and make the decision that you would like to take part, please inform Dr P who will pass your details to me, or you can contact me directly, using the details on this form. I will then have a discussion with you about what you can expect during the research process and offer an opportunity for you to ask any questions. You will then be asked to sign a 'consent to participate' form. A suitable time and place for the interview will then be arranged.

The interview will take place in a quiet room at the hospital where you are based. If this is not possible or convenient for you, the interview will take place on zoom, the video conferencing service. The interview will be audio-recorded and will last between 60-90 minutes. You will have the option of taking breaks during the interview. You would not be required to answer all the questions if you do not want to. Interviews will be transcribed afterwards by me, as the lead researcher. You can request a copy of your interview transcript if you would like to read it. It is expected that you will be involved in the study for a period of one month. This may be extended if you chose to receive a copy of the transcript of the interview, however, this is optional.

Will my taking part in the study be kept confidential?

Any issues discussed during the interview will be kept confidential. All of the responses you give to questions will only be seen by me and my research supervisor. A study number will be allocated to you and any identifiable data will no longer be used. I may use direct quotes from the interview, but individual participants will not be identified in any results arising from this study.

To protect the security of the audio recordings an encrypted recording device will be used. After the research is completed, all of the audio recordings will be destroyed. Anonymised transcripts of the recordings will be stored securely in The Essex University storage repository for a period of 5 years.

All data will be processed in accordance with the General Data Protection Act 2018. Responsible members of the Tavistock and Portman Foundation NHS Trust may be given access to data for monitoring and/or audit of the study to ensure the study is being carried out correctly and complying with regulations. Access to paper and electronic files would be given to authorised people, which would be set up on a limited basis for the duration of the monitoring/audit period. All involved will have a duty to you to maintain confidentiality as a research participant. See <https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/> for more information.

There is one important exception to the guarantee of confidentiality. If there are concerns raised about patient/public safety or professional malpractice, I am required to share this information with my research supervisor and Dr P. Local governance procedures and hospital protocol would apply.

What are the possible benefits of taking part?

I hope that the information you provide will contribute to improving services for patients in the future.

What are the possible risks of taking part?

There is a possibility that you may find the topic upsetting or distressing. You will be free to withdraw at any time during the interview.

What will happen to the results of the research study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Advanced Systemic Psychotherapy Practice and Research at The Tavistock and Portman NHS Foundation Trust. The research may also be published in academic journals or presented at conferences.

What would happen if I don't want to continue with the study?

You are free to withdraw from the study without having to give a reason. You will be able to withdraw the information that you have shared during the interview up until the analysis has commenced, after which withdrawal will no longer be possible as the information will have been anonymised and/or committed to the final report. If you choose to withdraw from the study before this point your information will be destroyed.

Further information/independent advice

If you have a problem or concern about the study and you feel that it has not been responded to satisfactorily, please contact the Trust Quality Assurance Officer using the details below.

Simon Carrington: academicquality@tavi-port.nhs.uk

Quality Assurance

The Tavistock and Portman NHS Foundation Trust

120 Belsize Road

London

NW3 5BA

Who has reviewed this study?

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If at any point you have questions or concerns regarding this study or would like to receive a report on the findings of the study once completed, please contact:

Pooja Bhambra

Tel: 07983 217 109

pooja.bhambra@westlondon.nhs.uk

Participant Information Sheet (Observation)



Participant Information Sheet

(Physician)

Research question

How do physicians and patients experience conversations about the end of life?

I would like to invite you to take part in a research study. Before you decide whether to take part, please read this information sheet to find out why the research is being done and what it involves.

Purpose of the study

The purpose of this study is to understand how conversations take place between doctors and patients in the context of end-of-life care. I want to try to understand what the obstacles are to having meaningful conversations and to explore how different viewpoints of doctors and patients reflect the way they think about dying.

I hope that by doing this research it will create change in how conversations happen between doctors and patients and to improve patient experience at the end of life.

As part of my research study, I would like to undertake an observation of the consultation process between doctor and patient. The duration of the observation will be four hours. This will involve me sitting in the consultation room with you and your patients, to observe how communication takes place.

Why have I been asked to take part?

You have been invited to take part because you are a doctor working with adult patients who have a diagnosis of advanced cancer.

Do I have to take part?

No. It is up to you to decide whether you take part. If you decide to take part, you will be asked to sign a consent form. You will be free to withdraw from the study at any time.

What is involved?

After you have read the information sheet and if you make the decision that you would like to take part, please inform Dr P who will pass your details to me, or you can contact me directly, using the details on this form. I will then have a discussion with you and provide information about what you can expect during the process and offer an opportunity for you to ask any questions. You will then be asked to sign a 'consent to participate' form. After observing the consultation, I will take detailed notes about what I have observed. The notes will be saved on a password protected computer. The notes will not include any identifiable data.

Will my taking part in the study be kept confidential?

Any issues discussed during the observation will be kept confidential. The notes I take will only be seen by me and my research supervisor.

All data for the research will be processed in accordance with the General Data Protection Act 2018. Responsible members of the Tavistock and Portman Foundation NHS Trust who is the sponsor for this study, may be given access to data for monitoring and/or audit of the study to ensure the study is being carried out correctly and complying with regulations. See <https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/> for more information.

There is one important exception to the guarantee of confidentiality. In the rare situation that there are concerns raised about patient/public safety or professional malpractice, I am required to share this information with my research supervisor and Dr P. Local governance procedures and hospital protocol would apply.

What are the possible benefits of taking part?

I hope that the information gathered from the observation process will contribute to improving services for patients in the future.

What are the possible risks of taking part?

You or the patient may have objections about a researcher being present in a consultation where you will be discussing important and possibly distressing matters with your patient. If during the consultation anyone feels uncomfortable or changed their mind about the consultation being observed, they can ask me to leave any time.

Further information/independent advice

If you have a problem or concern about the study and you feel that it has not been responded to satisfactorily, please contact the Trust Quality Assurance Officer using the details below.

Simon Carrington: academicquality@tavi-port.nhs.uk

Quality Assurance

The Tavistock and Portman NHS Foundation Trust

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If at any point you have questions or concerns regarding this study or would like to receive a report on the findings of the study once completed, please contact:

Pooja Bhambra

Tel: 07983 217 109

pooja.bhambra@westlondon.nhs.uk

Appendix 6: Participant Information Sheet (Interview)

The Tavistock and Portman 
NHS Foundation Trust

Participant Information Sheet (Relative/Companion)

Research Study

How do physicians and patients experience conversations about the end of life?

I would like to invite you to take part in a research study. Before you decide whether to take part, please read this information sheet to find out why the research is being done and what it involves.

Purpose of the study

The purpose of this study is to understand how conversations take place between doctors and patients in the context of end-of-life care. I want to try to understand what the obstacles are to having meaningful conversations and to explore how different viewpoints of doctors and patients reflect the way they think about dying.

I hope that by doing this research it will create change in how conversations happen between doctors and patients and to improve patient experience at the end of life.

Who should take part?

I would like to interview patients with a diagnosis of advanced cancer. I am hoping to interview approximately 4-6 patients.

Why have I been invited to take part?

You have been invited to take part because you are a relative/companion of a patient with a diagnosis of advanced cancer, who is currently receiving medical care and support at the hospital. Due to the sensitive nature of the conversation topic, I offer patients the option to bring a relative or companion with them to the interview. This information sheet has been given

to you by the patient because they would like you to be present in the interview, to provide them with support.

Do I have to take part?

No. It is up to you to decide whether to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw from the study at any time.

What is involved?

If when you have read the information sheet and make the decision that you would like to participate in the research, the patient will ask you to sign a ‘consent to contact’ form. The patient will then pass your details to me. I will then have a discussion with you and provide information about what you can expect during the research process and offer an opportunity for you to ask any questions. You will then be asked to sign a ‘consent to participate’ form. A suitable time and place for the interview will then be arranged with the patient and you.

The interview will take place in a quiet room at the hospital where the patient is receiving medical care. If this is not possible or convenient for them or you, the interview will take place on zoom, the video conferencing service. The interview will be audio-recorded and will last between 60-90 minutes. There will be the option of taking breaks during the interview. Interviews will be transcribed afterwards by me, as the lead researcher.

You are being invited to join the study purely in the capacity of a supportive role for the patient. This means that I will not be asking you any questions directly and I will not include in my research anything that you may contribute during the interview.

Will my taking part in the study be kept confidential?

Any issues discussed during the interview will be kept confidential. The notes I take will only be seen by me and my research supervisor. The information will not be placed in the patient records.

All data for the research will be processed in accordance with the General Data Protection Act 2018. Responsible members of the Tavistock and Portman Foundation NHS Trust who is the sponsor for this study, may be given access to data for monitoring and/or audit of the study to ensure the study is being carried out correctly and complying with regulations. See <https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/> for more information.

There is one important exception to the guarantee of confidentiality. If there are concerns raised about patient/public safety or professional malpractice, I am obliged to pass this information on to an appropriate person.

What are the possible benefits of taking part?

I hope that the information gathered from the interviews will contribute to improving services for patients in the future.

What are the possible risks of taking part?

There is a possibility that patients and their relatives/companions may find the interviews upsetting or distressing.

What will happen to the results of the research study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Advanced Systemic Psychotherapy Practice and Research at The Tavistock and Portman NHS Foundation Trust. The research may also be published in academic journals or presented at conferences.

What would happen if I don't want to continue with the study?

You are free to withdraw from the study without having to give a reason. Withdrawing from the study will not affect the patient or the medical care that they receive.

Further information/independent advice

If you have a problem or concern about the study and you feel that it has not been responded to satisfactorily, you can contact Patient Advice and Liaison Service, (PALS) which is an independent service available to patients, relatives and carers. You can contact PALS using the details below:

imperial.PALS@nhs.net:

020 3312 7777

You can also contact the Trust Quality Assurance Officer using the details below.

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Quality Assurance

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If at any point you have questions or concerns regarding this study or would like to receive a report on the findings of the study once completed, please contact:

Pooja Bhambra

Tel: 07983 217 109

pooja.bhambra@westlondon.nhs.uk

Participant Information Sheet (Observation)**Participant Information Sheet****Relative/Companion****Research Study**

How do physicians and patients experience conversations about the end of life?

I would like to invite you to take part in a research study. Before you decide whether to take part, please read this information sheet to find out why the research is being done and what it involves.

Purpose of the study

The purpose of this study is to understand how conversations take place between doctors and patients in the context of end-of-life care. I want to try to understand what the obstacles are to having meaningful conversations and to explore how different viewpoints of doctors and patients reflect the way they think about dying.

I hope that by doing this research it will create change in how conversations happen between doctors and patients and to improve patient experience at the end of life.

As part of my research study, I would like to undertake an observation of the consultation process between doctor and patient. This will involve me sitting in room with the patient and their doctor to observe how communication takes place.

Why have I been invited to take part?

Because of the sensitive nature of the conversation topic, I offer patients the option to bring a relative or companion with them to the consultations which will be observed. You have been

invited to take part because you are a relative/companion of a patient with a diagnosis of advanced cancer, who is currently receiving medical care and support at the hospital. This information sheet was given to you by the patient because the patient would like you to be present in the observation to provide them with support.

Do I have to take part?

No. It is up to you to decide whether to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw participation from the study at any time. Withdrawal from the study will have no impact on the clinical care the patient is receiving.

What is involved?

After you have read the information sheet and if you make the decision that you would like to provide a supportive role to the patient for the purpose of the research, the patient will ask you to sign a 'consent to contact' form. The patient will then pass your details to me. I will then have a discussion with you and provide information about what you can expect during the research process and offer an opportunity for you to ask any questions. You will then be asked to sign a 'consent to participate' form. After observing the consultation, I will take detailed notes about what I have observed. The notes will be saved on a password protected computer. The notes will not include any patient/relative identifiable data.

Will my taking part in the study be kept confidential?

Any issues discussed during the observation will be kept confidential. The notes I take will only be seen by me and my research supervisor. The information will not be recorded in the patient records.

All data for the research will be processed in accordance with the General Data Protection Act 2018. Responsible members of the Tavistock and Portman Foundation NHS Trust who is the sponsor for this study, may be given access to data for monitoring and/or audit of the study to ensure the study is being carried out correctly and complying with regulations. See <https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/> for more information.

There is one important exception to the guarantee of confidentiality. If there are concerns raised about patient/public safety or professional malpractice, the doctor or myself are obliged to pass this information on to an appropriate person.

What are the possible benefits of taking part?

I hope that the information gathered from the observation process will contribute to improving services for patients in the future.

What are the possible risks of taking part?

There is a possibility that patients and those supporting them may find consultations upsetting or distressing. The patient may have objections about a researcher being present in a consultation where they will be discussing important and possibly distressing matters with their doctor. If during the consultation anyone feels uncomfortable or changed their mind about the consultation being observed, they can ask me to leave at any time.

What will happen to the results of the research study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Advanced Systemic Psychotherapy Practice and Research at The Tavistock and Portman NHS Foundation Trust. The research may also be published in academic journals or presented at conferences.

Further information/independent advice

If you have a problem or concern about the study and you feel that it has not been responded to satisfactorily, you can contact Patient Advice and Liaison Service, (PALS) which is an independent service available to patients, relatives and carers. You can contact PALS using the details below:

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Tel: 07983 217 109

pooja.bhambra@westlondon.nhs.uk

Appendix 7: Consent Form



Professional Doctorate in Advanced Practice and Research: Systemic Psychotherapy
Researcher: Pooja Bhambra
Research Supervisor: Dr Inga-Britt Krause
IRAS Project number: 301926

PATIENT: CONSENT TO CONTACT FORM

Research question: How do physicians and patients experience conversations about the end of life?

Please
initial box

1. I confirm that I have read the information sheet for the above study. I give permission for the researcher to contact me.

☐

Name of participant

Date

Signature

Name of person
taking consent

Date

Signature

Participant Consent Form

The Tavistock and Portman 
NHS Foundation Trust

Professional Doctorate in Advanced Practice and Research: Systemic Psychotherapy
Researcher: Pooja Bhambra
Research Supervisor: Dr Inga-Britt Krause
IRAS Project number: 301926

PARTICIPATION CONSENT FORM

Research question: How do physicians and patients experience conversations about the end of life?

Please initial t

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study up until the point of data analysis without giving any reason, without my legal rights being affected. I understand that the data I have provided up to the point of withdrawal will be retained. ☐
3. I understand that the research interview will be audio recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations. ☐
4. I understand that all personal data relating to volunteer research participants is held and processed in the strictest confidence and in accordance with the Data Protection Act (2018). ☐
5. I understand that the collection and use of my data will be used to answer the research question in this study. ☐
6. I agree to take part in the above study. ☐
7. (For patients) I agree for the results of the study to be shared with my family. ☐

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Name of person taking consent	Date	Signature

Appendix 8: Interview/Topic Guide (Patients)



Topic Guide

I will conduct semi structured interviews which permits flexibility. This topic guide provides preliminary questions which will be used to create structure, but questions may be adapted or omitted based on participants' responses.

Questions for patients

1. Have you ever had a conversation with any of the doctors who look after you about the care at the end of your life? With whom? I would be interested to understand what the experience was like for you if you would like to talk to me.
2. How would you describe your relationship with your doctor?
3. What do you think makes for a good conversation when a doctor is talking to a patient about their illness?
4. What has been most helpful to you in conversations with your doctor?
5. Have you had conversations with other health professionals (i.e., clinical nurse specialist, GP)? If you have had more than one conversation, which was the most useful and why?

Prompts

How much did you feel listened to? How sad or anxious were you? How did the health professional respond to your feelings? What did they do, if anything, to comfort or look after you? Did you feel that the person was being kind? Compassionate?

6. Did you think about the conversation afterwards?
What effect did the conversation have on you?
7. When you had the conversation did it happen because you asked or was it suggested by the doctor?
What do you think triggered that conversation to happen at that time?
8. Do you think you both understood each other?
Did you notice anything in particular about the doctor's approach when giving you the news about your health?

Prompts

What did you notice about their attitudes? Was it personal to you? Did it feel tailored to you?

9. What was the most important thing that you thought should have been discussed during the conversations about your prognosis and future care?
Was there anything that was missed?

10. What do you think happens after death?
Is what you are describing connected to religious or spiritual beliefs? How did your thoughts influence how you responded to the news given by your doctor?

11. Is there anything else you would like me to know?

12. What would you like doctors to know about what is it like to be on the receiving end of a conversation about the end of life?

Closing question:

We have talked about deep and emotional things. Do you think there is anything we have talked about that your doctor would need to know?

If answered yes

What are those things?

Are you happy to talk to them about those things? Is there anything I can do to support you with this?

If you like, I could give a copy the transcript of the interview to your doctor, or we could write something together which we can give to them.

Interview/Topic Guide: Physicians



Topic Guide

I will conduct semi structured interviews which permits flexibility. This topic guide provides preliminary questions which will be used to create structure, but questions may be adapted or omitted based on participants' responses.

Questions for doctors

1. Can you tell me about your job and what you do?
2. What kinds of relationship do you have with your patients who have a diagnosis of terminal cancer?
3. What are the ways in which you find out what your patient thinks about death and the dying process?
4. What are the challenges of working in this area?

What are the gains?

5. What leads you to feel more or less comfortable to have conversations about the end of life?
6. What do you find are the obstacles to having effective conversations?
7. What do you think prompts these types of conversations?
8. What kind of formal or informal training/teaching have you had in breaking bad news?

How do you keep up to date with training?

9. Do you have a model or structure in your mind which influences how these conversations happen?
10. What are your personal and professional experiences which influence the style and/or structure of the conversation?

11. Do you have religious or spiritual beliefs about dying? If so, how might they influence how you have such conversations with your patients?

12. How do you judge how much information patients need to told?

13. How does the presence of relatives/friends (in the consultation) make a difference to how conversations happen?

Do you tend to see patients alone or encourage their family to participate?

14. How do you deal with situations where the patient doesn't understand or take in what you have said?

15. Can you tell me about a time when a conversation did not go well?

16. Can you tell me about a time when a conversation did go well?

What enabled this to be a better conversation?

17. How do you think about cultural difference in this context?

Are there any cultural adjustments you sometimes need to make in how and what you communicate?

18. Do you talk to patients about statistics regarding survival rates, or alternative clinical trials available to them, or do you wait for patients to ask you?

19. What happens after these conversations?

What support is available to you? Have you accessed such support?

If not, what are your reasons?

Appendix 9: Letters to patients

Dear Judith

As I reflect on the time that we spent together, I am filled with gratitude for your generosity in sharing so much about your experiences and, at a time when you were facing significant personal challenges. Your story has moved me in ways I did not anticipate.

I often think about how you described your ambivalence towards the 'after life'. You expressed the belief that you might simply fall asleep, and it would mark the end of your life. But you also expressed with tenderness, a quiet hope, that you were wrong. You hoped that you would meet your 'mam and nana', who you thought were 'there' and waiting for you. Your words are a constant reminder to me that facing the end of life necessarily means navigating ambivalence and complex emotions, while also attempting to make sense of what we cannot know for certain.

You said that you would come back and let me know about your experience of the afterlife, which I found humorous and moving. You taught me that even in the face of death, which threatens one's sense of connection, there is a way to hold on and stay connected, even if this is simply through words and memories. This letter is one example of staying connected. On a personal level, your story resonated with me as I lost my mother to cancer several years ago. Like you, I have also wondered if I will meet my mother again.

I want to acknowledge the contribution that you have made to my research. Your reflections have deepened my understanding about the complexity involved in end of life conversations and how to hold on to hope, in the face of uncertainty and death.

With my deepest gratitude

Pooja

Dear Janet

I have been thinking about our time together and the experiences that you shared with me. I was deeply moved by the way you spoke about your religious faith and how that helped you to process and accept your illness. Your words remain vivid in my mind; you told me, 'I still believe in God and trust in him. I know whatever his decision is his decision, and I abide by his decision'. I experienced this as very powerful - I could feel the strength of your faith. The way you spoke about your faith struck me as a profound perspective on approaching the end of life. Beyond the physical aspects of care, it gave me another dimension to think about in my research. It led me to ask the question, what matters most for patients who are approaching the end of life.

I have reflected on the story you shared about your visits to the local pharmacy. This was a pharmacy that you and your husband used frequently, and the staff knew you well. When you told the staff about your diagnosis, and you expressed in a light-hearted manner that 'my husband wants me to come and be with him' - in that moment you showed me that there was a place for humour despite the uncertainty which you faced. I also wondered if your words reflected the depth of your commitment to your husband and perhaps your longing to be reunited with him, in the afterlife. I understood this as a story of hope and that you did not see death as the end.

You shared with me that you 'hope and pray' that you would go to Heaven, as this is what you wanted 'more than anything else'. I noticed that during the interview you had your Bible nearby, signifying to me the importance of your faith. Looking back, I regret not having said more to you about how your story impacted on me. As we parted ways, my inner voice wanted to say, 'Janet, I hope you find peace and reunion with your husband, in Heaven' but I did not know how to say this to you directly. As I write to you now and reflect on all that we spoke about, I really do hope that you have found peace.

Your story gave me perspective on life, love and faith. These life lessons have not only shaped my research, but they also had an impact on my own thoughts and beliefs about what it means to approach the end of life. As I come to the end of writing this letter, I am filled with gratitude and respect for you. I recognise the strength it would have taken for you to engage in this study at a time that you were very unwell, and also that time was short. Thank you for spending some of that time with me.

With my deepest gratitude

Pooja

Dear Peter

I have been thinking about our meeting and the stories you shared with me. You told a powerful story about your experience of working as a ship engineer and the moral code that you lived by. It seemed to me that you navigated life with caution and care, motivated by a desire to avoid causing trouble for others or creating a fuss. What struck me most was your approach towards your illness - you described it as 'just another event in your life' 'nothing to worry about'. Despite the prognosis you had been given, you did not let illness define you. Your perspective on illness has left a lasting impression on me.

I remember that you described having low expectations of physicians and not expecting them to be 'chummy'. You felt that things should be kept on the 'strict professional'. I was moved by your consideration for health professionals and your acknowledgement that 'genuine mistakes can be made'. I admired the way you described your personal experiences with such dignity and how you honoured those who you had met along the way. I was aware of your boundaries and that you were guarded in how much you chose to share with me, which I understood to be out of respect for others, who were part of your story. I feel honoured that despite some reservations that you might have had, you chose to share your personal experiences with me.

When I think about your story, together with the stories shared by other patients who participated in my study, I am reminded about the unique perspective that you offered as the only male patient. Your expectations of physicians, the healthcare system and your approach to the end of the life was markedly different. It helped me to appreciate how gender may influence how conversations unfold between physicians and patients. This is just one example, but your story has shaped my research in many ways Peter, and I continue to keep your story in mind, as I move forward. I want to thank you for taking the time to speak with me and for your willingness to participate in my research, during a period that must have been incredibly difficult for you. I feel fortunate to have met you and to have had the opportunity to learn from you.

With my deepest gratitude

Pooja

Dear Fia

Since our meeting in 2023, I often find myself thinking about your story and your determination, in the face of illness. You told me a powerful story about the conversation that you had with a physician in 2018, which is when you were first given a diagnosis of cancer, and you were told that you had 'two weeks to live'. You described how you fought back and with such conviction you said, 'cancer won't kill me'. I met you five years after you had been given the initial diagnosis - I witnessed firsthand your courage and determination.

I was deeply moved when you told me about your faith in God and your belief that he would help you to 'sail through this'. You were certainly determined to live, and I thought the combination of faith and determination was remarkable. You helped me to understand the importance of faith and how it can give hope to some patients, during the most difficult times. You talked in detail about your experiences of having conversations with physicians and this gave me insight into the negative effects that a physician's communication and behaviour can have on a patient and, the challenges that patients experience. It made me think about patients who are not able to confront or challenge their physician in the way that you did and the effect of this.

Fia, I want to thank you for sharing your thoughts and feelings so openly, for your contributions to my research and the trust that you placed in me as a researcher. You have helped me to understand the intersection between illness, faith and human determination. Your story will not be forgotten.

With my deepest gratitude

Pooja

Appendix 10: Extract from my observation notes

The consultation was attended by an Asian woman with incurable cancer (60s). Patient attended with her daughter. The purpose of the consultation was to discuss palliative care options. Both mother and daughter appeared quite withdrawn, and mother seemed to be in physical discomfort, as she held her stomach tightly.

Present at the consultation was the Consultant Oncologist (who had never met the patient before), Nurse (who has met the patient before), a trainee doctor and me.

The consultant first reviewed how the patient was feeling. The patient described intolerable physical pain. After he told her the results of the most recent scan, the patient acknowledged that she had the feeling that the cancer had spread, and her focus was to understand options for pain relief. The consultant then gave her treatment options i.e., radiotherapy to target the cancer site. The patient expressed repeatedly that she did not want any treatment to prolong life but just to ease her pain. The consultant reiterated that the treatment was to reduce pain. The patient's daughter was visibly distressed at this point. Looking at her daughter, the patient said that she did not want to prolong her life because she did not want her daughter to suffer. To this, the consultant responded, 'she is already suffering'. I observed there to be a misunderstanding in their communication leading the consultant to feel that he needed to defend himself by saying 'I am not the enemy'. I wonder whether he felt he was being 'attacked' in some way by the patient. She seemed to me to be implicitly asking questions which perhaps he found difficult to address directly. I also wondered why the patient did not want to accept treatment to reduce her pain and whether it might have been helpful for the consultant to have tried to have a conversation with the

patient about this. To understand more about the patient's reasons for refusing treatment and also to clarify with the patient, whether they had understood that the treatment being offered was to reduce pain and not to prolong life.

Directly after the consultation, I asked the consultant what ideas he had about why the patient refused treatment, and in his initial response he was very dismissive of her behaviour. He then went on to explain that in her notes it said that she had seen her own father suffer from the effects of cancer treatment and for that reason she did not want to have treatment. It seemed obvious to me that this was information he could have used to have had a very different conversation with mother i.e., exploring the effect of the experience of caring for her father. I felt angry with his dismissive tone and lack of empathy shown. I am keen to interview him for the research to explore more about the ideas which inform his thinking. He has agreed to be interviewed.

Seeing the mother - daughter dyad I was immediately reminded of the consultation that I attended with my mother, when she was given a terminal diagnosis. I experienced a feeling of hopelessness once again. I observed that the patient's daughter did not verbally say anything except to ask about timescales for when her mother was likely to die, to which the consultant could not provide an answer. While the daughter communicated her distress through tears, nobody in the room acknowledged it— why not? I had wanted to reach my hand out to her, to acknowledge her pain and my sense that she must have been terrified. It seemed the professionals had all distanced themselves from the distress of the patient and her daughter. I wondered who else was in the family network and whether there was somebody else

who could have been part of these conversations and provided support. I felt concerned that after leaving the hospital, the daughter would be left to manage this on her own. I was left feeling hugely disappointed and angry about how badly the consultation had gone. It felt very transactional and there was no curiosity or effort shown to try and work with the patient's feelings of ambivalence or acknowledge the distress which was palpable.